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Investing In Change: Illuminating Interactive Systems in HIV Research, Communication Diffusion, and Financing in Lesotho

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Investing in Change:
Illuminating Interactive Systems in HIV Research,
Communication Diffusion, and Financing in Lesotho

by

Sharon Elizabeth Watson

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy
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DEDICATION

To my earthly father and my Heavenly Father, for believing in me, seeing what I could be, and loving me relentlessly, and unconditionally…especially when I proved most unworthy.
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As a “young” woman, finishing my undergraduate studies “on time”, quickly moving through my masters and towards my PhD I was so confident in what I could give, what I knew, and myself. Then life happened. And it is in this in between time, “the delay” that I truly learned what it is to be human. It is in the “delay” that the naïve go getter gave way to an anthropologist who realized how much more there was yet to learn. I am thankful that the road took some turns. To anyone who may read this, who thinks they are too old, or can’t balance children, marriage, taking care of parents, a sickness, the financial struggle of graduate school, whatever it may be…don’t give up. Hang in there. Experience makes the inquiry richer.

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ABSTRACT

In the field of HIV, more than 30 years into the epidemic, the need to ensure that what researchers learn makes its way into tangible actions in the real world is especially poignant. This dissertation addresses the critical divide between research production and its translation into practice. It advances ways to measure the investments of citizens and stakeholders in qualitative studies and offers new perspectives on the losses inadvertently caused by particular investments in health research and services. Unfortunately, many of the problems in how we practice and disseminate research are rampant throughout the health and development research sector. Therefore, while this anthropological dissertation focuses on HIV and Lesotho, several of the findings are applicable in other geographical and topical settings.

This dissertation explores how the practice of conducting qualitative research becomes a type of disease prevention intervention itself cutting across systems. Using a large qualitative HIV sexual, social, and behavioral health research project, as a case study, I illuminate how health research knowledge makes its way (or not) to the populations for whom it is intended. Following up four years later, using in-depth semi-structured and structured interviews, I probe practical and theoretical issues involving the original research assistants, a comparison group, and representatives from organizations targeted to be most likely to use the research findings. I pilot a communication diffusion measurement tool that visualizes the researchers’ ability to apply what they learned from the research experience in talking to their families, partners, acquaintances, work colleagues, and students/trainees. The results indicate significant differences between the original team and the comparison group’s communication diagrams, demonstrating the tool’s usefulness in visualizing who is talking to whom, with what magnitude, and the types of life moments that trigger opportunities to have quality conversations about HIV, sex, and Multiple Concurrent Partnerships (MCP).
As evidenced in this study, team members are part of the larger social system. They have the potential to influence the formal dissemination of HIV prevention information into policy and programming as well as the informal diffusion into their own life and in the lives of those they encounter in their social network. Nowhere in translation and dissemination research descriptions are the research team members discussed. Based on this research, I argue that, in addition to greater involvement of the public and stakeholders in translational research, there is a need to include the “implementers” of research beyond that of the principal investigators: the research staff. There is a need to further conceptualize the role of the “research team” in the translation of research to practice paradigm.

Data have been collected from grey documents, project reports, scientific papers, newspapers, and websites establishing current points of focus for well-funded global entities in context with our understanding of transmission and prevention dynamics and debates. Analysis of these sources reveals strong rhetoric for combined biomedical, social, behavioral and structural approaches but programming and funding reports reflect much more weight and financing to biomedical solutions. The findings from organizational representatives interviewed in this study reveal that the creation of research and diffusion of information will follow the funding. Similar to Lesotho, many researchers and health professionals in developing countries are hired into biomedical or clinical projects for employment. This project explores the HIV response as part of economic, social and health development in Lesotho supported by the aid industry, and presents data on how the investments of money influence the ways in which local leaders and everyday citizens define, communicate, and conceive solutions to the problem of HIV.

In the mid-term, translating biomedical findings into real world realities requires qualitative research. Ethically sound and well-trained qualitative researchers are fundamental in the creation and diffusion of knowledge. As the findings in this study indicate, the qualitative experience provides an opportunity to understand the epidemic that leads people to change their own behaviors, influence those around them, and have the desire to facilitate conversations to provoke social action and change. However, this study also demonstrates how people can go years talking, studying, and working in HIV without ever having an “awakening” or deeper understanding of HIV in their local reality. Study results
delve into the long-term effects on the local researchers, furthering our understanding of the different ways in which “capacity” is built in the local involvement. The dissertation also explores critical questions about qualitative research methods and ethics within a context of investigating a disease where everyone—researchers and the researched—are either infected or affected.

Based on this research, I argue that true education about HIV is a dialogical perpetual process of interrogating what we know, imagining what should be done and trying: Praxis. This heightened awareness of how our daily research practices link to larger systems will help us not to allow our do-gooder attempts to blind us to the harm we may inadvertently do, or to the lost opportunities we squander. Instead, we must capture and maximize our investments in research and people as agents of change and not only as patients, participants, or employees.
CHAPTER 1. THE PROBLEM: CLOSING THE GAP BETWEEN RESEARCH AND REALITY

According to the U.S. National Institutes of Health (NIH), “each year, billions of U.S. tax dollars are spent on research and hundreds of billions are spent on service delivery programs. However, relatively little is spent on, or known about, how best to ensure that the lessons learned from research inform and improve the quality of health and human services and the availability and utilization of evidence-based approaches” (NIH 2010). Traditional means of research dissemination are usually limited to manuscripts for submission to journals and presentations at meetings. “Missing, by and large, are plans, processes, and methods for focused translation and dissemination of discovered knowledge to potential practitioner end users” (NIH 2010). The traditional target audience for the dissemination of health research “end user” is that of clinical and public health practitioners. Today, stakeholders and gatekeepers are not necessarily confined to clinical and public health associations. They come from various settings such as political entities, lobbyist, pharmaceutical companies, universities, international firms, community organizations, and passionate individuals from the general public. In this thesis I argue that in order to achieve the goal of getting health information about socially undesirable diseases optimally used by the general population, research professionals must be critical of their own positioning and meaningfully involve local stakeholders in the research process. Meaningful involvement encompasses a shared knowledge production about the health problem and shared dissemination of this knowledge, formally and informally. By formal, I am referring to practices that are commissioned and supported by an entity that uses direct monetary services or career-based retribution. Informal refers to retribution not directly linked to economic but to alternative motivations. For example, sharing knowledge in informal settings such as
with family, friends, church groups, work colleagues or a “stranger” in the hair salon or bus stop. In these cases no one is providing a formal retribution but a person may be motivated to protect a loved one or feel that it is their responsibility to share what they know.

Professionals rarely conduct research without the investment in resources by some entity that hires individuals and compensate them for their contribution. The entity, the individuals, and the health problem do not exist in a vacuum but each of them is laden with their own historical, social, economic, and political background. People working in the health research sector must reflect upon the practices of how they conduct research and conceptualize dissemination. I would argue that this is especially important when the employment for research implementation takes place in the context of relative deprivation, “transition” economies, modernization, and historical inequalities. In these situations the act of hiring—employing and then implementing what we would like to think as apolitical, objective, and scientific research—may itself be expanding perceived notions of inequality and relative deprivation. In many settings like Lesotho, health sector employment is growing and providing work opportunities for the unemployed and often higher pay for the already employed. In these settings, informal dissemination begins with the posting of wanted ads as individuals begin to discuss the new posting and prepare for applications and interviews.

With limited resources health research and project implementation funding is competitive. Awards for funding often hinge on the applicant’s ability to justify the action through previously-conducted research or by adapting an evidence-based approach. Historically, funding leans more towards quantitative studies that can generate large amounts of generalizable data. Since the 90s, there is a growing trend towards utilizing qualitative data because of its ability to provide a window into the hidden complexities of an issue, making qualitative methods popular outside the traditional academic social sciences, particularly in market, public health, and international development research (Krueger and Casey 2000; Mack, Woodsong et al. 2005). There is also a movement to involve local researchers and community stakeholders in the research process—thereby giving ownership of findings and increasing the likelihood of dissemination and implementation (Khassay and Oakley 1999; Macaulay, Commanda et al.)
Furthermore, such involvement helps to support local capacity in coping with present and future problems and minimizes potential accusations of “exploitation.” Unfortunately, conducting high quality qualitative research is often expensive and time-consuming and requires well-trained human resources (Meyer 2004). Waste of these assets repeatedly occurs because of the inability to translate results and experience into practice (NIH 2010). The “waste” of resources should not be interpreted as occurring only within North-South donor relationships but also within “North” and economic “transitional” contexts. Furthermore, the resources wasted include not only the monetary support but also, and perhaps especially, the human resources. Results from this research demonstrate how the conundrum of paying well to attain the best talent for professional research projects often results in the extraction and investment of human intellectual resources “where the money is.” This consequently undermines the credibility of local intellectuals and stifles the natural growth of grassroots activism targeting HIV/AIDS. However, high quality training in qualitative methods and ethics is a capacity investment that lives long after the project ends and in various research and non-research settings.

1.1. Qualitative Research as a Form of Intervention

The pressure of deadlines and balancing quality and costs in scientific studies can sometimes trump the relationship with, and attention given to, the positionality of all collaborators and their potential role in the formal and informal improvement of health outcomes. As the scientific community attempts to integrate the aim of structural and long-term changes within systems, the importance of the inputs (or persons) that are hired for a particular scientific research project cannot be underestimated. Rather these inputs are increasingly important because each individual is simultaneously part of multiple systems. Latkin and colleagues (2010) propose a systems model for HIV-related behaviors that turns the lens towards the dynamic and social nature of factors working across six dimensions (setting, resources, science and technology, formal/informal social control/influences, and social interconnectedness) at the macro, meso, and micro levels influencing HIV prevention (Latkin, Weeks et al. 2010). They emphasize
that “in systems, elements influence each other at different levels and forms. The probability that an element will influence another and the intensity of the ensuing influence depends on the quantity and type of connections between them. Connections among a system’s elements can be random and either loose or tight” (Latkin, Weeks et al. 2010: S224). For example, a research colleague who is hired, in the field setting, as a data manager is not only part of the organization’s system as a piece that contributes to achieving a specific objective but is part of multiple other systems that span across time and space. He may also be a father, husband, son, uncle, bar-mate, soccer colleague, or the future director of an organization or perhaps a government minister. Thus, the acute manner in which his “role” is conceptualized, what type of knowledge about the particular health problem he is permitted to foster, will indeed influence whether the connections among the system’s elements will be random, lose, or tight.

If the practice of conducting research is seen as a type of disease prevention intervention itself, I see the human resource as having an exponential potential to increase the frequency and intensity of connections across systems. Furthering our example, if our local field data manager was treated as someone “above” the health problem, who knows everything about it, who is educated and considered a “culture” expert, little time or thought will be invested in creating space for understanding his personal and social perspectives about the health problem. Likewise, little effort will be made to invest in developing any other capacity beyond those he needs to fulfill his technical responsibility as “data manager.” This is done so that the team can get to scientific “results” that can be used to “implement” change. This short-sighted fallacy wastes the potentiality for this individual to be an agent of social change across systems. Anthropologists studying changes within and between populations have repeatedly highlighted the importance of human interactions in understanding cause and consequence in historical realities, as Boas reasoned:

While in natural sciences we are accustomed to consider a given number of causes and to study their effects, in historical happenings we are compelled to consider every phenomenon not only as effect but also as cause. This is true even in the particular application of the laws of physical nature, as for instance, in the study of astronomy in which the position of certain heavenly bodies at a given moment may be considered as the effect of gravitation, while, at the same time, their particular arrangement in space determines further changes (Boas 1920: 135) quoted in (McGee and Warms 2004:135).
Thus, the data manager is simultaneously part of the “cause” of the health problem as well as an element that can “effect” future changes. Most research professionals, and the entities that provide funding, hope their research supports long-term, capacity building, and health improvements; it is often not clear if this is in fact the case. Indeed, in some cases an uncritical belief in the good a research will bring blinds us to some of the unintended negative consequences and ethical quandaries we create. In the rush to move on to the next project (“I would love to stay but I have to pay loans, mortgage, procure the next grant, write for tenure”), many global health researchers often do not make an effort to find out what happened after the research. In many instances, the desire to return is present but the structural constraints of employment and funding mechanisms makes it extremely difficult to find the time and resources to turn back. Health researchers often do not know what difference, if any, their work provides. In this dissertation, I use a large qualitative sexual, social, and behavioral health research project as a case study to look back and illuminate the processes of knowledge production with the goal to improve our understanding of how health research knowledge makes its way (or not) to the populations for whom it is intended.

National and international funding agencies recognize the need to close the gap between research findings and the real world to justify the investments of citizens and stakeholders (EC 2007; NIH 2010; WTO 2010; dos Remedios 2013). Professional health researchers are typically dedicated individuals who invest their expertise to effect positive change (directly or indirectly). In the field of HIV, more than 30 years into the epidemic, the need to ensure that what researchers learn makes its way into tangible actions in the real world is especially poignant. This dissertation addresses the critical divide between research production and its translation into practice. It also advances ways to measure the investments of citizens and stakeholders in qualitative studies and offers new perspectives on the losses inadvertently caused by particular investments in health research and services. Unfortunately, many of the problems in how we practice and disseminate research are rampant throughout the health and development research sector.
Therefore, while this dissertation focuses on HIV and Lesotho, several of the findings are applicable in other geographical and topical settings.

1.2. Real World Lab: Case-Study Methodology

1.2.1. Description of 2007-2008 Gender and Multiple Concurrent Partner Study

The southern region of Africa continues to remain a central challenge in the HIV/AIDS global pandemic. In 2007, the region accounted for 35 percent of all people living with HIV worldwide and 32 percent of the world’s new HIV infections and AIDS deaths (USAID 2008). Today, of the estimated 38.1 million people living with HIV, 25.8 million, or 70% of the global total, are in sub-Saharan Africa (UNAIDS 2015a). In 2006, the Southern African Development Community (SADC) held an expert think tank meeting focusing on the regional nuances of the epidemic. One of the meeting’s main conclusions was that having multiple and concurrent sexual partners is one of the key drivers of the epidemic in the region (SADC 2006). Commonly, the term “concurrent sexual partner” refers to having more than one sexual partner over the same period of time, while “multiple sex partners” may be concurrent or sequential (MCP refers to both Multiple and Concurrent Partnerships).

The Kingdom of Lesotho a landlocked country within South Africa, has a population of 1.9 million, of which an estimated 310,000 are HIV infected (CIA 2011). Lesotho’s current adult HIV prevalence rate is 22.7%, one of the five highest in the world (NAC 2010). Studies from Lesotho seem to support the connection between the cultural and behavioral dimensions of MCP and the spread of HIV (Spiegel 1991; Romero-Daza and Himmelgreen 1998; Magrath 2005). A 1989-1990 WHO survey found that 55% of all men and 39% of women in Lesotho reported having had more than one regular partner in the previous year (Caraël 1995). Over the past ten years other quantitative studies documented the same risk behavior (FHI 2002; LDHS 2004). However, there was a lack of current contextual information describing with whom, where, and why this behavior occurs, making it difficult to turn this documented “evidence” into usable prevention steps.
In 2007, the Expanded United Nations Theme Group on HIV/AIDS, a group consisting of national and international policy and programming stakeholders and the U.S.A. President’s Emergency Plan for AIDS Relief (PEPFAR) in Lesotho, decided to conduct formative research on MCP to improve communication around HIV. Initial collaborators invited Family Health International (FHI) to join the partnership in order to provide technical expertise in creating and implementing a large-scale, collaborative, qualitative research design. Funding for the technical expertise from FHI was part of allocations earmarked from U.S. Congress to support Site Identification for pharmaceutical research into HIV preventive microbicides and vaccines. UNAIDS, having an information and resource supportive role, developed a strategic partnership with the Lesotho National AIDS Commission (NAC) as the leading implementer of the project. NAC’s mandate was to coordinate the national response to HIV/AIDS through the following: developing policy and strategy, mobilizing stakeholders to implement policies and plans, building technical and financial capacity among implementing partners, conducting monitoring and evaluation, reporting and advising the government, and implementing research to inform HIV/AIDS related decision-making.

The goal of the study was to produce strategic information on determinants of sexual behavior, focusing particularly on social, economic, and cultural factors that promote multiple concurrent sexual partnerships, with the purpose to inform national gender interventions targeting prevention of HIV. Much like many USAID-funded efforts, another potential audience for the findings included ‘Men and Gender Equality’ projects attempting to encourage men and boys to fulfill their potential as a positive force for change. The idea was that the strategic context-specific information produced around gender roles and sexuality by the MCP research project would help the development of these types of projects (Khobotlo, Hildebrand et al. 2009). With this in mind, the study focused on men 18 to 44 and women 15 to 34 years of age, with the following specific objectives:

1. Generate context-specific information on the practice of multiple and concurrent sexual partnerships within stable relationships.
2. Inform the review of the prevention component of the National Strategic Plan on HIV and AIDS (2006-2011) and of the upcoming national behavior change communication strategy.
3. Highlight community perceptions and understanding of HIV risk within stable relationships in order to strengthen community and civil society communication and advocacy for social change.

4. Strengthen evidence-based community dialogue on HIV prevention within stable relationships, particularly through improved mechanisms for involvement of men in dialogue and community response.

The principal partners in the MCP project hired a local team of researchers with little to no experience in qualitative research. They publicly advertised research positions in a local newspaper and selected nine team members, whom they trained in ethics, qualitative research, collaborative analysis, and HIV/AIDS and MCP. The project office was in the Lesotho UNAIDS headquarters, and the project director was a UNAIDS staff person. While direct management and physical location was with UNAIDS, NAC, as the implementing partner, employed the researchers. NAC hired the researchers on a full-time basis for a period of nine months to conduct the piloting of research tools, individual interviews, focus group discussions, data transcription, and to provide feedback in the interpretation of findings. From the original group of nine assistants, three researchers went on to work with the dissemination of the research findings to organizations and to stakeholders at the international, national, and community levels. During this dissemination process, which lasted two months, the local researchers worked with the principal investigators in the creation of a new participatory method to validate socially sensitive research results to stakeholders.

In 2008, the research concluded with a wealth of qualitative data, including 92 individual interviews, 30 focus group discussions, national/international stakeholder dissemination meetings (500-600 participants), and participatory validation meetings with stakeholders in the five research communities (128 participants) (Khobotlo, Hildebrand et al. 2009). As discussed above and described in more detail in Chapter 5, the original study protocol had expected outcomes that went beyond traditional means of dissemination, providing insights into more diversified ways of getting health information out to broader constituencies. Given the depth of the findings and the resources invested, it is important to ask what happened after the research. What pathway did this new knowledge take through the individuals and
structures through which it wound? What factors enhanced or hindered the translation of knowledge into action?

To answer these questions, the case study that provides the basis for this dissertation focuses on the original study team and the processes of diffusion of the knowledge gained and the lessons learned from the original MCP qualitative study. Using in-depth, semi-structured and structured interviews, I probe practical and theoretical issues involving the research assistants and the organizations targeted to be most likely to use the research findings.

This study draws upon Everett Rogers’ Diffusion of Innovations theory, which defines diffusion as “the process in which an innovation is communicated through certain channels over time among the members of a social system” (Rogers 2003: 5). An innovation is defined as “an idea, practice, or object that is perceived as new by an individual or other unit of adoption” (Rogers 2003: 12). A communication channel is "the means by which messages get from one individual to another" (Rogers 2003: 18). For the project, and basis for this dissertation, the new ideas and knowledge or information to be studied are the research partners’ and local researchers’ experience (knowledge gained, lessons learned) while participating in the research process. By tracing the diffusion of the innovations I bring to light some of the ways the new knowledge moved (or not) through members of a social system and into practical use for prevention efforts in the field, focusing on two specific areas:

1. Local Researchers’ Participation in Qualitative Research as a Form of Prevention Delivery

Objective 1: To describe how the results and experience of the research process affected local researcher’s ability to incorporate health knowledge in their life.

- In what ways can stakeholders evaluate the medium/long-term investment in training local researchers in qualitative methods to investigate a health problem?
- How does the experience and process of involving indigenous researchers in an HIV study further local “capacity” for disseminating disease prevention knowledge?
- How does such participation affect local researchers?
- What were the unanticipated consequences of local involvement?
2. Organizational Uptake of Qualitative Research Findings

Objective 2: To identify how research results are integrated or rejected by local change agents.

- To what extent were the results of the research study integrated into local agent initiatives?
- What were the factors that affected (either facilitating or preventing) such adoption?

The next sections introduce the methodology used to achieve these two objectives. In addition to the descriptions in this chapter, each result chapter describes in more detail the different approaches used to answer the research questions.

1.3. Methodology: Local Researchers’ Participation in Qualitative Research as a Form of Prevention

Wandersman and colleagues (2008) usefully divide capacity into two domains—innovation-specific capacity and general capacity. Innovation-specific capacity pertains to the capacity necessary to complete a specific present objective. General capacity is intended to enhance the infrastructure, skills, and motivation of an organization, but it does not specifically focus on an innovation (Wandersman, Duffy et al. 2008). With fixed budgets, outcomes, and timelines, innovation-specific capacity is more routinely used in the form of trainings, technical assistance, and coaching. In contrast, general capacity is more difficult to justify, and its success is harder to implement and measure. Relatively little empirical research has examined the effectiveness of training methods for disseminating prevention innovations (Wandersman, Duffy et al. 2008). Yet, with the scarce evidence making a direct link between general capacity and increased ability to implement innovations, some studies suggest that such efforts have beneficial effect on organizations and communities (Altman 1995; Arthur, Bennet et al. 2003; Chinman, Hannah et al. 2005; Fixsen, Naoom et al. 2005). What is partially established is that training and giving experience to locals helps to develop expertise and local capacity to investigate their present and future issues. As health research leaves the controlled environment of labs and hospitals and diffuses out into communities, the importance of using locals and capacity building becomes increasingly evident.
Similarly important is the need to measure more explicitly the associated consequences between training and the building of local capacity.

While we customarily would look at only the outcome—the research findings that go on to inform policy and practice—this research looks at the experience of indigenous researchers’ participation in research as a form of prevention itself. This study explores how the experience and process of conducting a qualitative research study including indigenous researchers furthers our notions of “capacity-building” for addressing a health issue. The intended consequences of building capacity of the research team included traditional outcomes like proficiency in HIV/AIDS, understanding of qualitative methods, ability to conduct interviews and focus group discussions, ethics awareness, expertise in transcription, and improved general competency with computer skills. All of these anticipated outcomes could have future benefits for the individuals, organizations, and country itself. The above outcomes are more easily measured in the short term—during or soon after the conclusion of the project. However, in transitioning to a medium- or long-term perspective on capacity building, I explore some of the outcomes, four years later (in 2012), which would not have been evident immediately after the conclusion of the study. Specifically, the type of outcomes that demonstrate the ways that building local capacity can be extended to include 1) using the knowledge generated through the experience of doing qualitative research to modify one’s own behavior as it relates to the prevention of HIV transmission, and 2) researchers taking actions to impact people, programs, and policies in their sphere of influence.

By investigating some of the long-term effects on the local researchers, this study will contribute to furthering our understanding of the different ways that “capacity” is built through local involvement. Does “capacity” building to implement a qualitative health research project influence the researcher’s “capacity” to cope with the health problem individually and communally? How does listening and documenting other people’s stories of risk, vulnerability, justifications etc., affect these individuals? The research team members had unique access to social and cultural information about multiple and concurrent partners (MCP) and HIV risk. They were also in a unique environment, within the context of Lesotho, where they were able to ask questions and talk about sex, HIV/AIDS, and MCP. Additionally,
they learned how to get others to feel comfortable and open up about issues that culturally and traditionally are believed to be off-limits. Did all this affect their perspectives on HIV risk? Did they change their individual behavior? Did it help or hurt their ability to cope in their high prevalence setting? How did the quality and intensity of the knowledge they discovered about their own people affect their sense of responsibility and accountability? Did their intimacy of the detailed stories of people provoke action or disillusionment?

Interestingly, throughout the MCP original study, participants kept thanking the researchers for an opportunity to talk. Researchers often had problems closing interviews and focus group discussions because people wanted to continue to talk about issues like HIV, sex, and cultural and gender expectations. Lesotho has been the site of several HIV prevention marketing campaigns with posters, commercials, testing fairs, and radio shows—but what seems to be lacking is space for individuals to ask questions and talk about issues of concern. The “Twende na Wakati” diffusion study (Rogers, Vaughan et al. 1999) pointed out that individuals who heard prevention radio shows but did not have an opportunity to talk were less likely to adopt the family planning or HIV/AIDS prevention messages presented in such shows. In this study I investigate if and how these individuals went on to create small spaces for people to talk, and thereby diffuse their qualitative MCP knowledge in informal conversations to others beyond the team.

In a setting like Lesotho, where facts about HIV can be recited but not necessarily understood, and sometimes even if understood not believed to be true, the credibility of the messenger is extremely important to the acceptance of an idea, as well as to the degree to which the idea can influence high-risk behaviors (Watson Lai, Mpemi et al. 2008). Everett Rogers’ theory of Diffusion of Innovations (DOI) discusses the advantage of homophily, which is, "the degree to which pairs of individuals who interact are similar in certain attributes, such as beliefs, education, social status, and the like" (Rogers 2003: 19) in the transmission of an innovation. While different organizations in Lesotho have hired “leaders” (politicians, musicians) and “peer educators” in a resource- and opportunity-deprived setting, this status automatically places a distance between “us” and “them”, the educators/leaders versus those in need of education.
Official peer educators and leaders often become heterophilic not only in the new knowledge they have but also in their status as being paid to talk about HIV. In some cases, being taught by an individual who was paid to educate made the “target audience” doubt the authenticity of the prevention messages *(Are you telling me this prevention message because you believe it and care or are you telling me because you get money?)* (Watson 2008). What is unique about following up on the members of the research team is that some are no longer part of any HIV project funding. They are no longer “paid” to work on HIV. This may as a result, render them more homophilic and more likely to transmit their knowledge about HIV and MCP. Furthermore, the nearly four years post-experience follow-up provides time to measure if the diffusion process occurred and how it varied in time and place.

1.3.1. Recruitment

The original MCP project was conducted over an eight-month period in 2008. During this time I spent a minimum of forty hours a week with the team members. Time together included both formal office work, informal social time, outdoor field-work recruiting, and technical support as they implemented interviews and focus groups. The research covered six districts of Lesotho, thereby forcing us into long car drives together and overnight stays in “hotels.” We literally walked miles together, from the middle of nowhere rural recruiting --you go that way, we go this way, walk out for two hours--to urban wealthy neighborhoods with big fences, watch dogs, security guards and cameras at the door. This information is given to convey the time and rapport built with the original nine team members in 2008. Between the time of 2009 and 2012, I had very little contact with the research team members. Correspondence included scarce email exchanges with a few researchers but no continuous exchange such as the use of Facebook, WhatsApp, Skype, etc..

I purposively selected thirteen individuals for this objective of the case study. All of the participants were between the ages of 21-32, at the time of the original study (26-37 at follow-up), self-identify as being Basotho, live in an urban area, have a secondary degree, from either within Lesotho or in South Africa, and have worked for an organization addressing HIV and AIDS. Putting together their
education level, professions, aspirations, and lifestyle I consider them all to be part of the Basotho middle class. The main focus of this study is on nine individuals (3M/6F) who spent between 8-9 months on the research team. I also recruited a comparison group of four individuals (3M/1F) to understand if and how the firsthand experience in conducting qualitative interviews, discussing sexual behaviors, HIV, and multiple concurrent partnerships influenced these individuals. The ideal potential recruitment pool for the comparison group included four individuals who shared the initial pre-pilot training with the “exposed” team but not the six-nine month intense period of conducting and transcribing interviews and focus groups. The comparison group had approximately three weeks of innovation specific training on talking about the body, sex, and HIV, qualitative research methods, and ethics. The intention of this design was to try to compare a group of individuals who all had similar innovation-specific capacity built, pertaining to the capacity necessary to complete the specific project objective with those that had a chance to engage in on-going practice based training and application. This approach draws upon the stated need for more qualitative studies incorporating networks and retrospective cohorts to understand the diffusion process.

Three of the four individuals hired by the project management team resigned from the MCP research team before having a chance to go out into communities and conduct interviews and focus groups. Out of these four individuals, two were recruited into this study. Attempts to track down the other two individuals were unsuccessful. In order to replace the comparative perspective provided by the two individuals lost to follow-up, I recruited two other individuals into the study. The eligibility criteria to recruit the replacement individuals were: they had to have worked for HIV organizations targeting Behavior Change Communications (BCC) around 2008/9; had training and experience in environments where sex, HIV, and multiple concurrent partnerships were part of their professional repertoire; they were Basotho; had a degree from Lesotho or South Africa; and within the same age range as the original MCP team members (26-37). In 2012, while visiting organizations in Lesotho identified as working with BCC and HIV, I inquired about individuals who fit the description. I identified two individuals from two different organizations. One of these individuals had experience with these topics in an office
environment while the other participated in a project similar to that of the MCP research team members going out into different communities and facilitating dialogues.

In 2011-2012 all thirteen individuals were contacted by phone or email and interviews were scheduled. Informed consent documents were sent by email, giving individuals a chance to ask questions prior to the appointment. I conducted interviews in Lesotho from February-March 2012. Most interviews were held at an agreed-upon meeting place in their private office or in the back area of a restaurant. I conducted two interviews over the phone with members of the original MCP team. All interviews were conducted in English, lasted between one and one-half to six hours, audio-recorded and later transcribed.

1.3.2. Study Population Description: Local Researchers

In order to present the complicated human reality within the southern African HIV epidemic, we cannot continue to only present research on traditional units of analysis on the HIV affected: the poor, the vulnerable, the diseased, the “youth”, the factory worker, the sex worker, or the student. It is time to turn the lens to include the educated, employed, middle class, as they are equally affected. Restrepo and Escobar (2005) argue for a world anthropology, where we try to establish space for reflection and discussion:

‘Anthropologies’ multiple changes and repeated crises reveal that it is a highly reflexive discipline that projects itself onto, and receives feedback from, the topics it studies. As a consequence, anthropology is finely attuned to the sociological changes of each period; in a globalized world this calls for more diverse international voices and perspectives actively participating in any assessment of the frontiers of anthropological knowledge. Studying each other as anthropologists becomes important from this perspective. Indeed, a globalized world is a perfect scenario for anthropologists to thrive, since one of anthropology’s basic lessons is respect for difference. A discipline that praises plurality and diversity needs to foster these standpoints within its own milieu (Restrepo and Escobar 2005: 119).

With this in mind, I present the arguments and theory of my peers, intellectuals, and professionals in Lesotho. Drawing upon traditional ethnography, I present the products of a relatively intense and long-term relationship allowing texts from interviews to reflect the open dialogue and commentary of these individuals on their own culture and lives. The local researchers of this dissertation study are
representative of the potential future leaders in Lesotho and beyond in Southern Africa as they migrate for further education and work. As such, what they gained (or failed to gain) from the MCP research experience may shape the lives of many for decades to come. Because of my small sample size, and the fact that some of what they say includes profoundly personal details about their own sex lives, relationships, and political critique, I do not divulge the identity of my participants.

At the time of the MCP study in 2008, the ages of these participants ranged in the early twenties to early thirties. A majority of the participants recently completed their university degree and were on the market looking for paid employment. Collectively these individuals had research experience from their own academic studies and short-term research contracts. Cumulatively, they had more background in quantitative than qualitative research. Six participants mentioned previous volunteer experience. Those who mentioned volunteer experience prior to the MCP project were younger and came from economically stable families. It is noteworthy that all the participants in 2008 held a secondary and tertiary degree.

The study sample has a diverse pool of social science tertiary degrees including law, anthropology, economics, sociology, public administration, psychology, political science, urban planning, development, communications, education, social work, and human geography. All of the participants mentioned a close kin as having a higher degree or a specialized profession. By the time I conducted the interviews in 2012 changes in both personal and professional realms were evident. Five individuals were pursuing or had completed a further degree of specialization and three had mentioned plans for further studies. In 2008 only two individuals were married; by 2012 six individuals were married and had children, four were unmarried but in stable long-term relationships, and three were unmarried single. At follow-up in 2012, the unemployment rate within this population was zero.

In the four-year period, some individuals crossed between work at the university, with NGOs/international organizations, and the government. Reflective of the important role of government and international funding in employment and the economy, none of these individuals noted working in the private sector during the 2008-2012 period. For those who took the government path, all noted
dissatisfaction with their pay and work environment; whereas those who took the path of NGOs and international organizations commented on periods of unemployment and instability. A majority of the study participants live in Maseru or within an hour driving distance from the city-center. A few live in South Africa for studies and work. Based on their relative buying power, compared to the average Basotho, employment status, current education level, education, and professional level of their close kin, as well as lifestyle and aspirations, I classify the study population as being in the upper middle class.

1.3.3. Data Collection Methods

Semi-structured interviews consisted of a predetermined set of open-ended questions, probes, and a few rating questions. The aim, however, was for respondents to speak as freely as possible and leave space for them to expand upon their answers. I structured the interviews around the following factors: the anticipated consequences of taking part in the research team, unanticipated consequences, their capacity to cope with the epidemic personally and communally, and a reconstruction of their networks of communication about HIV and MCP. I used the same guide with the four “non-exposed” participants taking out questions that did not pertain to them and adapting the wording to fit their experience with the original research team. I gave particular attention to asking about how and where they learned about MCSP and what exactly motivated the conversations they had (or did not have) with their network.
Communication network diagram: Rogers and colleagues outline the importance of knowing “who talks to whom and what they say to each other about the innovation” (Rogers, Vaughan et al. 1999: 193). I trace if the local researchers spread the innovation (e.g., the knowledge they acquired about MCP and HIV) and if they did, to whom and how if they did not spread the knowledge, uncovering the reasons. In order to make “visible” their communication networks, I reconstructed a communication network of who they have “educated” about MCP and HIV. The format of this activity is quite similar to the “Time Line Follow-Back (TLFB) method” that the research team members used to document the sexual histories of individuals they interviewed in the original study. As a consequence, their ability to understand the directions and implement the activity was easier for these participants than for someone exposed to the method for the first time. The TLFB was originally developed to assess alcohol use but has been shown to be valid for use in HIV behavioral research as well. It is a combination of open-ended interviewing techniques with findings from cognitive psychology about the value of memory aids that come together to aid the respondent in recalling detailed behavior patterns over an extended time period (Carey, Cerey et al. 2001). In general, participants are asked about a specific behavior. For example, for the original MCP study it was sex, and were asked to recall how many times and what was the context of each sexual act, every month over a one year recall period. The way in which it is implemented by the interviewer triggers interviewee recall to bring to the fore what would normally be deemed as insignificant or “forgotten” details.

In this section of the study focusing on the research team members (objective one), the “behavior patterns” or outcomes studied are their conversations about MCP and HIV. The activity asks participants to recall if during their time on the research team and afterwards if they ever had any quality conversations with people about HIV and MCP. The judgment of what is considered “quality” is left to the participant but to aid in operationalizing the question I explained that I was asking about any conversation where they used some of the knowledge or ways of talking about HIV, MCP, and sex that they learned from the project. If needed, I clarified the concept of quality by distinguishing that after the conversation you felt that something had changed in you or that you changed the other person. In the case
of “non-exposed” participants, I paid particular attention to the latter clarification of “quality.” I asked respondents to recall with whom, when, and where the conversation took place and to explain what made them decide that this particular conversation was “quality.” I also asked about attempts to have conversations that were not successful. As the respondent filled in names and dates of conversations, I probed about different contextual factors in these encounters.

At first glance, this may seem like an impossible task, after all, who remembers the topics of conversations they have had over a four-year period? What makes the activity realistic is that quality conversation about HIV and MCP are typically rare and emotionally charged, rendering them exceptional, and memory of the conversation more likely to be triggered with some probing. For the American reader, this trigger mechanism could be likened to recalling a quality conversation about abortion, elections, parent’s rights in immunization, or gun control. If anyone has had a conversation with someone where a true conversion of ideas have occurred inevitably emotions, convictions, and intellectual arguments were raised elevating the conversation beyond the norm and memorable if probed.

To my knowledge this is the first time anyone has used this methodology to measure conversations about HIV. My initial objective was to try to reconstruct if information about HIV and MCP flowed from the research team out to their network of acquaintances, friends, and family. My original research plan consisted of the following steps: 1) pilot the approach with the first ten interviews, then revise, and formalize the implementation steps, 2) implement the standardized revised version on each of the original research team members, 3) following the implementation of the standard version, ask each individual if they can do the same activity with some of the people they listed as having had quality conversations about HIV and MCP. If they say yes, ask them to attend a short training on how to use the instrument, 4) after the training, give copies of the informed consent, communication network worksheet and directions. Compensate original research team members for their transportation and their time in conducting additional interviews with their family, friends and acquaintances, and lastly, 5) if participants do not have the desire or accessibility to complete the activity, ask them if they can contact the people identified on their diagram and refer them to me. I regrettably aborted this plan. After arriving in Lesotho,
a month after the estimated time of IRB approval, I waited an additional four weeks for the IRB chairperson to return from an unexpected “mission” to approve the minor clarifications on my IRB application requested by the committee. Due to expenses and logistics, I could not extend my stay in Lesotho. Most questions I asked to all participants, but for some interviews there are missing data where a particular question or line of probing was not yet standardized.

1.3.4. Data Analysis

The analysis approach is both explanatory and comparative. By explanatory, I mean that I use a combination of deductive and inductive methods. Drawing on Morse and Mitcham’s stepwise conceptual research process (2002), I deconstructed concepts from existing literature and developed a skeletal conceptual framework for data collection that focused my inquiry but unlike strict confirmatory analysis left space for the discovery of content driven dynamics within the structure. Most influential in my analysis is the approach described by Guest, MacQueen and Namey (2012) as applied thematic analysis, where a mix of theoretical and methodological approaches in qualitative research are mixed to develop a synthesized methodological framework that is designed to identify and examine themes that is transparent, credible, and ethical. As they describe applied thematic analysis, “its primary concern is with presenting the stories and experiences voiced by study participants as accurately and comprehensively as possible” (Guest, MacQueen et al. 2012: 16). A central component of the applied thematic analysis approach is the development of a codebook which is a discrete analysis step where the observed meaning in the text is systematically sorted into categories, types, and relationships of meaning. In order to create the codebook, I audio-recorded all interviews and transcribed each interview verbatim using F4 software. Notes written during interviews on communication networks were scanned into electronic format. I uploaded research files into MAXQDA 11 Plus. All interviews were first read and structurally coded based on the pre-determined domains in the interview guide. I extracted descriptive information from interviews such as age, education, family education, economics, marital status, children, and employment and entered them as variables. During this first pass, larger-level emergent themes were identified and
defined. I applied tips developed by Ryan and Bernard in developing themes such as paying particular attention to thematic and linguistic clues such as repetition, indigenous categories/typologies, metaphors and analogies, transitions, similarities and differences, linguistic connectors, and silence/missing data (Ryan and Bernard 2000). I read all interviews a second time to check if I applied structured codes (codes developed from existing literature and the research guide) correctly and to apply new codes defined from the emergent themes. I made a third focused reading of structural and emergent codes and created sub-codes to reflect groupings or factors in responses. Using MAXQDA 11 I ran code frequencies, matrices, word searches (counting specific words in the text), and key-word-in-context (KWIC) to take into account the text surrounding the words of interest and to document the relationships between pieces of text such as word or concept co-occurrences (Guest, MacQueen et al. 2012). I stratified the diffusion network information by gender, MCP original team members vs comparison group, “high” diffusers and low diffuser, and quantified differences amongst groups. I also created visual diagrams to aid in contrasting the quantity and with whom the participants talked.

1.4. Methodology: Organizational Uptake of Qualitative MCP Research Findings

One of the main critiques of the utility of qualitative research for policy and action is that it is cumbersome and takes too much time to conduct and synthesize (Rist 1994). As a result, qualitative research has often taken the form of simpler Knowledge, Attitudes, and Practices studies or rapid appraisals when informing policy makers and practitioners who are often working on tight timelines (Estrella and Gaventa 1998; Chambers 2007). However, this research was created with and for policy makers in an effort to be relevant and timely in disseminating findings (Khobotlo, Hildebrand et al. 2009). Therefore, it offers a unique window into the potential, and points to improve, for making complex large qualitative data sets user-friendly. Additionally, qualitative studies similar to this one are increasingly being conducted in order to inform as well as adapt studies and interventions. Learning how the diffusion and uptake process occurred with target audiences in such a case study will undoubtedly improve our
understanding of the dissemination process and increase the likelihood for other studies to have the most impact for the resources invested.

From the original study dissemination objectives there were several distinct organizational and policy targets for the MCP qualitative findings. While the research partners and team made their efforts in dissemination, the next question is: what was the uptake of these findings? Applying Rogers’ DOI, I pay particular attention to identify social networks, champions, and points of resistance in the diffusion of research results. I use his concept of the difference between homophiliac and heterophiliac interactions in the transmission of an innovation to see if those who self-identify as being indigenous (Mosotho) or an expatriate display any differences in their reception and application of the MCP research results (Rogers 2003).

1.4.1. Recruitment

I reviewed project reports to identify organizations that were targeted audiences for the research findings as well as current organizations targeting behavior change communication and HIV prevention (many of these are funded by US private and public funding). Organizations were contacted by phone for an appointment. I also asked the organizations contacted if they knew of other organizations targeting behavior change and the prevention of sexual transmission of HIV. In light of the high prevalence of staff turnover and structural reform in many of these organizations, some individuals no longer worked with the target organizations or were newly placed within the last three years. A total of ten organizational representatives were interviewed. Some participants had actually worked for more than one prevention organization, bringing the number of organizations discussed to fifteen. In these cases, efforts were made to discuss the specific experience with MCP findings and especially how each organization learned about research or “evidence”. Since there were a few different MCP studies and activities, I probed to understand clearly which MCP research respondents were referencing and how they were using this knowledge.
1.4.2. Data Collection Methods

Structured interviews: The interviews consisted of a standard closed-ended, and a few open-ended, responses to determine how the respondents knew about the findings, how they were integrated into their prevention efforts, and in general how they learn about research or “evidence”.

Document Review: While in Lesotho I gathered grey documents from different organizational representatives and searched online for others. These documents included policies, reports, research reports, outreach materials, and pamphlets. Of special note, the National AIDS Commission was not in operation during my visit nor was its website. In previous years they were responsible for monitoring, evaluation and coordination of the many organizations in Lesotho. Since they were no longer available, I used lists of organizations from policy reports, Letsema/Sentebale’s website, and a draft list of SBCC organizations from the Lesotho John Hopkins Communication Change 2012 mapping exercise.

1.4.3. Data Analysis

I transcribed interviews and downloaded them into MAXQDA, coding structural and emerging themes (as described in 1.3.4). Based on the organizations listed in some of the grey documents and on the Letsema/Sentebale website, I downloaded and input organizations into an Excel spreadsheet. Reading grey documents and online website descriptions they were categorized by prevention activities. I then separated out all the organizations documented as working with behavioral communication and change. From this list, based on references made in grey documents and online descriptions, I categorized the BCC prevention organizations by type of main objective activities such as testing and counseling, parent to child transmission, vulnerable children, support (food, livelihoods), and specific mention of sexual education such as “life skills”, condoms, awareness, multiple concurrent partnerships, and dialogue. I then ran frequencies and created bar graphs to display the categories.
1.5. Protection of Participant Identity

The original research project was one of several research projects at the time on sexual behaviors and HIV in Lesotho. However, the information in the final MCP research project report and information found on the internet lists the names of potential participants in this dissertation, making it possible for a person to trace the identity of participants. In order to add a layer of ambiguity, each participant has a pseudonym and/or participant number. They were not told their own pseudonym and attempts are made to edit identification of responses from a single individual. Thus, a person may be able to determine the identity of some of the participants within the entire study but they would not be able to disentangle who said what. Nonetheless, the actual participants who know each other well, will most likely be able to “identify” their own voice and the voice of their friends within the text. Confidentiality is not the sole responsibility of the principal investigator here, but shared with those who participated.

1.6. Overview of Chapters

Background: In Chapter 2, I discuss the specific HIV and AIDS statistics for sub-Saharan Africa and the hyper-endemic zones of east and southern Africa and the “why” behind these high numbers. I then outline a few of the key debates pertinent to prevention strategies proposed for ending the epidemic in high prevalence zones. After presenting some of these debates, I critically discuss in detail the 2015-2030 strategy shared by large global stakeholders such as UNAIDS, US government and the WHO known as the “Fast-Track” approach. The purpose of presenting the strategy is to establish where the current points of focus and attention exist for well-funded global entities in context with our understanding of transmission and prevention dynamics. In Chapter 3 a historical background of Lesotho is presented, discussing the history of the country, government organization and economic situation to historicize the problem of HIV in this particular country. The objective of Chapter 4 is to present the concept of diffusion of information as it relates to translating knowledge into practices that help humans. I discuss health science approaches to the problem of diffusing research into practice. I explore how
elevating particular research practices to praxis, reflection and action a heightened awareness of how everyday practices link to larger systems, in qualitative research and capacity building, can improve HIV prevention information diffusion.

**Results:** Chapter 5 delves into the details of what we know about MCP in Lesotho, how this wealth of information about MCP gets integrated into local initiatives and what factors affect (either facilitating or preventing) their adoption. The overall goal of Chapter 6 is to present a quick glimpse into how the middle class research population discusses how people in Lesotho talk about HIV and MCP in 2012, providing a context for understanding the consequences of their research experience. Chapter 7 presents data bringing to light the general and specific capacity building consequences on local researchers after implementing a qualitative health research project. Chapter 8 presents the results of some of the long-term effects on the local researchers furthering our understanding of the different ways that “capacity” is built in the local involvement. The chapter explores critical questions about qualitative research methods and ethics within a context of investigating a disease where everyone—researchers and the researched—are either infected or affected. In Chapter 9 I trace the HIV and MCP communication diffusions of the original research team and a small comparison group in order to investigate if and how these individuals shared what they learned. Chapter 10 presents participant discussions on the sociopolitical and development aspects of the HIV Response in Lesotho.

**Discussion:** Chapter 11 summarizes the main findings of the study with the aim of linking them to practical recommendations for research implementation, dissemination and measuring change. It transitions to looking towards solutions by exploring challenges and points of encouragement in current HIV research and intervention programming in Lesotho.

**Conclusion:** Chapter 12 concludes by applying the research results to create a broader explanatory theory encompassing the problem and future ways of working towards solutions. The chapter also revisits some of the main recommendations specific to MCP in Lesotho from this dissertation as well some of the recommendations provided by other researchers and policy makers on the topic.
CHAPTER 2. HIV, PREVENTION, HYPER-ENDEMIC ZONES IN AFRICA

Trends in prevention and funding priorities in the hyper-endemic zones of sub-Saharan Africa rapidly change, making it difficult to maintain a well-founded grasp on what we “know” about HIV and AIDS. The priorities of large global stakeholders are oftentimes setting the agenda, consequently leaving out important cultural and context specific aspects of prevention, making the importance of inter-generational and cross paradigm dialogue between and amongst professionals and locals working in HIV prevention even more essential. In this chapter, I first discuss the specific statistics for sub-Saharan Africa and the hyper-endemic zones of east and southern Africa. This discussion opens up into the broader contributions of HIV experts to our understanding of the “why” behind these high numbers and consequently how these understandings influence prevention efforts. I then outline a few of the key debates pertinent to prevention strategies proposed for ending the epidemic in high prevalence zones. After presenting some of these debates I critically discuss in detail the 2015-2030 strategy shared by large global stakeholders such as UNAIDS, US government, and the WHO known as the “Fast-Track” approach. The purpose of presenting the strategy is to establish where the current points of focus and attention exist for well-funded global entities in context with our understanding of transmission and prevention dynamics.

2.1. HIV Death and Disease Burden in sub-Saharan Africa

HIV spans across all income group countries. UNAIDS estimates that since 2000, 38.1 million people have become infected with HIV and 25.3 million people have died of AIDS-related illnesses (UNAIDS 2015a). In 2014, an estimated 36.9 million people were living with HIV, and 1.2 million
people died of AIDS-related illnesses (UNAIDS 2015a). The WHO 2015 HIV/AIDS report, approximates that only 51% of all people living with HIV know that they have the virus (WHO 2015a).

Of the estimated 38.1 million people living with HIV, 25.8 million, or 70% of the global total, are in sub-Saharan Africa (UNAIDS 2015a). Sometimes this number is portrayed as reflective of the reality in all sub-Saharan Africa. The epidemic varies greatly between countries and within countries. For example, putting together all of the sub-Saharan region the HIV prevalence is 4.7%. The difference between and within the worst and least affected countries and regions within sub-Saharan Africa also vary greatly (UNAIDS 2014). For example, Senegal reports a 0.5% prevalence while Swaziland 27.4% has the highest prevalence of any country worldwide, yet South Africa has the numerically largest epidemic of any country with 6.8 million people living with HIV and an estimated adult prevalence of 18.9% (UNAIDS 2014).

Southern Africa is the worst affected region and is widely regarded as the 'epicenter' of the global HIV epidemic. Within the Southern Africa region AIDS mortality, morbidity, and disability are extremely high. Lancet reports on global diseases, mortality, and morbidity note that in South Africa, with 58 million citizens and the second residence for many people from neighboring countries, HIV/AIDS was the leading cause of death and disability in 2013 (Global Burden of Disease Study 2013 Collaborators, Vos et al. 2014; Murray, Ortbald et al. 2014). The reports also note Zimbabwe, Malawi, and Mozambique as also having HIV/AIDS as the leading cause of death and disability (Global Burden of Disease Study 2013 Collaborators, Vos et al. 2014). Other countries often listed in the top ten prevalence include Zambia, Namibia, Botswana and Tanzania, with Swaziland and Lesotho often listed at the top of the list. In Lesotho, HIV prevalence was 22.9% in 2013, an estimated 360,000 people were living with HIV and 16,000 died from AIDS-related illnesses in 2013 (UNAIDS 2014). According to UNAIDS the HIV incidence declined slightly from 30,000 new infections in 2005 to 26,000 new infections in 2013 (UNAIDS 2014).
2.2. Why is the Epidemic so Bad in Some Areas of sub-Saharan Africa and NOT Elsewhere?

In this section I discuss the broader contributions of experts to our understanding of the “why” behind the high prevalence of HIV in certain areas of sub-Saharan Africa, and consequently how these understandings influence prevention efforts. Throughout the epidemic in sub-Saharan Africa anthropologists and other experts have walked the thin line of attempting not to “exoticize” Africans while trying to describe behaviors that could make sense of why the epidemic is so bad in certain areas of sub-Saharan Africa and NOT elsewhere. Significant contributions to this end are the historical and cultural factors influencing the epidemic. As Green describes:

Anthropologists and others have written persuasively of the historical and cultural underpinnings of these relationships: the effect of long-term patterns of oscillatory labor migration; the economic inequality that has created desire for consumer goods that fuels many sexual relationships; cultural patterns of polygyny that have created contemporary expectations of multiple partners (among men) even when polygyny and the jural responsibilities and societal expectations that accompany it are no longer practiced (Green and Herling Ruark 2011: 248).

Explanations for the “why” behind the high rates in sub-Saharan Africa are not aspects of the epidemic frozen in chronological time according to when it was discussed in scientific circles. Instead, these ideas and explanations about the “why” persist within and outside of the hyper-epidemic areas shaping how people justify prevention approaches.

2.2.1. Sex and Culture

Cultural practices that involve sex such as widow cleansing (the practice in which a widow engages in symbolic or actual ritual intercourse with her dead husband’s male relatives), dry sex (utilizing various methods to dry or tighten the vagina), vaginal cleansing (utilizing soaps, cloth, and leaves to cleanse) and ritual circumcisions using the same blood-tainted tool are thought to be part of the problem (Brown, Ayowa et al. 1993; Buve, Caraël et al. 2001; Nyindo 2005; Low N and Chersich MF 2011). While these may be attributing factors, some have argued that generalizing and exaggerating the
The attribution of these factors is a wrong target for prevention (for example, widow cleansing is often not reported in many high prevalence zones), whereas preference for “wet” sex is found in many high prevalence zones. Some of these practices are not incompatible with safer sexual behaviors and by myopically focusing on these practices we alienate rather than facilitate cooperation (Sandala, Lurie et al. 1995; Gausset 2001). Another lens used to describe the why behind the epidemic’s rapid spread was the “sexual system” of Africans. This system included the relative sexual freedom of black women in comparison to other women in the world, higher rates of casual and premarital sex, polygamy, and the cultural desire for many children (Caldwell, Caldwell et al. 1989; Caldwell and Caldwell 1993; Orubuloye, Caldwell et al. 1994). While polygamy and the cultural desire for many children is for the most part true, as a cultural ideal, some studies suggested that Africans were not more promiscuous than heterosexuals in other parts of the world and that African men and women reported similar and, in some cases, fewer lifetime sexual partners than many Western countries (Buve, Caraël et al. 2001; Caraël 2006). Multi-center studies in the early nineties, compiled by the World Health Organization documented the average sexual debut in Africa to be in the late teens, in fact similar to the average age in Europe and the United States. These studies also demonstrated that men in Tanzania, Kenya, Lesotho, and Zambia reported less casual sex partners than the men in Thailand and Brazil who reported five or more partners in the previous year (Cleland and Ferry 1995).

**2.2.2. Structural Violence and Political Economy**

The late eighties and nineties were dominated by behavior change models such as self-efficacy, learning theories, social cognitive theory, theory of reasoned action, stages of change, and the health action process (Smith and Whiteside 2010; UNAIDS 2010; AIDS.gov 2016). These models all rely on the individual recognizing their “behavior” as something in need of change and then taking the control or going through various processes to change the behavior in question. While this is definitely important in HIV prevention, it is unlike gambling, drinking alcohol, or eating, in that an individual’s “risky” sexual act is not at all “individual”. Furthermore, there is a complex web of social and environmental factors
influencing perceptions and expectations for what is “normal” or sex not in need of “change” (Pisani 2008; Green and Herling Ruark 2011).

Structural violence is the theoretical framework for the analysis of institutionalized processes of inequality that create risk in everyday life (Farmer 1992; Scheper-Hughes 1992). Anthropologists and others have used this paradigm to show how the structural violence of poverty and other inequalities form the context of belief and action. The strength of this paradigm is that it fills the gap describing the constraining environment for “behavioral change”. It shows how macro and micro economic forces that perpetuate social inequalities constrain an individual’s life choices. Using this framework, social scientists demonstrated the fallacy and danger in the previously dominant individualistic behavioral paradigms. In so doing, they shifted the HIV/AIDS paradigm to contextualize and integrate social inequalities, political economy and cultural and structural concerns (Schoepf 1992; Sobo 1995; Gifford, Suanching et al. 1999; Parker, Easton et al. 2000; Schoepf 2001; Susser 2001; Teunis 2001; Basuki, Wolffers et al. 2002; Schoepf 2003a; Schoepf 2003b). Related to this paradigm, estimates and models highlighted dynamics related to poverty, inequality, and education that shape the context in which individuals make decisions about sex to explain the why behind high prevalence zones. For example, structural forces of poverty, access to education, inequality, and gender result in uneducated, disempowered women and families separated for employment. Within these structural constraints they developed different types of relationships to fulfill sexual, emotional, and practical needs rendering them more susceptible to transmission (Romero-Daza and Himmelgreen 1998).

However, this perspective is criticized for being overly critical to the extent where human agency is confined to the point of near determinism from structural factors and further that stories of structural violence often assume a “convention-laden” voice of suffering to be heard in a public, international sphere that unfortunately does not exist (Butt 2002). Or where a broadbrush usage of the structural violence concept obfuscates the multiple layers of analysis related and embedded in the linkages between violence, suffering and power (Bourgois and Scheper-Hughes 2004). The theory was also extracted to make large-scale generalizations to explain the high prevalence in sub-Saharan Africa (Epstein 2007). In
attempts to simplify complex interactions of structural factors, while conveying a story worthy of funding, the narrative of the sub-Saharan epidemic transformed into a type of justification that overshadowed the dynamic and localized ways that structural factors influenced the trajectory of the epidemic (Pisani 2008). For example, the simplistic argument that HIV would be higher in poorer countries, much higher in countries where, where male literacy is higher than females, and areas with more males in the cities than women (Mead 2000), did not “prove” always true when overlaid on some of the high and low prevalence countries. For example, Lesotho has one of the highest literacy rates in the world, females are more literate than men, HIV is lowest in the poorest households and highest in the richest and women with more education are more likely to be infected with HIV than women with no schooling (LDHS 2004). Rather than dismissing the core value of the structural lens, based on a misappropriated use of the theory, anthropologists and others have continued to demonstrate the importance of incorporating the complexity and dynamism in local, social, political, economic, and gender nuances influencing the epidemic. This is evidenced in theories and practice attempting to integrate structural approaches for explanatory purposes, but more importantly moving towards solutions (Blankenship, Friedman et al. 2006; Bonell, Hargreaves et al. 2006; Latkin, Weeks et al. 2010; Wamoyi J, Mshana G et al. 2014; Brown, Reeders et al. 2015). For example, Fox’s analysis of over 140 countries demonstrates nuances that her research found, where inequality trumps wealth in terms of association with increased individual risk of HIV infection and the paradoxical reality in epidemic trends where wealthier regions/countries and individuals with less wealth were more likely to be infected with HIV in contrast to poorer regions/countries with individuals with more wealth were more likely to be infected with HIV (Fox 2012).

2.2.3. Biology, Ecology, Hunger and Poverty

Another paradigm to explain the high rates of vulnerability in Africa is ascribed to the long-term effects of malnutrition and infections weakening immune systems and creating ripe territory for the virus to quickly spread. Under this paradigm, researchers like Eileen Stillwagon (2005) brought to the fore the
problem of thinking about HIV transmission solely in behavioral and cultural sexual dynamics to show the need for a broader conceptualization of transmission to include the overall health and state of the immune system (Stillwagon 2005). Researchers have demonstrated cases of a high degree of geographic overlap between the highest-prevalence NTDs (soil-transmitted helminths, schistosomiasis, onchocerciasis, lymphatic filariasis, and trachoma) with malaria and HIV, exhibiting a high degree of co-infection and affecting disease progression of HIV and AIDS, tuberculosis (TB), and malarial disease (Simon 2016). Dual infection increases the concentration of HIV in the blood making HIV positive malaria with sufferers more likely to transmit. There are also problems with the misdiagnosis of chronic genital schistosomiasis for an STD, which when left untreated continues to provoke lesions, bloody discharges, ulcers, and “malodorous discharge” (Kjetland, Hegertun et al. 2014; Stecher, Kallestrup et al. 2015). They argue that the combination of immunological, epidemiological, and clinical factors interact in ways that are underestimated in understanding the spread and coverage of these diseases in sub-Saharan Africa as well as the possibility of confounding results in clinical trials (Stillwagon 2005; Ivan, Crowther et al. 2012; Kjetland, Hegertun et al. 2014).

Harvard molecular biologist Essex (1999) proposed that the type of virus in sub-Saharan Africa facilitated a more virulent spread of transmission. HIV-1 is much more virulent than HIV-2, and the subtypes of HIV-1, such as C, E, and A, are transmitted more efficiently than HIV-1 B, which is the major subtype in the United States and Europe. However, critics have pointed out that the same virulent strains have been found in European and U.S. patients but did not seem to accompany higher rates of HIV, thereby, while the increased virulence of HIV-1 and particular subtypes may contribute it does not fully explain the why behind the high rates (Epstein 2007). Nonetheless the knowledge about molecular evolutionary changes of the virus are fundamental for vaccine and other technological means of preventing transmission (Nkolola and Essex 2006). Malnutrition, weakened immune systems, and strong viral variations clearly played a role in the spread of the virus and should be taken into consideration in formulating prevention and treatment approaches. A blanket explanation for higher rates based on this argument cannot be blindly applied. Some researchers have argued this by highlighting countries, such as
Liberia, Congo, Sierra Leone, Ethiopia, and Somali, countries with high malnutrition and parasite loads but having relatively lower rates of HIV than many countries in sub-Saharan Africa (Epstein 2007; Mishra, Bignami-Van Assche et al. 2007).

2.2.4. Structural Factors and the Epidemiological Pump

Another justification was the notion that high-risk groups had mingled with low-risk groups spreading the epidemic beyond the public health “target” population of sex workers, truck drivers, soldiers, mineworkers, and migrant workers. In this paradigm, the number of partners is less important than the with whom. Roy Anderson of Oxford University described the African epidemic as an “epidemiological pump,” where sex, unlike in gay men, drug users and their partners, crossed social boundaries between rich and poor, urban and rural, old and young, creating the right mix to spread the disease throughout the general population. The consequence of this idea on prevention was that if transmission could be stopped at the root “high-risk” sources, by their using condoms and treating STDs, the virus would not spread (Anderson, May et al. 1991; Hunter 1993; Buve, Caraël et al. 2001). The epidemiological pump aligned well with anthropological approaches outlining the “why” behind the pump as related to the unique historical, social, and economic structures that fostered the spread of HIV in countries most severely hit by the epidemic. However, unlike other similar settings, like India and Thailand, the prevalence rates within the general population never exceeded that of the “high-risk” groups of sex workers, their clients, migrant workers, truck drivers, and soldiers. In East and Southern Africa people in the general population, teachers, public employees, and members of the government had similar prevalence and sometimes even higher rates than “high-risk” groups (Williams, Gilgen et al. 2000; Coffee, Garnett et al. 2005).

2.2.5. Multiple and Concurrent Partnerships

What is clear is that there are complex structural, cultural, biological, and economic dynamics accounting for the spread of HIV through the general population in sub-Saharan Africa. According to
Epstein (2007) one of the main factors, not given enough attention, is the role of multiple and concurrent partnerships. Within this paradigm promiscuity and other difficult to identify “high-risk groups” are the trigger. What increases the rate of transmission is the nature of having more than one partner (multiple partners) at the same time (concurrently). In other words, a doctor in Belgium may have five sexual partnership in a year, with a five-year record of twenty-five sexual partners. He is married and lives with his wife in a practically separated sexual way. Instead, he keeps a girlfriend outside of the marriage, changing them every couple of months. Nevertheless, he has girlfriends one at a time. In contrast is the woman in Lesotho who has a “friend” back home in the village, a husband in the city where she works and lives most of the time, and her school days sweetheart who lives in the town where she does monthly rounds for her medical practice. In the past five years she has kept these same three partners. Both of these people have their sexual and emotional needs met by the different partners in their life, both can be interpreted as being “faithful” in their own way. Putting HIV into the equation changes everything. Simultaneous sexual partnerships are argued to be more dangerous than serial monogamy “because they link people up in a giant web of sexual relationships that serves as a superhighway for the rapid spread of HIV” (Epstein 2007: 55).

There are two points in time when the virus load peaks within the body; when it first enters the body and after the immune system is compromised, when the patient has AIDS symptoms. A recently infected person may be a hundred or even a thousand times more likely to transmit the virus than someone who has been infected for months or years (Chakraborty, Sen et al. 2001; Pilcher, Tien et al. 2004). The problem with the first peak during concurrency is that this person is not diagnosed as HIV positive. Returning to our previous example, the Basotho woman can simultaneously infect all three partners in that one month period. Unlike the Belgium man, practicing serial monogamy, whereby the first peak passes before he moves on to the next partner having a lower viral load and less likely to pass on the virus. Furthermore, the different pattern of behavior by the woman also means that her extra partners could easily transmit the disease to their other long-term partners.
Early scientific work developing the multiple and concurrent sexual network paradigm included case studies, sexual behavioral studies, and mathematical modeling (Hudson, Hennis et al. 1988; Watts and May 1992; Hudson 1996; Morris and Kretzschmar 1997). Epstein (2008) describes how British physician Christopher Hudson working in a London STD clinic observed the differences between his white patients reporting more genital warts and his black patients reporting more gonorrhea. He conducted a sexual behavior study and found that his black patients, who were predominantly recent immigrants from the Caribbean, reported a different type of sexual history. Both groups had the same average number of lifetime partners but the white group practiced more serial monogamy while the blacks were more likely to have steady, long-term “concurrent” relationships. Genital warts are infectious over a long period of time whereas gonorrhea is infectious only for about six months. Putting together the sexual histories of concurrency meant that gonorrhea could spread much faster in the black population whereas it would run its course and be less infectious in the white serial monogamist group. Applying his gonorrhea theory to HIV in Uganda the evidence seemed supportive (Hudson, Hennis et al. 1988).

Sociologist and statistician Martina Morris and Mirjam Kretzschmar used sexual behavioral studies along with computer modeling to quantify the effect of sexual networking on HIV transmission in Uganda, US, and Thailand (Morris and Kretzschmar 1997). They found that US respondents reported more partners but less concurrency, thus the theory of concurrency seemed to match the projected HIV rate. In fact, WHO surveys for the late 1980’s found that in several countries the rate of self-reported concurrency to be quite high. In Tanzania, 18 percent of men and 10 percent of women said they had more than one long-term partner; in Zambia, 22 percent of men and 10 percent of women and in Lesotho 55% of men and 40% of women did (Cleland and Ferry 1995; Morris, Epstein et al. 2010). All of these countries are currently in the world’s top ten HIV rates list. Additional elements important to the theory include the type of sexual partner and the length of time of concurrency. For example, in some cases short-term partners are more likely to use condoms (one night stand, sex worker) versus more stable relationships. The duration of concurrency, frequency, quantity and type of sex also increase the probability of transmitting the virus. Thus, in the heterosexual general population epidemics it is not a
racial group or country, but those within a certain grouping who have more long-term overlapping partnerships, with regular coital exposure, who are found to have a greater HIV epidemic severity (Morris, Epstein et al. 2010). Furthermore, concurrency as a risk factor for HIV is not pertinent to only the concurrency “practitioner” but also to the partner. A US study found no correlation between concurrency and an individual’s risk of sexually transmitted infection, but people whose partner had concurrent partners were three and half times more likely to be infected than those whose partner did not have concurrent partners (Gorbach, Drumright et al. 2005). An additional gender element to the concurrency argument is that levels of HIV within the general population could only reach these high levels if both men and women within a population have more than one partner. Using a mathematical framework for dynamic partnerships a small increase in the level of concurrency can lead to crossing the epidemic threshold in heterosexual partnerships, but concurrency in the MSM population is not as decisive (Leung and Kretzschmar 2015).

The concurrency hypothesis as an explanation for the rapid spread of HIV in sub-Saharan Africa is fervently debated. Sawers and Stillwagon (2010) argue that qualitative evidence offered on concurrency is “irrelevant since, among other reasons, there is no comparison of Africa with other regions” they also critique the mathematical models used to correlate concurrency with the rapid spread of HIV and the quality of data sources and ways of defining and measuring concurrency (Sawers and Stillwagon 2010). Using concurrency models published in 2010 they incorporate “coital dilution” (lower coital frequency) in non-primary partners and argue that slightly lower coital frequencies lead to epidemic extinction and repeat their call for alternative explanations for HIV epidemics in sub-Saharan Africa (Sawers, Isaac et al. 2011). Sawers (2013) critiques the concurrency hypothesis explanation for exceptionally high HIV prevalence pointing to recent surveys using a different questionnaire design and definitions where reported “concurrency” ranged between 0.8% to 7.6% in the region, an amount that could not generate sustainable epidemic trajectories (Sawers 2013). For example, asking how many overlapping partners you have today, this year, or in a lifetime changes greatly rates of “concurrency.” Others have operationalized concurrency as a test of whether concurrency practiced by an index case predicts their HIV status, thereby
a negative finding disconfirms the concurrency hypothesis, reporting no link with concurrency (Lagarde, Auvert et al. 2001; Jewkes, Dunkle et al. 2006; Mattson, Bailey et al. 2007; Mishra and Bignami-Van Assche 2009). Proponents of the concurrency hypothesis argue that this is actually a test of the wrong relationship because you would need a study design that enrolls both partners (including those non-cohabitating or on the down low) to measure the correlation between index case concurrency and their partner’s HIV status. Some studies that have collected data on partner’s status and/or behavior and HIV biomarkers, have supported the concurrency hypothesis (Hugonnet, Mosha et al. 2002; Johnson, Alarcon et al. 2003; Mermin, Musinguzi et al. 2008; Guwatudde, Wabwire-Mangen et al. 2009). This is also true for studies of other STIs (Potterat, Zimmerman-Rogers et al. 1999; Koumans, Farely et al. 2001).

Despite the debates, there is a broad consensus that MCP is indeed a factor in the transmission of HIV in the hyper-endemic areas of southern and eastern Africa (Mah and Halperin 2010; Mah and Shelton 2011). The magnitude of its role varies greatly within and between populations but several countries in the hyper-endemic zones have quantitative and qualitative evidence confirming the co-existence of high rates of concurrency and HIV within the population. In fact, after the 2006 Southern African Development Community (SADC) Think Tank Meeting stakeholders placed MCP on the prevention agenda (SADC 2006). Several studies, such as the original study serving as the case study in this dissertation, investigated the rates and social dynamics of MCP in the hyper-epidemic zones of sub-Saharan Africa. In 2009, the Harvard AIDS Prevention Research project sponsored a research meeting with UNAIDS and The World Bank that convened key experts on MCP-related prevention from the South African region, including representatives from UNAIDS, World Bank, Population Services International (PSI), and several national HIV initiatives (UNAIDS 2009). Participants reached the consensus that the top priority was to discourage multiple and concurrent partners and condom promotion as secondary. The meeting also reviewed lessons learned from other MCP programs and developed action plans for immediate application. Some of the actions considered appealing to clan and national pride; creative use of fear-based messages balanced with personal efficacy messages to change dangerous behaviors; and values (Green and Herling Ruark 2011). For this latter component the importance of
values not being imposed from the outside but allowing chiefs, indigenous leaders, African independent churches (syncretic sects blending traditional religion and culture with Christianity i.e. Zionist, Shembe), indigenous religions, Muslims, and Christians to build upon their own perceptions of what values to uphold and what to throw out (Green and Herling Ruark 2011).

Thus, in the late 2000s the importance of concurrency seemed to be a concept understood and shared as a prevention high priority. Yet, when it comes to programming and broader social action directly targeting MCP the message seems to be underplayed by the shift in focus to male circumcision, condom promotion, testing, and treatment.

### 2.3. HIV Prevention Debates for Ending the HIV Epidemic in sub-Saharan Africa

Over the last ten years there has been ongoing debate about “evidence” based solutions. Evidence is linked to justifications for funding. During this period social scientists and many indigenous leaders have implemented social and behavioral approaches to change root causes fueling the epidemic and to create environments supportive of protective changes. However, there is limited evidence about the effectiveness of behavior and social change movements and interventions. Green argues that these interventions are relatively new and little money gets spent to evaluate them; “Yet this absence of evidence (which is not evidence of absence) has led much of the AIDS community to become profoundly discouraged about HIV prevention” (Green and Herling Ruark 2011: 243). Some researchers argue that some of the best solutions have never been measured. For others, this weak evidence supporting change in HIV incidence means that it is better to focus on the types of efforts that have hard scientific evidence supporting their efficacy. These solutions include, testing, condoms, PrEP (pre-exposure prophylaxis, the use of anti-HIV medication that keeps HIV negative people from becoming infected), PEP (post-exposure prevention), ARVs (medications that treat HIV), and voluntary medical male circumcision. Many times evidence for these solutions begin in laboratory or clinical trial settings and have statistical evidence to demonstrate decreases in the biological passage of the virus. Social and cultural change is important in only how they affect the adoption of these solutions.
As the road ahead in HIV prevention is constructed, priorities are set, and funding is allocated, debates about aspects of prevention become even more important. The following section highlights some of the key debates pertinent to prevention strategies proposed for ending the epidemic in high prevalence zones in sub-Saharan Africa.

2.3.1. Abstinence Only and Virginity

Naïve and simplistic arguments about HIV prevention have posited that when faced with the threat of a life-threatening disease, “no sex” seems an easy and feasible choice. That would be easy if death were automatic and painful, but the human reality of a sexual relationship is instantaneous and tangible, while transmission of HIV is a probability and not an immediate threat to life. In some contexts, especially religious, abstinence is an idealized prevention expectation. However, studies show a consistent gap between good intentions and real practice. A U.S. study compared the sexual activity of adolescent virginity pledgers with matched nonpledgers (Rosenbaum 2009). Adolescents who reported taking a virginity pledge on the 1996 survey (n = 289) were matched with nonpledgers (n = 645) on factors including prepledge religiosity and attitudes toward sex and birth control. Pledgers and matched nonpledgers were compared 5 years after the pledge on self-reported sexual behaviors and positive test results for Chlamydia trachomatis, Neisseria gonorrhoeae, and Trichomonas vaginalis; and safe sex outside of marriage by use of birth control and condoms in the past year and at last sex. 82% of pledgers denied having ever pledged. Pledgers and matched nonpledgers did not differ in premarital sex, sexually transmitted diseases, and anal or oral sex variables. Pledgers had 0.1 fewer past-year partners but did not differ in lifetime sexual partners and age of first sex. Fewer pledgers than matched nonpledgers used birth control and condoms in the past year and birth control at last sex. The investigators concluded that pledgers are less likely to protect themselves from pregnancy and disease before marriage and clinicians should provide birth control information to all adolescents, especially virginity pledgers (Rosenbaum 2009).
Landor and Simons (2014), using a sample of emerging-adults aged 18-24 years old (n = 1,380), examined the influence of religiosity on pledge signing and adherence. Findings indicated that while religious participation was positively associated with signing a pledge, there is a moderating effect of religious commitment. In other words, when religious commitment is high adherence to the pledge is greater. Participant pledgers with high religiosity had delayed sexual debut, and fewer oral and intercourse partners, However, for pledge signers with low religious commitment there are unintended negative consequences of higher oral and intercourse sex partners in comparison to religiously committed pledgers and nonpledgers (Landor and Simons 2014). Thus it is important for faith-based HIV prevention interventions not to assume physical presence and participation in church is equivalent to a type of commitment that sustains sexually protective behaviors, such as abstinence. The authors note, “with an “all or nothing” abstinence approach to sexual decision making, once the pledge has been broken or violated, there is little reason not to continue to have sex with other partners” (2014:1011). As a result pledge signers with high religious participation but low religious commitment (those lacking the necessary beliefs to reinforce the abstinence pledge) are especially vulnerable to making risky decisions about sex when they find themselves in sexually charged situations (Perrin and DeJoy 2003). In so doing, the stress on the pledge for females results in an unintended negative consequence of increased oral sex (to preserve the non-penetrative pledge) and a post-failure to the pledge demotivation. Landor and Simons also suggest the link of abstinence only education with pledging, resulting in women not knowing enough about STD’s, pregnancy and protective practices to negotiate vulnerable situations adequately.

Closely related to arguments on abstinence and virginity pledging is, the type, if any, of sexual education provided in schools. A recent review and meta-analysis of low and middle-income countries school based sex education and HIV prevention found that out of the 64 studies included, only nine focused exclusively on or emphasized abstinence; the other 55 provided comprehensive sexual education. Thirty-three of the studies were able to be meta-analyzed across five HIV-related outcomes. The results were highly supportive of the effectiveness of sex education in schools reducing HIV related risk.
Students had higher HIV knowledge, self-efficacy relating to refusing sex or condom use, fewer sexual partners, and less initiation of first sex during follow-up (Fonner, Armstrong et al. 2014).

Pisani (2008) argues based on Northern Thai data, that in settings where men would buy sex and women would remain abstinent until marriage the cultural transition of young women having premarital sex facilitates young men having sex with young women and not sex workers, thereby actually decreasing the risk of HIV in the total population. In other words, premarital sex decreases HIV transmission (Pisani 2008: 197). Further unintended consequences of the emphasis on vaginal virginity, like increased oral sex partners, is also an increase in the practice of anal sex in young heterosexual women to preserve hymen and prevent pregnancy (Klein-Alonso 1993; Halperin 1999; Hildebrand, Ahumada et al. 2013). Furthermore, longitudinal studies have demonstrated that women who report anal sex are over five times more likely to pick up HIV from their infected partner than women who only have vaginal sex (DeVincenzi 1994).

For some in the AIDS literature, press, and public forums virginity testing is seen as an outdated, destructive practice that is a violation of human rights and leads to the shaming, marginalization, and humiliation of young girls (International Forensic Expert Group 2015). But for some, this practice is believed to serve as protection to young girls. Leclerc-Madlala found that in her research in South Africa that virginity testing helped to build support networks for girls, because the girls came to look out for one another and had an indigenous route for reporting sexual abuse. Proponents argue that some forms of virginity testing protects girls from HIV infection, controls premarital sex, and helps to bring negative sanctions on men who seduce, coerce, or rape girls (Leclerc-Madlala 2001; George 2007). Many ethnolinguistic groups place value on premarital virginity not only for girls but also for boys (Tangwa 2005). Customary law in many settings forbid premarital sex. In several African cultures a fine is imposed on a man for deflowerment. If pregnancy is a consequence the fine is increased, for example one cow for loss of virginity, five for a pregnancy. It is argued that fear of this fine kept people practicing nonpenetrative sex. There are still traditional schools that teach life skills and responsible sexual behavior such as abstinence, moderation, and nonpenetrative sex (Green, Dlamini et al. 2009). In a study of fifteen
sub-Saharan countries Bingenheimer (2010) concluded that there is considerable evidence suggesting that some men, even today, are subject to a rigid set of social controls that prohibit and severely sanction premarital and extramarital sex (Bingenheimer 2010).

2.3.2. Condoms

A review of studies among discordant couples, comparing those who report always using and never using, suggest that condoms are not 100% perfect, there are infrequent defects, bursting, and room for human error in correct usage but they found the proportionate reduction in HIV sero-conversion with condom use, to be approximately 80% (Weller and Davis 2002). Proponents of condoms argue that condoms are not used because they are not available due to stock outs or women who cannot negotiate condoms usage. There is a clear gender dynamic in condom usage, with men reporting higher consistent condom usage than women (Mehra, Östergren et al. 2014; Reis, Melo et al. 2016). Other factors influencing women’s usage of condoms include the fear of being judged for having a condom, the inconvenience, the reduction in sexual pleasure, the blocking of fertility, and the symbolic value of separation. Condoms demonstrate much effectiveness but translating their use into everyday practice is a continued challenge. The problem is not that condoms are not effective in preventing HIV, condoms reduce the probability of transmission greatly (Steiner MJ 1999; Warner and Steiner 2002). The real problem is who wants to use them? A review of comparative studies of behavioral interventions for improving condom use attempted to identify interventions associated with effective condom usage measured with biological assessments, found that few studies, and little clinical evidence, showed the effectiveness for interventions promoting condom use for dual protection of HIV and AIDS, however some showed a reduction in STIs (Carvalho, Gonçalves et al. 2011; Lopez, Otterness et al. 2013). Findings like this are usually shown to demonstrate the failure of behavioral interventions in increasing condom usage rather than the continual, persistent, rejection of humans to habitually adapt to condom usage as an “advantageous” aspect of sex. There is positive evidence showing condom usage with outside partners as an effective strategy for prevention; evidence from Uganda showed that using a condom with
at least one outside partner did not have a greater risk of getting HIV than those with no outside partner, but those who had an outside partner who did not use condoms had a significantly higher risk of HIV infection (Mermin, Musinguzi et al. 2008).

There is a popular argument supported by parents, indigenous leaders, and churches that condoms and talk of condoms promote sexual promiscuity. There is little empirical evidence to support this. In fact, there are fundamental methodological challenges in measuring subjective associations with condom promotion and sexual promiscuity that hinder the production of “evidence”. However there is some research demonstrating the subtle role of sexual imagery and ideas on the likelihood of increasing willingness for casual sex. One recent experimental study among university men with low behavioral intentions for casual sex at baseline found that sexual primes increased behavior willingness for casual sex. Example of primes include pop-up advertising and images on websites, sexually charged commercials, junk email, etc… of special note, it appeared that more sexually “conservative” men were swayed more by sexual cues (Roberts, Gibbons et al. 2014). In 2005 a prospective study of approximately 400 Ugandan men seemed to have supported the notion that certain condom promotion communication content might encourage higher risk sex. The intervention group participated in a condom promotion program that taught condom technical use skills, encouraged condom use and provided coupons for free condoms. The control group received a brief informational presentation about AIDS as well as condom coupons. The men in the intervention used more condoms but also increased their number of sexual partners by 31%, in comparison to those in the control group who decreased their number of partners by 17% (Kajubi, Kamya et al. 2005).

A recent study of HIV-serodiscordant couples in Nairobi, Kenya, recruited from two longitudinal cohorts, found few couples reporting dual usage of contraceptives and condoms. In fact, none of the HIV-seropositive men or women reported using non-condom contraception. Participants discussed the important role men play in using condoms and contraception as well as the association of “dual” contraceptives as unfaithfulness. Other influencing factors were perceptions of side effects and reproductive desire; the authors note, “Many participants actively desired pregnancy, but few were able to
accurately define monthly fertility windows” (Roxby, Ben-Youssef et al. 2016). The researcher’s conclusions were, “Biomedical HIV prevention, including male circumcision, pre-exposure prophylaxis or antiretroviral therapy to reduce HIV transmission, may be more acceptable strategies to promote safer sexual relations among HIV-serodiscordant couples and safer conception when desired” (Roxby, Ben-Youssef et al. 2016). There was no mention of educating about the body, fertility windows, or couples’ communication. Most of the reviews demonstrating the challenge in using condoms recommend PreP or antiretroviral therapy as the solution, none mention “education” increasing “understanding” as a recommendation (Carvalho, Gonçalves et al. 2011; Lopez, Otterness et al. 2013; Roxby, Ben-Youssef et al. 2016).

2.3.3. Partner Reduction

The Bush administration’s stress on “Be Faithful” messages, unfortunately, did not equal “reduce your partners.” Instead, “being faithful” was translated into financially supporting the family, making sure any outside sexual behavior is discreet, being faithful to the marital commitment to children and larger kinship network (Cox, Babalola et al. 2014; Mugweni, Pearson et al. 2015). The message unaccompanied by explanations on why and how partner reduction reduces transmission rates became a completely different message. Modern realities with high unemployment, women seeking education, material needs for getting married increasingly expensive, consequently delaying the age of marriage and increasing the probability of having more partners. Still today, many aid structures promote single female headed households. For example, public housing authorities who give low income rent to single mothers and actually check houses for the presence of live-in males is not a supportive environment for partner reduction. Another important factor are employment structures that require individuals to live near work, without partner or children, such as being a housemaid, factory-worker, mine worker, or farmworker which are all common occupations for Basotho.

Anthropologist Hirsch and colleagues (2008) in their five-country study of “love, marriage and HIV” argue that messages encouraging partner reduction may lead to greater risk-taking. They highlight
that in Nigeria and Uganda all the emphasis on monogamy made the use of condoms avoided because of its association with immoral sex and men’s infidelity was forced underground and thereby more risky (Hirsch, Wardlow et al. 2008). Others argue that only partner reduction and male circumcision have been shown to impact HIV infection rates at the population level. Reduction in number of partners is argued by some as the primary factor explaining HIV declines in Uganda, which experienced the greatest HIV prevalence decline of any country (Kilian, Gregson et al. 1999; Green 2003; Shelton, Halperin et al. 2004; Stoneburner 2004; Green, Halperin et al. 2006). Partner reduction is associated with prevalence decline in eight countries in Africa (Green, Mah et al. 2009). Some researchers underline that no other factor, including levels of condom use or numbers of people tested, has been associated with all cases of HIV prevalence decline in generalized epidemics (Buve, Caraël et al. 2001; Caraël and Holmes 2001; Shelton, Halperin et al. 2004). Some, argue that the true key to ending the generalized epidemic in SSA is placing primary emphasis on discouraging multiple partner sex of any sort: casual, concurrent, commercial, and condom protected (Green and Herling Ruark 2011: 14). For proponents, it is partner reduction, not abstinence, playing a key role wherever HIV rates have fallen. Part of the decline is attributable to the increased use of condoms. However, in Zimbabwe and Kenya the HIV rate began to decline in the late 1990’s; Rates of condom use had been increasing in these countries over the decade but it was not until rates of multiple partnerships decreased did the rate of HIV fall (Low-Beer and Stoneburner 2003). This is in contrast with Botswana, South Africa, and Lesotho where condoms where emphasized as the main method of prevention and no partner reduction occurred in the 1990’s, witnessed a rise in HIV rates. In all three of these countries condoms were used more frequently than in Uganda when the HIV rate was falling (Low-Beer and Stoneburner 2003; Epstein 2007). Mishra and colleagues found a strong linear relationship between African women’s number of lifetime sexual partners and their odds of being HIV-infected, even when other factors including age, education, and marital status were accounted for (Mishra, Agrawal et al. 2009).
2.3.4. Marriage as a Deadly Institution?

In the last ten years, some have argued that marriage is an institution that is highly risky to women in terms of HIV infection (Dunkle, Stephenson et al. 2008) (Kristoff 2005) (Gates 2006) (Swezey and Tietelbaum 2008). The rationale is that African women who are faithful become the victims of their husband’s behaviors, that older and more sexually experienced partners put women at risk, that women are typically faithful but men are not, and that women cannot negotiate condoms within marriage. Green and Ruark (2011) synthesize several examples of how these arguments spread through the popular press. One example includes (Dunkle, Stephenson et al. 2008: 2183). A UN collaborative report on Women and HIV/AIDS highlighted that in sub-Saharan Africa, 60 to 80 per cent of HIV-positive women report having had sexual relations only with their husbands, yet they do not provide a source for their figure. Stephen Lewis, the UN’s special envoy for HIV/AIDS in Africa stated in a speech at the Harvard School of Public Health, “that one of the most dangerous environments for a woman in Africa is to be married” (Green, 2011 #195; Green and Herling Ruark 2011). In addition to scholarly articles and major AIDS organizations this argument is also seen in popular media reports like the New York Times, “what kills young women is not promiscuity, but marriage. Indeed just about the deadliest thing a woman in southern Africa can do is get married” (Kristoff 2005) quoted in (Green and Herling Ruark 2011: 188) and Newsweek “Worldwide 80% of women newly infected with HIV are practicing monogamy within a marriage or a long-term relationship. This shatters the myth that marriage is a natural refuge from AIDS” (Gates 2006) quoted in (Green and Herling Ruark 2011: 188). Supporting evidence includes data from a UNAIDS multicenter study conducted in the late 1990s in two low-prevalence African cities (Cotonou, Benin and Yaounde, Cameroon) and two high prevalence cities (Kisumi, Kenya and Ndola, Zambia) found married girls between the ages of 15-19 and 20-24 to have higher HIV prevalence rates than their never-married sexually active counterparts. In Kisumi, the difference was ten percent greater in the 15-19 age range (22% vs 33%) and the same ten percent difference was found in Ndola (17% vs. 27%), however the difference in prevalence between married and unmarried in the 20-24 age range was less marked (Glynn, M et al. 2001). The anthropological edited volume AIDS, Culture, and Africa (Swezey and
Tietelbaum 2008) presented supportive qualitative examples of the vulnerability of women within marriages or long-term unions. Swezey and Tietelbaum (2008) argue specifically that marriage does not mitigate risk for contracting HIV, citing data that indicate that men bring HIV into marriage at twice the rate women do (Swezey and Tietelbaum 2008).

Other anthropologists consider the same data and see that approximately one-third of infections acquired by women in a union appear to come from an outside partner, and not from the husband or primary partner (Green and Herling Ruark 2011). The authors of the same UNAIDS multicenter study later emphasized several potential confounders and dynamics that were consequentially given less attention. Both marriage and HIV prevalence rose sharply with age, girls who get married earlier have earlier sexual debut and more premarital partners. Young married men were much more likely to be HIV infected than never-married, sexually active men of the same age. The authors conclude that most HIV in women is acquired before marriage and suggest that many men may be predominantly infected by their wives. Nearly twice as many women were infected at the time of their first marriage. For both men and women fewer than half of existing infections were acquired from the spouse (Glynn, Caraël et al. 2003). Clark using DHS and multicenter data found that girls who married were under more pressure to get pregnant and thus had more frequent unprotected sex (Clark 2004). Several authors have argued against blanket statements about the “risk of marriage” in Africa and rather recommend to pay attention to the nuances in increasing chances of acquisition in the context of earlier sexual debut (married and unmarried) and increased number of lifetime partners. Many of the areas with the highest rates of HIV also have the lowest rates of marriage and later ages of marriage, such as Botswana, Swaziland, and South Africa (Green, Mah et al. 2009). Multiple studies have shown that married persons or those in other long-term stable relationships have lower HIV prevalence rates than divorcees and widows of the same age (Caraël 1994; Ntozi 1997; Spark-du Preez, Zaba et al. 2004). Widowed, divorced, and separated women have by far the highest risk of HIV infection of any group of women as well as the highest risk of having multiple partnerships (Hattori and Nii-Amoo Dodoo 2007). According to the 2004 DHS women in Lesotho between the ages of 15 and 49 had an HIV prevalence rate of 56% if divorced or separated, 47%
if widowed, 27% if married/living together, and 24% if never married ever had sex category (LDHS 2004).

In some African countries, there are actually more men at risk of infection within marriage (from infected spouses) than women (de Walque 2007). In fact, some researchers argue that the portrayal of African women as passive victims is grossly inaccurate, minimizing the complex reality of how women, as all over the world, are active agents seeking sexual partnership before and outside of marriage for a variety of reasons (Leclerc-Madlala 2003; Whelehan 2009; Green and Herling Ruark 2011).

Anthropologist Suzanne Leclerc-Madlala describes this agency in cross-generational relationships as a way “through which young women gain materially, affirm self-worth, achieve social goals, increase longer term life chances, or otherwise add value and enjoyment to life” (Leclerc-Madlala 2008: S17). In their study in Malawi, anthropologists Linda Tawfik and Susan Watkins (2007) found that extramarital sex for women was not out of dire economic need; instead, women spoke about love, lust, passion and revenge. Dissatisfaction, sexual or otherwise, with a spouse was a major motive for seeking an extramarital partner. Women also had affairs out of revenge for the infidelity of their husbands. The researchers found the women of their study far from the perceived views and rhetoric from Geneva and Lilongwe of poor, powerless, women, seeking partnerships out of economic need. Several recent ethnographic studies document the diversity of motivations, beyond “economic need” for extramarital/union relationships despite social norms dictating that women should not have sex outside marriage (Hattori and Nii-Amoo Dodoo 2007; Cox, Babalola et al. 2014; Knopf, Agot et al. 2014; Ruark, Dlamini et al. 2014; Mugweni, Pearson et al. 2015).

A study of discordant couples involving fourteen sites in seven African countries found that twenty-six percent of new infections among the uninfected partner were acquired from outside the relationship—22% of new infections among women and 48% among men (Baeten, Donnell et al. 2009). This also points to the importance of couples counseling and helping discordant couples (where one partner is HIV+ and the other HIV-) to receive education on partner reduction, being as monogamous as possible, and using condoms. What is to be remembered is that the hyper-epidemics in southern Africa
would end if there was not a continuous stream of new infections into unions. Unfortunately, the reality of AIDS is becoming so strangely normalized that people overlook the simple prevention fact that even if every uninfected partner became infected, this would not perpetuate the epidemic at the population level unless infected people infected more than one partner (Green and Herling Ruark 2011). For epidemics to be sustained, the “reproductive number”—the number of people infected by each person—must be greater than one (Green and Herling Ruark 2011). Staying with one partner or as few as possible is extremely protective at the population level. At the individual level, sex with multiple partners can lead to superinfection (an already HIV infected person acquires a second strain of HIV) making AIDS worse and harder to treat for both individuals and populations (Green and Herling Ruark 2011). Green (2001) points out that even in the most severe HIV epidemics a majority of couples are still uninfected. For example, in Lesotho with one of the highest prevalence rates in the world, two-thirds of couples are NOT HIV infected and will not become so as long as both partners (or all partners in a polygamous union) do not seek an additional partner, remaining committed to their marital promise or upholding the exclusivity of the partnership (Green and Herling Ruark 2011).

The debate about the portrayal of marriage as “dangerous” in Africa is not contained to scientific journals, but forms part of the social ideology for women and men living in sub-Saharan Africa. What does the overwhelming reliance on the story of women as victim of the African man do to relationships and marriages? How many people in Lesotho are given the message that 66% of couples are HIV free versus the message use a condom every time? Furthermore, several recent studies on the success of using PrEP (Pre-Exposure Prophylaxis or HIV medicines to prevent infection), have shown that there are higher levels of adherence and better outcomes for women who share their usage with their male partners (Lanham, Wilcher et al. 2014; Montgomery, van der Straten et al. 2015). Thus, even in “women” empowered technical solutions the importance of male and female relationships, marriage, commitment and communications is still an important prevention factor.
2.3.5. Testing as Prevention

According to the Global AIDS Response Progress Report (WHO, UNAIDS, UNICEF), 68 countries reported on the status of stock-outs of rapid HIV kits in 2014 (UNAIDS 2015g). In conjunction to the Fast-Track (discussed in detail in section 2.4) approach, the WHO is providing further guidelines to increase testing. For several years, WHO guidelines have urged health services providers to use the opt-out approach, whereby patients are tested for HIV unless they actively object. Currently, they are strongly recommending community-based HIV testing services and discussing the potential of HIV self-testing. WHO’s new “test for triage” approach and recommendation for lay provider delivered HIV testing services to be used in settings where there are barriers to introducing, or scaling-up, community-based HIV testing (WHO 2015b). Proponents of “testing for all” believe that the more people tested for HIV means more people knowing their status and adopting positive living strategies. “Testing for all” supporters highlight the benefits in linking testing with automatic treatment if found positive and also argue that if an individual knows their status they will have more motivation to use condoms and adopt other protective behavior changes. However, the evidence for this logical step of being more motivated to make protective changes is not as straightforward. For example, in rural Zimbabwe, women who were counseled and then tested positive were more likely to use condoms than women who had never been tested (Gregson, Nyamukapa et al. 2002). While, another study of 1,034 teachers found teachers who had ever been tested for HIV as less likely to have used condoms consistently than those who had never been tested (Menna, Ali et al. 2015).

Some scholars try to point out that testing and knowing your status itself does not necessarily translate to practicing protective behaviors. Under the opt-out policy for health providers routinely providing testing, the assumption is that health providers will provide quality counseling and testing. This is often not the case. Even professional counseling and testing counselors complain that they often are not given the time to conduct education and good counseling because they have to hit particular testing targets (Pisano 2008, Epstein 2007). Oftentimes, health providers, including medical doctors, have received minimal training on specific HIV counseling. Amidst multiple competing responsibilities and
large patient loads, for many health workers HIV testing becomes routine like cholesterol results. Furthermore, beyond actual reporting requirements there are few mechanisms evaluating health provider HIV education or counseling quality. For example, a brief PubMed search on “evaluating health provider HIV counseling” listed only research within HIV interventions and none assessing nonintervention “normal” everyday clinical practice.

2.3.6. Treatment as Prevention

In the “test and treat” debate, it is clear that advocates for testing and treating are currently receiving vast support through policy and funding allocation. Advocates for this approach draw on evidence demonstrating that decreased viral loads among those who are infected, but in treatment, prevent onward infections and have the potential to end the HIV epidemic (IAS 2010). Support for this approach grew widely after Granich et al (2009) using a mathematical model concluded that testing 90% of a population annually and treating immediately every person found HIV-positive may lead to the elimination of HIV in that population within a time period of around 50 years (Granich and et al 2009). In mid-2015 the WHO made an early-release guideline on when to start antiretroviral therapy (ART) and pre-exposure prophylaxis (PrEP) for HIV, making available two key recommendations that were developed during the revision process in 2015. First, antiretroviral therapy (ART) should be initiated in everyone living with HIV at any CD4 cell count. Second, the use of daily oral pre-exposure prophylaxis (PrEP) is recommended as a prevention choice for people at substantial risk of HIV infection as part of combination prevention approaches (WHO 2015). The first of these recommendations is based on evidence from clinical trials and observational studies showing that earlier use of ART results in better clinical outcomes for people living with HIV compared with delayed treatment (Cohen, Chen et al. 2011). (Cohen, Chen et al. 2011) enrolled 1763 couples from nine countries in which one partner was HIV-1–positive and the other was HIV-1–negative; 54% of the subjects were from Africa, and 50% of infected partners were men. They observed a total of thirty-nine (incidence rate, 1.2 per 100 person-years) HIV-1 transmissions only one of which occurred in the early therapy group and all other transmission occurred
in the delayed therapy group who waited for a decline in CD4 count or the onset of HIV 1-related symptoms. However, 28 of the transmissions were linked within the couple while eleven HIV transmissions were brought into the couple from a non participating outside sexual partner. Since the Cohen study, other large clinical trials have clearly demonstrated the efficacy of testing and immediate initiation of treatment to reduce viral loads (INSIGHT START Study Group, Lundgren JD et al. 2015; Temprano ANRS 12136 Study Group 2015). These studies confirmed evidence that starting treatment immediately, regardless of viral load, leads to viral suppression reducing significantly the probability of passing the virus. In 2016, the ANRS 12249 study initiated in 2012 reconfirmed the evidence of early treatment and successful viral suppression (Dabis, Iwuji et al. 2016). The study included 28,153 people in 22 catchment zones of KwaZulu Natal South Africa, found that both the control and intervention had similar outcomes for testing, uptake of treatment and viral suppression. 92.3% and 93.4% of participants received testing and were diagnosed, and of those who began treatment whether from the intervention—immediate initiators, or from the control—later treatment initiators both witnessed high proportions of viral suppression 93.4% (I) and 93.6% (C). However, the proportion of those who actually remained on treatment was low and quite similar between the two groups only 49.2 (I) and 46.0% (C). Once again demonstrating the challenge of maintaining adherence to treatment for those who early initiated and getting people to use the medicines when their immune systems appear relatively strong. Furthermore, the universal test and treat strategy implemented had no measurable effect on HIV incidence over the course of the trial (Dabis, Iwuji et al. 2016).

The second recommendation is based on clinical trial results confirming the efficacy of the ARV drug Tenofovir for use as PrEP to prevent people from acquiring HIV in a wide variety of settings and populations (WHO 2015). The South African Centre for the AIDS Programme of Research in South Africa, referred to as CAPRISA, research team demonstrated that in a very high incidence population, women who used the microbicide gel, before and after sex, had a 39% lower chance of becoming HIV infected than women who used a placebo. For women who used the microbicide more than 80% of the time, risk was reduced by 54% (Abdool Karim, Abdool Karim et al. 2010). Following this evidence, the
WHO started promoting PrEP as a priority for populations with an HIV incidence of 3 per 100 person-years or higher. Consequentially, PrEP is in the transitional phase of becoming an additional prevention choice in a comprehensive package of services that also includes HIV testing, counseling, male and female condoms, lubricants, ARV treatment for partners with HIV infection, voluntary medical male circumcision, and harm reduction interventions for people who use drugs. Antiretroviral therapy that reduces viral replication limits the transmission of human immunodeficiency virus type 1 (HIV-1) in serodiscordant couples. A recent prospective, observational PARTNER (Partners of People on ART—A New Evaluation of the Risks) study was conducted at 75 clinical sites in 14 European countries among serodifferent heterosexual and MSM couples in which the HIV-positive partner was using suppressive ART and who reported condomless sex (not all couples shared internal ejaculation), during median follow-up of 1.3 years per couple, found no documented cases of within-couple HIV transmission (upper 95% confidence limit, 0.30/100 couple-years of follow-up) (Rodger, Cambiano et al. 2016). Yet similar to the (Cohen, Chen et al 2011) study a total of 11 of the originally HIV-negative partners were observed to acquire HIV during eligible follow-up, were not phylogenetically linked transmissions, of these eight (73%) reported that they had had recent condomless sex with others apart from their study partner. Both studies documenting the strength of discordant partner protection through adherence to treatment, or early start and treatment, showed the problem of new infections occurring through third party sexual encounters. Thus, even in treatment for prevention models partner reduction seems to still be an underestimated prevention factor.

Those who argue against the “test and treat” model believe that the efficacy of this approach is not as clear cut as proponents make it out to be. Some modelers suggest that the increased viral resistance created by having people on treatment longer could lead to increased number of new infections (Sood, Wagner et al. 2013). For example in the case of Nevirapine, first line treatment is successful and toxicity is not a problem (MacIntyre and Gray 2000), but there are ongoing studies evaluating the issues of developing treatment resistance for mothers and babies (Wagner, Kress et al. 2010). Increasing rates of resistance to first line treatment is already a reality in southern Africa, for example centers of excellence
in Lesotho are currently treating people with second and third line treatments (BIPAI 2016). Other modelers point out the complexity in arriving at the desired elimination of HIV threshold due to increased infectivity before most people get tested and the particular reproductive number, or the number of cases one HIV case generates on average over the course of its infectious period (Kretzschmar, Schim van der Loeff et al. 2012; Kretzschmar, Schim van der Loeff et al. 2013). Others point out that the approach must treat more seriously the documented challenges of cost, logistics, and acceptability that would need to be overcome in order to arrive at the very high levels of testing and treatment adherence necessary to end the epidemic (De Cock, Gilks et al. 2009; Garnett and Baggaley 2009; Shelton 2011; Gupta, Wainberg et al. 2013). Clinical trials often provide counseling and support above what is available in the general care system, especially the logistics of using a prevention product and negotiating its use with partners (Shelton 2011). In the case of the CAPRISA trial, this type of support was an important aspect in getting people to use the gel, yet it is not mentioned in the recommendations. Others argue on the basis of ethical concerns of putting a large number of people on a treatment regimen where the long-term negative health consequences are unknown and the level of protection for others is uncertain (Garnett and Baggaley 2009). The health and nutrition aspects of living positively are ignored, both in the sense that people carrying the virus can live for long periods paying particular attention to reinforcing their immune system with a healthy lifestyle and nutrition, rather than imposing a mix of strong drugs into their system before it is necessary. Furthermore, there are individuals who can easily be treated and initiate treatment but live within a context where they cannot afford the correct diet for their bodies to tolerate well the medicine regime. Evidence from South Africa found patients who actually had free access to medicine yet refused treatment until their CD4 counts were lower (Venter 2009). Other researchers working in South Africa document serious challenges in the loss to follow up of patients initiating treatment (Dalal, MacPhail et al. 2008; Cornell, Grimsrud et al. 2010). Dalal (2008) found that nearly one in six patients receiving antiretrovirals in a resource-constrained environment had discontinued follow-up over a 15-month period. Furthermore, mortality was high in these patients and few cited financial difficulty or medication toxicity
as reasons for suspending treatment. This again demonstrating the complex dynamics at play in assuming a natural trajectory in testing, starting and staying on treatment in real world settings.

Another argument against the focus on testing and treating has to do less with the physical aspects of resistance and toxicity and more to do with the psychological and behavioral implications of people viewing HIV as “treatable” and less threatening resulting in a generalized weakening of prevention efforts. The assumption is that the focus shifting towards “treatment” would weaken prevention efforts at the individual level as well as shift the funding and programmatic focus towards predominantly pharmaceutical based prevention, at the neglect of non-pharmaceutical based HIV prevention efforts.

Pisani provides a historical example about treatment giving a façade of safety and decreasing the protective fear factor (Pisani 2008: 164-165). Among gay men in San Francisco, condom use during anal sex went up to 70% by 1985 and remained at that level through 1994. Around the time that treatment was introduced, condom usage decreased. Reports of rectal gonorrhea and syphilis started increasing as well. Levels of gonorrhea had halved between 1989 and 1994 and then post 1994 returned to earlier levels.

Pisano (2008) points out that by 2001, half of all HIV positive men stopped using condoms. Nearly a third of men who had tested positive did not use condoms with a negative partner or with one whose status was unknown. Despite the argument of more people knowing their status, being on treatment, and having lower viral loads new HIV infections among men seeking testing rose from 1.3% to 4.7% in the two years following increased access to treatment. There were also similar rises in risk and infection rates among gay men in London, Amsterdam, and Vancouver. Pisano articulates the difficulty in conveying the possible dangers and unintended consequence of increasing access to treatment:

The minute you open your mouth with a ‘yes, but’ about antiretroviral treatment, you are branded a monster. ‘So what are you saying, that we should just let people die?’ Of course not. But I don’t think it is fair to demand that people be honest about sex and drugs, and then refuse to be honest about what will happen as we expand access to treatment. More treatment means more people with HIV, potentially taking more risk and exposing more people to the virus. We need to make sure that we have the money and the staff to bump up prevention services as more people get treated. And we need to see treatment as an opportunity to draw people into prevention programmes, rather than let people think: ‘I’m on antiretrovirals, I’m alright, Jack.’ (Pisani 2008: 165).
Other anthropologists are documenting the shifts that with treatment, AIDS is being seen as a treatable chronic disease (Mendenhall and Norris 2015). AIDS is no longer a disease to fear. In a study in Uganda on the changing perceptions of risk and HIV, one focus group respondent commented, “Ever since people began getting ARVs, it has caused them to have irresponsible sex. They don’t fear each other anymore, that they might infect each other with the AIDS virus” (Green and Herling Ruark 2011: 108).

In January 2008, recommendations on condom use for HIV positive persons were published in Switzerland, which allowed for unprotected sex under well-defined circumstances (the so-called "Swiss statement"). The Swiss HIV Cohort Study (Hasse 2010) from April 2007 through March 2009 found that participants were more likely to report unprotected sex with stable partners if they were receiving antiretroviral therapy, if HIV replication was suppressed, and after the publication of the "Swiss statement." Condom use varied widely and differed by type of partner with higher use with HIV negative partners (89%), occasional partners (88%), stable partners (80%), and lowest with visits with other HIV-positive partners (48%) (Hasse 2010). This research supports arguments of the consequential effect of risk compensation as well as increasing the probability of re-infection. Another recent similar example is evident in an epidemiological modelling exercise based on ten years of surveillance data from the Los Angeles County used to simulate the test-and-treat policy (Sood, Wagner et al. 2013). Study results indicated that the test-and-treat model resulted in a 34% reduction in new infections, 19% reduction in deaths, and 39% reduction in new AIDS cases by 2023. However, these results were counterbalanced by a near doubling of the prevalence of multidrug resistance (MDR) (9.06% compared to 4.79%) in 2023. They also found that the effects of increasing testing and treatment were not complimentary. They concluded that the test-and-treat does generate substantial benefits but will not eliminate the epidemic for MSMs in LA county and will lead to large increases in MDR (Sood, Wagner et al. 2013).

2.4. The Fast-Track Response 2015-2020

In the following section, I critically discuss in detail the 2015-2030 strategy shared by large global stakeholders such as UNAIDS, US government, and the WHO known as the “Fast-Track”
combination prevention approach (UNAIDS 2015). The purpose of presenting the strategy is to establish where the current points of focus and attention exist for well-funded global entities in the context of our discussion on HIV transmission and prevention dynamics. The US Government, WHO, and UNAIDS hold significant influence in terms of the type of decisions and approaches taken for HIV prevention around the world. Together they influence greatly the generation and disbursement of funding for the epidemic. I will first briefly highlight the US Strategy and then describe more fully the UNAIDS Fast-Track approach of which much of the US strategy mirrors.

According to 2015 data from the Centers for Disease Control and Prevention (CDC), there are an estimated 1.2 million people living with HIV in the US, of whom one in eight are unaware of their HIV status. CDC also estimates that 50% of Americans who are diagnosed with HIV are not retained in medical care and that only 37% are accessing HIV treatment. The new US strategy, similar to the UNAIDS Fast-Track, calls for 90% of people living with HIV to be aware of their status, aims to increase the percentage of people living with HIV who are retained in medical care to at least 90%, and to ensure that 80% of all people diagnosed with HIV have a suppressed viral load which reduces the likelihood of transmitting the virus by around 96% (ONAP 2015). President Obama (2015) describes the strategy as seizing upon rapid shifts in science and policy and the notion of equity stressing “that every American could get access to life-extending care, no matter who they were, where they lived or how much money they had” (Obama 2015). The strategy recommends that efforts be concentrated on people who are being left behind in the response to HIV, such as gay men, men who have sex with men, African American men and women, young people, people who inject drugs, and transgender women. It calls for full access to comprehensive pre-exposure prophylaxis (PrEP) services for those for whom they are appropriate and desired. The strategy also prioritizes certain geographic areas where HIV incidence is high and linkage to, and retention, in care is low, including the southern US and specific major metropolitan areas, like Washington, DC (ONAP 2015).
The UNAIDS Fast-Track approach structures its report under the broader themes of commitment, focus, synergies, innovation, coverage, and accountability. The first bullet point of the key points in the UNAIDS Fast-Track approach states:

To reduce new HIV infections globally to fewer than 500,000 by 2020, a step towards ending the HIV epidemic as a public health threat by 2030, we need to Fast-Track the response, including renewed commitment to, sustained funding for and scaled-up implementation of HIV prevention programmes (UNAIDS 2015: 3) (bolded by author for emphasis).

Key to this approach is the argument that the epidemic “is mostly sustained by pockets of high rates of transmission” (UNAIDS 2015: 2) where HIV prevention efforts need to focus. According to the document, these pockets include “key populations” such as sex workers, their clients, men who have sex with men and injection drug users for most of the world, and in eastern and southern Africa, which bears the heaviest burden, young women and their older male sexual partners. UNAIDS diplomatically recognizes that no single HIV prevention approach alone can stop the epidemic and calls for a focused combination packages that offers:

- a mix of proven high-impact HIV prevention interventions. These include condom provision, immediate initiation of antiretroviral therapy (ART) and pre-exposure prophylaxis (PREP).
- Specific populations and locations require additional tools such as harm reduction (needle-syringe and opioid substitution therapy programmes for people who inject drugs and voluntary medical male circumcision (VMMC) for men in eastern and southern Africa (UNAIDS 2015: 3).

While other prevention interventions are mentioned in the body of the report, only these technical, medicalized, solutions are highlighted in the key point summary. UNAIDS authors go on to argue that “more than ever, HIV prevention and treatment need to be delivered together in all dimensions of programming, including service delivery, demand generation and support for treatment adherence” (UNAIDS 2015: 3). The report stresses innovation within the above stated programming along with innovation for improved condoms, new male circumcision devices, and long acting ARVs. The report also acknowledges the vigorous debates in the field about the actual factors that contribute to the decline in prevalence among young people such as the possible role of increased age at first sex, decreasing the
number of partners, and increasing condom use among youth but the factor most emphasized in the Fast-Track approach are condoms.

2.4.1. Commitment

The language of the report makes it difficult to distinguish if the topic of discussion is a Wall Street investment opportunity or a public health investment, “Commitment to a national HIV prevention strategy requires specifics. Decision-makers need clear and effective packages of investments that they can consider” (UNAIDS 2015: 7). The term “demand generation” is a business term used to describe the focused marketing of a product or service in order to drive awareness and interest by the consumer. The phrase is used over ten times in the forty-five pages of text in the Fast-Track document. The report authors implement argumentation based on business and financial argumentation rather than public health arguments of saving lives for example, “Financial commitment to HIV prevention now saves money in the future. Every new HIV infection averted will save future treatment and care costs” (UNAIDS 2015: 7). When the document refers to HIV prevention it must be clear that the money they are raising is to be invested in specific types of prevention efforts.

A UNAIDS modelling exercise used for the strategy suggests that nearly 25% of future HIV investments should go to effective combination HIV prevention interventions, with the rest supporting treatment and critical enablers, to achieve the 90-90-90 targets and reduce new HIV infections by 75%. The document never defines critical enablers but vaguely refers to health systems strengthening social protection and gender and equality norms. The 90-90-90 refers to the targets of 90% of people living with HIV knowing their HIV status, 90% of people who know their HIV-positive status on antiretroviral treatment and 90% of people on treatment with suppressed viral loads. The notion of prevention as separate from the old paradigm of “treatment” drugs now blends into “combination HIV prevention interventions” where treatment money is considered part of prevention money. Figure 2 represents “A balanced and efficient AIDS response portfolio” displaying the investment required by 2020 of US $31.9 billion (UNAIDS 2015: 8):
Twenty-six percent of the prevention money includes pharmaceuticals, such as PrEP, and cash transfers (cash payment or grant). In addition to the appeal for more funding towards this prevention approach the concept of “commitment” calls for “leaders personal commitment as role models and advocates that can transform people’s norms” (UNAIDS 2015: 8). The Fast-Track authors argue that prevention is in need of the support of political and religious leaders who can raise community awareness and “influence norms regarding HIV prevention, including condom use, pre-exposure prophylaxis (PrEP), voluntary medical male circumcision and early treatment” (UNAIDS 2015: 8). The report criticizes early advocacy measures that tended to involve only short, ad hoc, special events with leaders but now maintains the need for ongoing technical and strategic advice for leaders to keep them informed of scientific developments and priority prevention communication needs. The authors also highlight and reinforce the importance of influential role models from the arts, music, business, media and sports.

While this call for “commitment” by Fast-Track researchers criticizes those short-term, ad-hoc, special events with leaders, they do not acknowledged the way in which these leaders have been
incentivized into supporting these events by organizations like UNAIDS. The use of “incentives” by Western aid officials to get leaders to “join” the fight against AIDS is well documented (Chin 2007; Epstein 2007; Pisani 2008). For those working in the HIV industry the payment for “leadership” and “engagement” either directly, or through workshops, per diems, computers, or travel is a norm. Three generations into the epidemic perhaps we should be talking more about the damage already done by a superficial “commitment” from leaders receiving money to be “leaders” and whose personal lives often directly contradict the model they are to portray. Furthermore, in some contexts, there exists doubts on whether the technical advice given is actually understood and owned by these leaders rather than “recommended” in enticing packages of inducements (Chin 2007; Epstein 2007; Pisani 2008).

2.4.2. Focus

The Fast-Track report section “focus” describes the need to use resources optimally by combining proven high impact tools. The description of these “high impact tools” tends to emphasize the factual aspects of technical solutions. The bullet points below are taken from the document with original order and bolding:

- **Condoms remain the only available tool for triple protection against HIV, other STIs and unintended pregnancy.**
- **ARVs can prevent as well as treat HIV.**
- **Pre-exposure prophylaxis (PrEP) with ARVs can be highly effective**
- **Voluntary medical male circumcision (VMMC) provides high protection to millions of men in sub-Saharan Africa.**
- **Strong evidence has existed for some time for the effectiveness of harm reduction interventions such as needle–syringe programmes and opioid substitution therapy (OST) among people who inject drugs.**
- **Specific programmes using **communication and social change** approaches for HIV prevention can be effective.** (UNAIDS 2015: 8)

The last bullet point mentioning communication and social change approaches is the only statement of the six written with qualifications (UNAIDS 2015: 17-21). Throughout the report, when the authors mention behavior change and communication (BCC) with prevention it is discussed in terms of its inadequacy as a
stand-alone prevention method but rather (BCC) as a means for “generating demand” for clinical and technical solutions, for example:

Most documented effects are in the form of self-reported behavioural change rather than biological outcomes such as reduction in HIV incidence and behavioural studies point to moderate effects on sexual behaviour. Therefore, relying on any one of these HIV prevention approaches alone in any context would likely not be sufficient, but in combination with the biomedical interventions discussed above, they may increase impact. Many of these programmes have supportive functions. Mass and interpersonal communication are critical in demand generation for all HIV services (UNAIDS 2015: 19).

Discussion of key population and priority areas highlights how prevention programs are most effective when they address the social, gender, and age groups with the highest HIV incidence rates and the largest numbers of new HIV infections, based on “epidemiologic and sociodemographic analyses of data to determine which population groups are most affected and their size” (ibid:14). Furthermore, these populations should be involved in designing, implementing and monitoring HIV prevention programs.

According to the authors, focusing HIV prevention packages on people at greatest risk and key locations can increase prevention impact without increasing expenditure.

…this would require not only intensifying programmes where they are needed most but also reducing spending where programmes are needed less. Shifting programme focus can be politically difficult, particularly where the epidemic is still seen as affecting everyone and resources are allocated uniformly. For this reason, analyses of incidence disaggregated by location, population and mode of transmission are essential to making the case for refocusing resources in order to reduce incidence further (UNAIDS 2015: 13).

The type of focus described in the document implies and necessitates large scale testing. It would require the testing of individuals who do not easily access current methods used for surveillance. Current surveillance systems rely heavily on antenatal surveillance systems, public health care clinics, and population sampling from demographic health surveys. This focused approach sounds good but has the danger of prioritizing only what can be enumerated. Considering how many people avoid surveys and of those who accept to be surveyed reject the testing option in demographic health surveys, or the multitude of people in the emerging middle class who seek private health care, the numbers collected may not tell the entire story of the epidemic. Furthermore, in many settings myopically focusing on the populations
with the most incidence, there is the possibility of channeling resources and energies towards the individual and not discovering indirect nuances influencing the individuals behavior. Turning the focus only towards incidence also creates the vulnerability of neglecting to look at what works, what is different about those who have low incidence.

2.4.3. Innovation

Figure 3 depicts the innovations highlighted in the report as ready for implementation at scale (UNAIDS 2015:29).

![Innovation](image)

*Figure 3: Innovations highlighted in Fast-Track report as ready for implementation at scale (UNAIDS 2015:29) Copyright 2015 UNAIDS. Reprinted with permission.*

The report highlights logistical aspects of PREP implementation such as testing, toxicity monitoring, and support for adherence. Emphasis is placed on providing recommendations on how countries can develop and test different “demand generation” and adherence models, accelerate the process of registering ARVs for PrEP use, developing national guidelines and to “overcome political obstacles to implementation of PrEP” (UNAIDS 2015: 30).

**Voluntary Male Medical Circumcision.** After ecological and observational evidence had been available for some time (Green 2003), male circumcision was proven effective in three trials, in South Africa (Auvert, Taljaard et al. 2005), Kenya (Bailey, Moses et al. 2007), and Uganda (Gray, Kigozo et al. 2007).
In 2007, WHO issued recommendations on male circumcision for HIV prevention. Although it took a few years for countries to develop policies and set up programs, today around 10 million men have received VMMC services in eastern and southern Africa, many of which are younger men. This demonstrates that in a relatively short amount of time, broader societal change can take place. The Fast-Track approach highlights the new technology in circumcision devices that will increase the availability and acceptability of the procedure allowing nurses and other health workers to perform the procedure.

**Cash Transfers:** The report repeatedly notes the potential use of cash transfers (cash payment, financial incentive or grants given based on a categorization such as need, vulnerability to HIV, food insecurity etc.), yet it does not highlight the contextual factors in the studies where it was found to have an impact on HIV, nor those where no impact was measured. One example highlighted as a success story included the World Bank’s HIV lottery program in Lesotho (Björkman Nyqvist, Corno et al. 2015). In the study, 3,029 young adults in rural Lesotho were randomized and assigned to either the control arm or one of two intervention arms where they were eligible to receive a lottery ticket every four months with a chance to win either $50 or $100 conditionally on testing negative on two treatable STIs. The report documents that the intervention resulted in 21.4% reduction in HIV incidence over two years. As reported lottery incentives work more for what the authors refer to “risk-loving” individuals, a category assigned to individuals based on their perceived value of a risky gamble, showing that “risk loving” individuals reduce their number of unprotected sexual acts by .3/month for every $1 increase in the expected prize. Over the two year trial period, “HIV negative individuals with preferences for risk ex-ante were as likely as risk-averse individuals to become infected with HIV in the intervention groups, while risk-loving individuals were more than twice as likely as risk-averse individuals to become infected with HIV in the control group” (Björkman Nyqvist, Corno et al. 2015). The blanket support for a lottery system masks the diversity within the population of the non “risk loving” individuals for which the program made less of a difference. Furthermore, the report does not take into account the actual household income of the young people participating. The eligibility criteria was simply “males and females, aged 18-32 years, residing in 29 rural and peri-urban villages across 5 districts in Lesotho” (Björkman Nyqvist, Corno et al. 2015).
the factor of “risk preference” was reported there was no consideration for other social demographic factors.

**HIV Testing:** The report also identified the field of HIV testing as a source of major prevention innovations, including rapid diagnostic tests, community-based testing service models, and self-testing. They stress the need to strategically link these innovations to HIV services that can provide entry points for treatment and prevention.

### 2.4.4. Synergies

The concept of synergies within the Fast-Track document refers to the package of HIV services that should consist of a combination of biomedical HIV prevention tools (condoms, testing and treatment) along with “demand generation and behavioral components” (UNAIDS 2015: 23). The report notes that all packages “require” a strong community empowerment element and need to be linked to a wider system of “critical enablers” and structural health and development synergies, such as health systems strengthening (including blood safety, STI treatment), social protection (including cash transfers to vulnerable populations) and gender equality and norms.

The discussion of synergies uses many terms from structural analysis and participatory approaches but in reality apply the social terms to clinical solutions. The focus is on “community engagement” and “structural and development synergies” as they relate to biomedical HIV prevention tools. The social protection described relate to a prescribed population who must be separated, evaluated, and measured to be “vulnerable.” For high-prevalence countries in Africa, where the epidemic often includes women and men not perceived to be in “high-risk groups” the report emphasizes, again, condoms as being relevant in all settings as an “easily accessible HIV prevention option”. They also note that:

Social and behaviour change programmes need to be reinvigorated and focused more on social patterns and norms that influence key sexual risks such as having multiple partners and age-disparate sex. Cash transfers, incentives, and other economic empowerment strategies may have an impact on HIV incidence in some settings as well as other, wider health and social benefits.
Generally, most of these will not be funded out of HIV budgets. The optimal combination of services may not be uniform nationally (UNAIDS 2015: 24).

Success in the use of antiretrovirals used to prevent or decrease transmission probabilities are often broken down by level of adherence. Figure 4 shows the levels of HIV prevention success based on the levels of adherence to the treatment demonstrating the important relationship between individual buy-in and use of an HIV prevention medicine and its direct result on HIV incidence reduction.

![Bar chart showing HIV incidence risk reduction in antiretroviral trials accompanied by level of adherence (UNAIDS 2015: 18). Copyright 2015 UNAIDS. Reprinted with permission.](image)

Figure 4 clearly demonstrates that if people adhere to a prevention method, it works. In thinking about the same type of incidence reduction but in the context of social and behavioral interventions, rather than pharmaceutical, researchers have documented some effect on HIV and even greater impact on preventing STDs (Cornish, Priego-Hernandez et al. 2014). Unlike medicine, social and behavioral interventions cannot be broken down into groups by “adherence” to show that if you participate/listen it works. PREP research and implementation is highly funded yet social interventions that cannot disaggregate by “adherence” but several of which have demonstrated lowering HIV incidence, as well as
wider health and relationship benefits such as less partner violence, less transactional sex, partner reductions, increased levels of respect, “will not be funded out of HIV budgets” (UNAIDS 2015: 24).

Thus, programs that have proven to influence key sexual risks such as multiple partners and age-disparate sex “will not be funded out of HIV budgets” but a pill, gel, or suppository that may have some minor side effects, challenges in adherence, and no documented effect on partner reduction, violence, transactional sex, or reduction of age disparate sex is of higher prevention funding priority.

2.4.5. Scale and Intensity: Making Sure Prevention Covers the Need

The Fast-Track report emphasizes the need to deliver HIV prevention interventions at full scale. Noting that previously, these programs were implemented with a lack of sufficient intensity, coverage, and time needed for success. One example underlined for scale, coverage, and intensity are HIV prevention programs for young people in high prevalence settings. Citing a UNICEF report highlighting the fact that fewer than four out of ten young people in southern and eastern Africa, have full basic knowledge about HIV transmission, and that many adolescents and young people who are at risk of HIV do not believe that to be the case (UNICEF 2012). This example provided in the report actually contradicts the previous area of “focus” discussing a move from general knowledge building about HIV and the targeting of high incidence groups. These young people may actually have lower incidence but they are still in need of “focus” and better forms of education to have a basic, working knowledge of HIV and the realities of risk in their local context. Instead they will most likely receive “communication” for “demand generation” to get tested, and to use condoms, ARVs, and PREP. The broader question not proposed in the report is why is it that HIV prevention interventions are not implemented with sufficient intensity, coverage, and time needed for success? What will be done differently in the Fast-Track Approach of 2015-2030 not to repeat previous mistakes? Why is it that the report does not mention the constraints of funding cycles and reporting?

The authors of the report state the problem as if its entire resolution depended on in country dynamics. Funding agencies, like PEPFAR, Global Fund, and USAID place enormous pressure to provide
numbers. Emphasis is often placed on numbers met and money spent, rather than on the quality of the interaction towards preventing the spread of HIV. Epstein describes a PEPFAR project where seven counselors left after PEPFAR pressure made their work an impossible task. Many good people working in the AIDS industry burn out, or leave, because of the pressure of trying to meet impossible targets with impossible means—not enough vehicles, staff, funding for fuel, condoms. As one ex-counselor in Epstein’s research comments,

You cannot give quality counseling anymore because PEPFAR has counseling quotas. If you have to do one thousand people by the end of the month, you end up not doing good counseling. It compromises people’s dignity. And the stress on people from the paperwork! All the time we were thinking, I have to fill this form because PEPFAR is coming! They’re not asking, ‘Are we really meeting the needs of these people?’ (Epstein 2007: 221)

Central to the lack of sufficient intensity, coverage, and time needed for success is what the AIDS industry itself demands from the people that they give money. Like Epstein’s example from South Africa, Pisani in China describes a Chinese colleague’s frustration about not having enough time to do real work, “count, count, count and no money for prevention…they’ve all given me money to count! If I didn’t count for each of them that would be corruption” (Pisani 2008: 288). While these examples are nearly ten years old, they demonstrate a cross-context international phenomenon a dynamic which is also a theme brought out in this dissertation’s recent results (Chapters 5 and 10) in Lesotho. In fact, I posit that this constraint of funding structures, over-dependence on quantitative measures, and short reporting cycles is at the root of much of the lack of intensity and coverage problems in HIV prevention. The Fast-Track document never mentions this problem.

2.4.5. Accountability

In regards to accountability, the report reminds the reader, “Governments, including their treasuries, and international donors will need to allocate the resources required. HIV prevention is not expensive. In fact, implemented at sufficient scale and with sufficient intensity, it saves money” (UNAIDS 2015: 44). The rhetoric in the document continues to minimize the ever increasing amount of
funding needed while simultaneously selling the investment of money. In the discussion of accountability the report emphasizes:

> even more importantly, communities will need to use their power to push this Fast-Track HIV prevention targets and hold governments, donors and themselves accountable. With community ownership, the target of reducing new HIV infections by 75% by 2020, and virtually eliminating them by 2030, can be achieved”(UNAIDS 2015: 44).

What power do communities have to push the Fast-Track prevention targets? To what are communities holding themselves accountable? If most of the funding is going towards clinics, testing, treatment and medicines for prevention how will communities facilitate “ownership” of reducing new infections? There is no discussion in the report of supporting local activists, young people, traditional healers, religious, and village leaders, in owning the problem and proposing locally based strategy’s for reducing infections by 75%.

Large level funders supporting the Fast-Track approach do not seem to take into consideration the role of local solutions. Locals are typically hired to facilitate the implementation of the types of policy decisions described in the Fast-Track report without much attention to the ways in which locals may provide solutions that are not part of a plan based on technology, testing and treatment. A plan that in the case of Lesotho, is completely dependent on outside funding. Furthermore, large initiatives like the Fast-Track attempt to apply a uniform solution to extremely diverse local contexts and cultural norms. This is often at the neglect of recognizing unique social, political and economic dynamics influencing the Fast-Track implementation. Nor is the immense influence of the thirty years of a “professional” HIV response in low and middle income countries recognized. For much HIV-related work by locals, and before any Western trained professional may work in sub-Saharan Africa, an outside entity must have the money and “interest” to fund them. The next chapter describes in detail the local political, social and economic context in Lesotho where the Fast-Track approach is currently being implemented. The chapter also describes the important role HIV-related technology and work play in the local economy.
CHAPTER 3: HISTORICIZING THE PRESENT POLITICAL ECONOMY IN LESOTHO

As discussed in the previous chapter, Western-trained anthropologists usually work in sub-Saharan Africa through an outside entity which has the money and “interest” to fund them. This is also applicable to much HIV-related work by insiders in Lesotho. The initial and continuing HIV response in Lesotho is dominated by outside funding. Some of these key funding institutions include the United Nations, the World Bank, the Global Fund, the Millenium Challenge Account, USAID, CDC, PEPFAR and the Clinton Health Access Initiative Foundation. The previous chapter highlighted recent debates and current HIV prevention approaches. The Fast-Track approach was described in detail because it reflects the priorities of the major international funding entities working in Lesotho.

The original 2008 MCP project used as a case study in this dissertation was one of the many projects funded and sustained by these large international funding entities. The employment opportunity for the qualitative research experience would not have happened without these foreign investments. A fundamental, but often overlooked, question is: why does Lesotho depend on so much aid? For a country less than the size of the U.S. state of Maryland, what difference has thirty years of a constant influx of foreign aid had in the country? The social, political and economic context in Lesotho is key to understanding the effect of the 2008 MCP study on the researchers and local agents of change. Without this context references made in participant responses and the interpretation of particular policy and programming decision would be lost, these dynamics are not mere background but fundamental to understanding the translation of research into practice.
3.1.1. The Basotho

Amidst the turmoil of tribal violence, European land grabbing, mineral extraction, slavery, new weapons, new diseases, war, starvation, cannibalism, and Christianity forcing its way into cultures, arose one of the most fascinating, wise, forward-thinking and just leaders of all time, King Moshoshoe. Under his leadership, the story of the Basotho as a true nation-state of peoples, protected, unified, and acknowledging under a leader began in 1822. Casalis’s missionary report states, “we have undoubted proof that the Basutos have, for at least five generations, possessed the territory on which we found them in 1833” (Casalis 1997 [1861]: 156). Indeed Sotho speaking groups were one of the many groups in the Southern African region since the 1200s. King Moshoshoe, during a period of disillusionment at the tragic realization of the fissure between theory and practice, reveals both his frustration in leaders seeking their own interest and the cultural diversity within the region:

I knew the Zulus, AmaXhosa, the Tembu, the Botlkoa, the Barolong, the Bathlaping, the Korannas, the Bushmen, the Griquas, the Basuto. Their chiefs are all alike: they all have nothing in view but their own interests. But I said to myself: Peradventure the white man’s government is different. They fear God Jehovah, and no doubt his commands. But alas, no! They too, I perceive, seek nothing but their own interests and trample the rights of others underfoot. (Casalis 1997 [1861]: 20).

In his lifetime of compromise and diplomacy, King Moshoshoe protected his people and saw their land and possessions, threatened, carved up and taken by the Dutch, British, and Boers. Within the context of avoiding annihilation of his people he sought protection from the British and Queen Victoria, who established a “protectorate” in Lesotho. The “protectorate” was facilitated by the British much like the colonies and lasted until independence in 1966 (Gill 1986). Perhaps due to the physical location and the rural nature of Lesotho, there was not an influx of “other” people, such as from England, India, or China, as in most British ruled colonies. Thus, from the times of Moshoshoe to present the Basotho have remained a relatively homogenous nation-state with 99.7% Sotho and .3% “other,” including other Africans, Europeans, and Asians (CIA 2016). Early Christian missionaries worked closely with state leaders exchanging ideas, ammunition, and diplomatic assistance in navigating the new political terrain. As a result, official statistics report 80% Christianity, a majority of which are Roman Catholic, followed
by Evangelicals, Anglicans, and other Protestant groups. There is also a history of Ethiopian and Zionist churches, as well as traditional indigenous practices that reject Western Christianity and emphasize African leadership, traditional forms of worship, leadership, and spiritual healing. Similar to other settings in the southern African region, it is difficult to quantify how many individuals purely practice one set of beliefs, a mix, or nothing.

3.1.2. Race, Class and Identity

In conversations with expatriates working in Lesotho, some have argued that because Lesotho was never a colony, is predominantly ethnically homogeneous, and was not under apartheid, it does not suffer the ramifications of “race” and identity as in South Africa (Watson 2008a). But how could race and racism not be a part of the social fabric of Lesotho, where Basotho harking back to the colonial “protectorate” days into the present have navigated a reality where whites, although a minority, happened to possess positions of leadership and power? If the Basotho predominantly worked the mines, fields, and houses of South Africa under apartheid, and through post-apartheid tensions, how could they not experience the pangs of being treated differently because of their color and “race”? Within Lesotho and in the region in general, being treated as the “other” is not only reserved to the traditional polychotomy of European descent “whites”, “Indians” or “coloreds,” but exists between other black groups as well. Furthermore, segregation by class and race was and is still present in Lesotho. A 2012 article excerpt (see appendix A) describes the separate living in Lesotho which was strictly enforced (but without “force” as in South Africa) by the British colonial presence. The writer describes racial, wealth and power dynamics of the 50’s and 60’s intertwining supernatural, biomedical and traditional justifications (Malieketseng 2012). She describes the demography of racial and class housing divisions in the past, Maseru West and New Europa for whites, Basotho senior civil servants in Stadium area and lower level civil servants in Maseru Locations (Sea Point, Matsoalareng). In reference to the revolutionary period around the first post-independence general elections, in 1970, The Basotho Congress Party (BCP) attempted to dismantle
“white areas” by integrating Basotho families. The author describes the underlying racial tensions between white employers and Basotho employees at the time:

Our employers were very disturbed by these changes and tried to drum in our ears how evil Mokhehle (BCP Leader) was. We just nodded our heads for the sake of our daily bread while our hearts were telling us something very different—whites must go to hell (Malieketseng 2012).

After winning the elections in 1970, the BCP leadership was imprisoned and exiled from the country. Not until the next democratic elections in 1993 would the BCP lead a democratic government in Lesotho. The type of large social and political changes desired by the BCP, and hoped by people like the author in this article were quickly suspended. Reflective of the retardation of change in Lesotho, today, the neighborhood lines described in the article about the 1950s and 60s still persist however the “white” area now includes additional expatriates and wealthy Basotho. Overt racism may not be a part of the social fabric today, however in regards; to the subjective sentiment of “whites must go to hell” or animosity towards “western dominance” is still a present reality in various contexts (Malieketseng 2012; SundayExpress 2015).

Part of this frustration may be linked to the fact that social and economic success for Basotho is often connected to how well they navigate between the native and “administrative” world dominated by foreigners and English speaking requisites. For example, the Basotho educational system is structured predominantly upon the British school system. Most standardized tests for promotion in educational levels or certifications are in British English. For many in Lesotho, upward mobility depends on how well they can express themselves and test in the other “official language” of English to the expense of their mother tongue. A friend of mine recalls, 20 years after the fact, a reading comprehension question on a national examination containing multiple references to an “ice rink,” a mysterious concept for him at the time and one that did not allow him to get a perfect score.

Turkon (2009a) describes how Basotho mark class consciousness linguistically by the strategic use of native language and terms borrowed from colonizers, “Basotho tend to interpret class statuses by drawing on personal qualities that are either deemed to be noble and desirable in a traditional sense or
reflective of behaviors that are associated with some of the worst qualities associated with the colonizers and more generally westerners” (Turkon 2009a: 86). The production of cultural domination is not one-sided, Basotho also exploit the differences between “us” and “them” as seen in participant references in this dissertation to “Ugandans,” “Chinese,” and “Nigerians” that are often laced with negative undertones. Land policies also aggravate the sensation of a tangible difference between “us” and “them,” for example an Ethiopian living, working, and paying taxes in Lesotho for over 20 years cannot hold a title to land in Lesotho but has the privilege to rent. Land policies in Lesotho protect the indigenous link between the land and nation-state as the Land Act, 1979 explicates:

Land in Lesotho is absolutely and irrevocably vested in the Basotho Nation and no person other than a citizens of Lesotho who is a Mosotho or a company the majority shareholding of which is held by citizens of Lesotho who are Basotho or a partnership of which the majority of partners are citizens of Lesotho who are Basotho or bodies registered under the Societies Act, 1966 may hold a title, i.e., a lease, to land in Lesotho (Selebalo 2001:2).

This exclusion of foreigners from land ownership and the traditional system of land-tenure rather than “ownership” is often criticized as hampering “investment”(Wellings 1986; Makoa 1999b; Mbata 2001) and development, yet, at the same time, has most likely served as a protective mechanism for indigenous land management, identity, and communal collaboration. With the rapidly increasing chasm between the rich and the poor, the dynamics of this protection are changing with more nationals having the amount of capital required to be shareholders in investment companies with foreigners (KPMG 2012; USDoS 2014; LNDC 2016), opening the door for greed to trump identity and solidarity with traditional less capitalistic mechanisms of social organization.

3.1.3. Government Structure

Since post-independence in 1966, the government is structured as a parliamentary constitutional monarchy—with a king, Prime Minister, executive, and judicial branch. The first twenty years of statehood were ruled by the Basuto National Party (Gill 1986). However, from 1985 through 1993, Lesotho was under military rule. After the 1998 elections, violent protests and military mutiny erupted;
South African and Botswanan forces were sent in by the Southern Africa Development Community. The
dynamics of what occurred are still unclear, but lives were lost and massive losses of property incurred
(Makoa 1999). In the early 1990s, there were tensions regarding recognition of the King’s influence in the
political system. King Moshoeshoe II went into exile in 1990. He was reinstated as King in 1995 but died
in 1996 in a mysterious car accident at 1 am while “checking on his cattle”. His son King Letsie III ruled
during his exile, after his death, and up to the present day. Today, the monarch is quoted as a “living
symbol of national unity” with no executive or legislative powers but power to nominate particular
positions within the government (CIA 2016).

The head of government is the Prime Minister. The legislative branch consists of the senate with
33 seats (22 principal chiefs and 11 senators nominated by the king) and the National Assembly with 120
seats, 80 members directly elected, and 40 by proportional representation vote (CIA 2016). Lesotho is
often described as a “young” democracy hailed as having its first “officially” peaceful elections in 2002.
While under much oversight, the 2002 elections were documented as “peaceful,” whereas the National
Assembly 2007 elections were contested (CIA 2016). However, while the official reports stated that the
election was without violence, fair, and was peacefully conducted, the on the ground reality was much
different, as I witnessed it firsthand. The atmosphere was heavy with fear; there were rumors of
kidnappings, disappearances, and deaths and many headed over to South Africa for safety rather than stay
in the country and vote. While Lesotho depends on South Africa for protection from “external” threat, the
government maintains a strong military force and officially spends 1.94% of GDP, ranking 43rd of 132
countries in GDP percentage devoted to military use (CIA 2016). In May 2012, competitive elections
involving 18 parties brought in Prime Minister Motsoahae Thomas Thabane with a coalition government,
the first in Lesotho's history, overthrowing the 14-year incumbent, Pakalitha Mosisili who transferred
power after a month. The coalition government lasted briefly, Mosisili returned to power in snap elections
in February 2015 after the collapse of the coalition government and an alleged attempted military coup
(CIA 2016). The CIA factbook fails to mention the murder of former General Mahao (lawyer and
National University of Lesotho graduate) or the allegations of torture and detainment of 24 soldiers from
the previous regime. The current political crisis in Lesotho should not be seen as a recent “change” for the worse, but rather a continuation of a long standing pattern of corruption, military instability, and the undermining of political progress; this is a pattern repeated with almost cyclical regularity (SALC 2016). Popular dissatisfaction with the government is not reserved for election periods, many people report disgust with government corruption, leaders that do not work or represent the needs of the people, and the necessity to align themselves with particular political groups in order to get jobs and scholarships. The judicial process is selectively slow. During various conversations in 2012, people talked in hushed tones about not feeling free to criticize the system. Furthermore, the judicial system is repeatedly undermined by threats to lawyers of important cases, soldiers attending court cases with AK47s, and attempts to unseat the Judge President nominated under the previous regime (SALC 2016). Media sources in Lesotho are tightly linked with the state. The government maintains control over most private broadcast media; there is one state-owned TV station and two state-owned radio stations, and for those with greater means satellite TV subscription service is available and transmissions of multiple international broadcasters is obtainable (CIA 2016).

3.1.4. Economic Diversity in Lesotho Inequality and Poverty

Current informational statistics and descriptions of Lesotho often highlight the needs or the problems within Lesotho. Most descriptions recount Lesotho as a landlocked country within Africa, approximately the size of the US state of Maryland, with an HIV adult prevalence of 23.1%, the second highest in the world, and a life expectancy of 52 years, and where 40% of the population lives on less than $1.25 a day (USAID 2004; Gayfer, Flint et al. 2005; IrishAid 2016; WorldBank 2016). There is also an emphasis placed on the rural population, the number of subsistence farmers, and remittances from South Africa. These are all true, of course, but there is an omission of certain facts resulting in a picture that emphasizes poverty but glosses over inequality.

The commonly depicted image of the Basotho is typically of rural, vulnerable, HIV stricken, poor people. In some areas, this is true, and in need of attention, but attention must also be paid to the rate of
change and growth within the country. There is a growing semblance of a middle class, who have money to frequent the booming service sector of restaurants, casinos, movie theatres, high tech recreational facilities, and shopping centers. In my ten years of work in Lesotho, I have seen the luxury of having a car become a diffused necessity of the middle class. Cell phones have rapidly overtaken landlines; for example, there are an estimated 51,200 fixed landlines with three subscriptions per 100 inhabitants in contrast to 2.1 million cell phone subscriptions, with 110 subscriptions per 100 inhabitants (CIA 2016). Elite suburban neighborhoods are growing in number and quality. These trends in Lesotho are reflective of larger trends on the continent. In fact, the number of middle class Africans has tripled over the last 30 years to 313 million people, or more than 34% of the continent’s population, according to a report from the African Development Bank (AfDB 2011). The report ‘The Middle of the Pyramid: Dynamics of the Middle Class in Africa,’ defines the African middle class as individuals whose annual income exceeds USD 3,900 in purchasing power parity terms but also acknowledges other factors such as education, professions, aspirations, and lifestyle. The report argues that the growth in the middle class is good news for Africa, but also points out the continued high levels of income inequality on the continent. For example, the continent has an extremely rich elite with 100,000 Africans having a net worth of USD 800 billion in 2008, or about 60% of Africa’s GDP or 80% of sub-Saharan Africa’s (AfDB 2011).

The reality in Lesotho reflects this dynamic. The rapidly increasing chasm between the rich and the poor finds its context in a strange blend of political instability, highly literate and educated population, and general unemployment. Middle class citizens describe the elite class as having education, money, and power to send their children to exclusive schools and receive healthcare from private health centers, typically in South Africa. These perceptions are mostly accurate; the Gini index, which measures the degree of inequality in the distribution of income in a country, rated Lesotho (as of 1995) as having the highest magnitude of inequality in country income distribution in the world. The Gini coefficient is a number between 0 and 1, where 0 corresponds with perfect equality (where everyone has the same income) and 1 corresponds with perfect inequality (where one person has all the income—and everyone else has zero income). Over the past twenty years, the Lesotho Gini index has been one of the top five in
the world measured by the UNDP, CIA, and World Bank. The following table shows a small country comparison of rich to poor ratios (R/P), with the income of the richest 10% over the poorest 10%, average income of the richest and poorest 20% and the GINI coefficient (CIA 2013; UNDP 2016).

<table>
<thead>
<tr>
<th>Country</th>
<th>R/P 10%</th>
<th>R/P 20%</th>
<th>% Gini WB</th>
<th>Year</th>
<th>CIA 10%</th>
<th>Year</th>
<th>%Gini CIA</th>
<th>Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sweden</td>
<td>6.2</td>
<td>4.4</td>
<td>27.3</td>
<td>2012</td>
<td>6.2</td>
<td>2000</td>
<td>24.9</td>
<td>2013</td>
</tr>
<tr>
<td>UK</td>
<td>13.8</td>
<td>7.2</td>
<td>32.6</td>
<td>2012</td>
<td>13.6</td>
<td>1999</td>
<td>32.4</td>
<td>2012</td>
</tr>
<tr>
<td>USA</td>
<td>15.9</td>
<td>8.4</td>
<td>41.1</td>
<td>2013</td>
<td>15</td>
<td>2007est</td>
<td>45</td>
<td>2007</td>
</tr>
<tr>
<td>Lesotho</td>
<td>39.8</td>
<td>44.2</td>
<td>54.2</td>
<td>2010</td>
<td>48.2</td>
<td>2002est</td>
<td>63.2</td>
<td>1995</td>
</tr>
<tr>
<td>South Africa</td>
<td>33.1</td>
<td>17.9</td>
<td>63.4</td>
<td>2011</td>
<td>31.9</td>
<td>2000</td>
<td>62.5</td>
<td>2013</td>
</tr>
</tbody>
</table>

Anyone who has traveled to South Africa can easily testify to the level of poverty, but it is the magnitude and proximity of blatant inequalities that is most jarring. The very best of the “first” world surrounded by pockets of desolate poverty—no toilets, electricity, and cardboard houses. Enjoying the comfort, beauty, style, and fantastic sense of humor and character of South Africa is typically accompanied by the ever present nagging fear of hijacking, robbery, or rape. Lesotho, an island within South Africa, has some similar zones of urban poverty and certainly, its own cases of violence related to inequality, but it is nothing like South Africa. Merely by crossing the border from South Africa into Lesotho, the visual difference is evident. There are spread-out villages, farming landscapes, rondavels, less barbed wire, and few high fences and walls. This visual difference reflects the historical difference between the two. Unlike in South Africa, the Basotho were never forcefully displaced into settlements. They may migrate for work and education, but they maintain the link with the “village” the ancestors, family land, animal husbandry, and cultivation. A person can be poor in cash terms but rich in property of animals or farming production. For people living and working in and between Lesotho and South Africa the past twenty years have been marked by post-apartheid freedom and seemingly limitless possibilities,
but they have also been marred by a consistent and steady growth in large income inequalities, corruption, and political instability.

If descriptions are not congruent with “needy,” then Lesotho research and donor descriptions conspicuously ignore them (USAID 2004; Gayfer, Flint et al. 2005; IrishAid 2016; WorldBank 2016). What is less divulged is that Lesotho invests 13% of its GDP into education, the highest percentage investment in the world; South Africa ranks 42nd, the USA 63rd, Germany 74th and Italy 93rd (CIA 2016). Literacy measured by the percentage of the population age 15 and over that can read and write is 79.4% (70.1% of males and 88.3% of females) (CIA 2016). The health expenditure as a percentage of GDP spent by institutions or individuals for the application of medical, paramedical, and or nursing knowledge and technology for health was 11.6% in 2012, that is the tenth highest in the world with France ranking 9th and Austria 11th. Switzerland, Germany, Denmark, Canada and the UK all-have lower percentages, while the U.S. has the highest percentage of GDP health expenditure at 17.9% (CIA 2016). Interestingly, Lesotho, with a significant US presence aiding development (USDoS 2014), like the US has simultaneously high GINI inequality and high expenses for health services and technology.

3.1.5. Driving Forces in the Economy

Lesotho’s economy does not just depend on remittances from mineworkers, farmers, and domestics in South Africa; it also depends on custom taxes and hydroelectric water fees from South Africa. In fact, Lesotho is a country that receives food aid for droughts, and through the Highlands Water Project, actually controls, stores, and redirects water to South Africa. Over the years, the exact amount of royalties for water transferred is not clear (LHWP 2011). The World Bank, the African Development Bank, the European Investment Bank, and other bilateral donors finance the project. A 2010 project report notes that the conclusion of the first phase of the project has made Lesotho almost completely self-sufficient in the production of electricity and generated approximately $70 million in 2010 from sales of electricity and water to South Africa (Lesotho Highlands Water Project Phase 1 2012). Lesotho is also a
member of the Southern Africa Customs Union (SACU), and revenues from SACU accounted for roughly 44% of total government revenue in 2014 (CIA 2016).

Furthermore, the income generated and invested from diamond mines in Lesotho has not always been transparent. Diamonds are produced at the Letseng, Mothae, Liqhobong, and Kao mines; Combined they are estimated to have produced 240,000 carats of diamonds in 2014, worth $300 million, although this may be a much lower estimate than the true profits (Jamasmie 2016). The Letseng mine is estimated to produce diamonds with an average value of $2172/carat, making it one of the world’s richest mines on an average price per-carat basis (Oancea 2008). Official reports note “diamond mining in Lesotho has grown in recent years and may contribute 8.5% to GDP by 2015, according to current forecasts” (CIA 2016). Interestingly, diamond mining in Lesotho was reported as early as the 1950’s, yet only recently do these “profits” make their way into national financial reports. International stakeholders from the UK, South Africa, Ireland, Canada, Bermuda, and the US are associated with the Lesotho diamond mining industry (Mathews 2013; Mbendi 2016).

Diamonds, and the British presence has, and continues to play, a significant role in the economy and style of governing in Lesotho. Historical connotations of Cecil Rhodes brings to mind the prestige of “Rhodes scholars”, or Rhodes University. However, Rhodes was also highly influential in the expansion of British power in Africa; he wanted to see a wide belt of British territory extending from the Cape to Cairo, and placed his multimillion wealth at the disposition of the government to achieve this dream. Rhodes was highly influenced and took the words of his Oxford lecturer John Ruskin as his motto:

This is what England must do or perish; she must found colonies as far and as fast as she is able…seizing every piece of fruitful waste ground she can set foot on, and there teaching her colonists that their chief virtue is to be fidelity to their country (quoted in Andre Maurois, Cecil Rhodes (London, 1953:44) in (Wilson 1975: 147).

Rhodes as a booming capitalist, active politician, and imperialist used his power to influence the alliances and annexation of southern African Land. It is said that he admired the Boers and believed that the complex problems of the region could be solved by total British rule, completely negating the capacity...
of African indigenous rule and management. In 1880s Cecil Rhodes bought out several small mining companies to create De Beers Consolidated Mines Ltd. By 1890, his private company specializing in diamond mining, trading, and manufacturing controlled 90% of the world’s diamond production (Nationsencyclopedia 2015). Today De Beers website describes itself as “a catalyst for delivering socio-economic benefit, and we use our position as the world’s leading diamond company and our close partnerships with governments to drive enduring change across the industry and in the communities where we operate” (DeBeers 2016).

Working our way back into the present era, chairman of De Beers, Ernest Oppenheimer noted in 1927 that, “Common sense tells us that the only way to increase the value of diamonds is to make them scarce, that is to reduce production” (Nationsencyclopedia 2015). Over the last hundred years, critics have presented strong evidence against De Beers for monopolistic practices and various unethical practices to control the diamond market. One of De Beers mines in Lesotho was open and lucrative between 1977 and 1982 and then closed by De Beers. The mine reopened in 2000 under a collaboration between the government, Letseng Diamonds, and a black empowerment group New Mining Corporation of South Africa. It continues to be productive into the present day (Mbendi 2016). After the shooting of one of the South African empowerment investors, the mine underwent bidding (Mbendi 2016). Out of the twelve possible bids it went to the private company Gem, whose CEO is Clifford Elphik, former Managing director of E. Oppenheimer & Son, the investment arm of the Oppenheimer family and personal assistant to Harry Oppenheimer before he died at age 91 (Even-Zohar 2007). He also played a key role in the privatization process of De Beers (in 2001) and in the moving of the business Anglo American from South Africa to London. In a recent interview Elphick, echoing Oppenheimer’s sentiments, stated, “Gem is not interested in being big and unprofitable, it would rather be small and highly profitable.” The $118.5 million deal ended with Gem Diamonds owning 70% and Lesotho owning 30%. As one diamond financing reporter explains:

Purchase a small producing diamond mine for $130 million in Lesotho, buy a few more non-producing concessions in the Democratic Republic of Congo, raise $200 million privately on the London market, and then, if your name happens to be Clifford Elphick, you go and list on the
London Stock Exchange at a corporate value of well over $1.09 billion. All of this happened within the span of roughly half a year. Actually, Elphick’s Gem Diamond Ltd. was only established in July 2005, starting literally from scratch – just a few months after he left the employ of the Oppenheimer family. (Even-Zohar 2007)

What the article does not mention, is that Elphick, as Oppenheimer’s personal assistant, would have known the real value of the mine closed in 1982 and could offer to buy it for $130 million knowing what value it still had left in it. Evidently, Elphick’s work in Lesotho is doing well, one investment article was titled, “Gem Diamonds reported group cash on hand of US$86.1 million for the third quarter of 2015” (Mbendi 2016). This type of sitting on a diamond mine, waiting for the right market time, brings into question the types of profits and investments that could have been made within the Lesotho economy had the mine continued or if the country was able to negotiate better ownership and stakeholder conditions. The UNDP $1.25 a day statistic, is often cited in descriptions of Lesotho, yet people fail to mention stakeholder profits going to London, Luxembourg, New York and Vancouver, anywhere but Lesotho (Gem Diamonds 2016). At a local level, the amount of income within the 30% going to the government and how it is used is not transparent (BTI 2016). Despite the massive inequalities between the rich and the poor, having diamonds as a natural resource, and providing water and electricity to South Africa Lesotho continues to receive copious amounts of international private and public aid.

Quantitative economic statistics about Lesotho, reflect some of the incongruences of the presentation of Lesotho as a poor, rural, needy country. The rural population is quoted as being around 75% while urban dwellers officially make up 27.3% of the population living in Maseru (CIA 2016). However, this does not fully represent the urban and rural diversity seen in Lesotho. There are also a few semi-urban centers with high population density, where one can find relatively “urban” salaried jobs, commercial work, and urban style living comforts with frequent exchanges between urban centers in Lesotho or South Africa. There are some extremely difficult to reach, mountainous, rural zones beyond Maseru, however, the statistic of 75% rural, misrepresents the geographical, service based and economic
diversity within the highlands, lowlands, peri-urban, rural, and semi-rural areas and especially the semi-urban centers along the South African border.

General unemployment is 28.1% and among youth, between the ages of 15 and 24, the rate is 34.4%; this is the eighteenth highest in the world (CIA 2016). For those working, the labor force is divided into two main categories, agriculture and industry/services. Agriculture includes farming, fishing, and forestry accounting for 86%. Industry includes mining, manufacturing, energy production, and construction. Services cover government activities, communications, transportation, finance, and all other private economic activities that do not produce material goods.

<table>
<thead>
<tr>
<th>GDP Composition-by sector of origin</th>
<th>Labor Force-by occupation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agriculture</td>
<td>5.4%</td>
</tr>
<tr>
<td>Industry</td>
<td>28.6</td>
</tr>
<tr>
<td>Services</td>
<td>66% (2014 est)</td>
</tr>
</tbody>
</table>

Industry and services combined account for 94.6% of the GDP and yet only 14% of the labor force occupation, while 86% of the labor force is occupied in agriculture which makes up only 5.4% of the GDP. This reflects a clear disjuncture between the work of the labor force and the monetary measure of the value of all goods and services produced (GDP). In Lesotho more is contributed to GDP by industry and services but remarkably less people participate in this type of labor.

### 3.1.6. Women’s Economic Involvement

The gendered undertones of “industry” usually conjure up male employment (CIA 2016). Development descriptions of Lesotho typically highlight the high incidence of violence towards women and the portrayal of women as “victims” of economic and sexual choices of men (GenderLinks 2014;
Yet, the typical stereotype of poor African illiterate women depending on men, having a large number of children does not apply in Lesotho, where the estimated total fertility rate is 2.72 children and as of 2010 the contraceptive prevalence rate was 47% (CIA 2016). Furthermore, women in Lesotho are allowed and supported to study (women have higher rates of literacy than men) and pursue “professional” careers; they are represented in traditional leadership positions, such as female chiefs, hold management positions in the private and public sector, and serve in legislative and judicial arms of the government (BTI 2016).

Women play a significant role in the formal and informal economy. For example, women are the dominant beneficiaries of the textile and apparel industry employment within Lesotho. In the mid 2000’s Lesotho took advantage of the US African Growth and Opportunity Act (AGOA). The legislation written and promoted from the US, allows the US president to determine which African countries are eligible to receive trade preferences and duty-free entry into the US on certain goods based on their political environment, “visa system,” and compliance with AGOA “rules” (ITA 2015). Under this legislation, Lesotho sourced goods for US brands and retailers including Foot Locker, Gap, Gloria Vanderbilt, J.C. Penney, Levi Strauss, Saks, Sears, Timberland, and Wal-Mart (Riley and Benvenisti 2010). At one point Lesotho was the largest exporter of garments to the US from sub-Saharan Africa. Some posit that in the early 2000’s factory work employed more Basotho than government employment, up to 54,000 a majority of which were women (Riley and Benvenisti 2010). These predominantly Chinese-managed textile and garment factories are still considered Lesotho’s largest private employer. The legislation has created many new employment opportunities, but rather than exploiting the use of in country mohair or extending the line of production to include indigenously grown materials, textiles are imported from China. Lesotho offered cheap labor, factory minimum wage of $93 per month (higher than the “average” salary of $83)(Riley and Benvenisti 2010; CIA 2016), and a ripe setting for global emissions exchange thus companies could minimize costs associated with wages and expensive environmental precautions while maximizing profits for companies and stakeholders. Investing in Lesotho is a brilliant equation for most investment stakeholders. By using/developing a country with the highest difference between the few rich
and the multitude in poverty companies formulate a low average salary and keep human resource expenses low. In the case of Lesotho this resulted in bringing women from all over the country to centralized factory locations, away from their family for work, which may have simultaneously lowered the price of t-shirts in the U.S., kept the Walton family on the Forbes list of the richest families in the world, while creating a perfect trajectory for the spread of HIV.

The structural links in creating a perfect trajectory for the spread of HIV via woman working in apparel factories supplying low cost labor, is not a fact to be “proven” but a description of a probable chain of aggravating events. We do know that the apparel sector boosted the Lesotho economy, as one of (and at one point) highest employers (54,000 people predominantly women). For women in Lesotho, HIV prevalence increases with wealth quintile (20% for lowest wealth quintile and 29% for highest wealth quintile) and is significantly higher among working women (33% compared to 23% (DHS 2004; Corno & de Walque 2007; Khobotlo et al. 2009). The factory apparel sector attracted and employed more women than men. Women came from rural areas to work in urban based factories. Like most of the South African sub-region urban HIV prevalence tends to exceed rural prevalence. In the case of Lesotho, urban prevalence is consistently higher than rural prevalence. This is despite the relatively close links and high mobility between rural and urban communities. The 2004, 2009 and 2014 Lesotho Demographic Health Surveys consistently find the urban HIV prevalence significantly higher by nearly ten percent (29.1% urban and rural prevalence 21.9% (p<0.001) in 2004 and 30% urban vs 22% in 2014). Prevalence in urban women was 33.0% compared with 24.3% for rural women in 2004 and 36% urban vs 26% rural in 2014. Leclerc-Madlala argues that this difference may be due in part to risks related to internal labour migration to urban areas, where new arrivals often live in informal settlements, away from the controlling environment of the village, and in need of money to cover costs. Furthermore, the relative greater wealth in urban areas may support risk behaviours such as sex-for-consumption, where sexual relationships are sought and maintained to acquire consumption goods (in addition to sex-for-survival), contributing to high HIV prevalence levels (Leclerc-Madlala 2004). Others argue that similar to other migrant workers in Lesotho, vulnerability to HIV is exacerbated by living conditions. These conditions often include single
sex hostels precluding bringing family members or “settling down” with a new partner, limited home leave, constrained schedules for seeking health services, boredom and loneliness, and lack of social cohesion creating a sense of anonymity, all coming together fostering an increase in number of sexual partners to fulfill sexual, emotional and economic needs (IOM 2006). The 2007 ALAFA survey found that 45% of apparel workers in Maseru were HIV-positive, (ALAFA, 2008:12). In fact, factory workers are second to only sex workers (71%) for HIV prevalence by high-risk category – men who have sex with men, inmates, pregnant women, and the general population all have lower rates. There is also documentation that a majority of sex workers in urban Maseru and Leribe transitioned from lower paid factory work to more lucrative sex work (IOM 2006). The role of factory labor is a clear example of how structural factors at the international level, such as the institution and dissolution of the AGOA and national level management of working and living conditions converged to intensify the epidemic in Lesotho. Obviously, there is a need for this type of labor but better attention should be paid to how these economic opportunities are implemented so as to minimize these types of unintended negative consequences. Apparel Lesotho Alliance to Fight AIDS (ALAFA), is often hailed for its work-based HIV prevention and treatment outreach, and yet, little is said of the apparel industry’s structural practices that may have and still increase transmission probabilities.

3.1.7. Employment Dynamics and In-country Spending

Unfortunately, much like the abandonment of Wal-Marts all over the Midwest U.S., those built up with tax-free incentives and then closed down when the incentives expire, most of the factories in Lesotho are closing as well. After the Multi Fibre Arrangement (MFA) governing world trade in textiles and garments expired in 2004, limits and quotas imposed on developing countries for export to developed countries were lifted (Adhikar and Yamamoto 2009). Since this expiration, China has aggressively provided even lower production costs and higher profits for American companies. In recent years the number of people employed by the textile industry is steadily decreasing, today approximately 36,000
Basotho, are still employed in the industry (CIA 2016). There are constant battles between unions, workers, and the Chinese management over work conditions.

Official descriptions of Lesotho never convey the significant Chinese presence within the textile industry or in the local economy, but it is a physical reality that cannot go unnoticed. For example, the Chinese embassy in Lesotho is an enormous complex, and the Chinese are significant investors in the newest private Malaysian owned University competing with the National University of Lesotho for both students and their government sponsorships. The government has a close working relationship with Chinese investors. A 2012 article (see Appendix B) demonstrates the types of structural practices by the government that frustrate some Basotho and aggravate the sentiment of the government simultaneously lacking to protect local needs while fostering foreign exploitation. The article explains how the government agreed to allow a portion of Chinese worker salaries to go outside of Lesotho without paying taxes. President of the Lesotho Textile Exporters Association (LTEA) notes the arrangement to pay some salaries directly overseas was one of the conditions to invest in Lesotho, noting that this is common practice for harnessing expatriate talent in foreign countries (Tlali 2012). Thus, throughout the height of the Lesotho textile export boom the highest paid factory managers and administrators did not pay taxes in Lesotho.

According to many locals, Chinese businesses in Lesotho deploy aggressive strategies using questionable business, moral, and health practices that undermine the indigenous economies. Some of the participants in this research complained about the Chinese working with local elite profiting with special architecture and engineering projects throughout the country. Next door to the Nando’s, a South African owned international restaurant chain, in Maseru is a Chinese restaurant clad with live caged cats, dogs, and other various animals, a small Chinese grocery store, an open restaurant floor with authentic spinning tables, a karaoke stage and secret side rooms with Chinese businessmen going in and rarely seen coming out. No matter how rural Lesotho may be, it is always easy to find a Chinese owned shop. One very important problem with this Chinese take over can be seen in my visits between 2004, 2007, and 2012. I witnessed the opening of a Chinese shop in the University town of Roma, which subsequently saw the
rapid demise of local competition and the reign of higher-priced lower quality goods. Another serious problem is the presence of the Chinese mafia, who threaten Chinese families and businesses (Watson 2008b). Because the Chinese presence is resented by Basotho authorities, they do not even step in to assist or protect those effected.

Further problems with the biased view of labor within Lesotho include the fact that population based employment surveys may not always accurately reflect employment realities, often times including those found at “home” in an agreed upon “agriculture” response. According to the World Bank remittances from Basotho working abroad contributed to 24.4% of the total GDP in 2013, one of the highest remittance contributions in the world (BTI 2016). While subsistence agriculture is said to occupy at least 86% of the working population, Lesotho contradictorily imports 80% of its food. Moreover, 90% of the goods Basotho consume are from South Africa (CIA 2016). Another factor for consideration is that in 2002 an estimated 35% of the active male wage earners worked in South Africa. While mining employment has decreased, other activities stepped in, such as preparations for the 2010 South African World Cup. Thus, employment surveys would also avoid those workers who are pulled away from Lesotho for various opportunities.

Services including government activities and all private economic activities compose 66% of the GDP. Typical country descriptions of Lesotho stress the large presence of the government in the economy. The government is, in fact, reported as the largest single employer in the country (CIA 2016). What is also strangely missing from economic reports are the casino revenues and the total amount of employment and salaries provided by churches, NGOs, and international organizations. There are multiple projects and organizations targeting, food security, child nutrition, education, health and “development,” and over 600 organizations alone working in the realm of HIV, yet this type of category of employment is omitted from official employment reports (Letsema 2015). Just to provide one example, Mothers2Mothers is a Prevention of Mother to Child Transmission (PMTCT) service operating in four districts of Lesotho, sponsored by a plethora of entities in South Africa, UK, and the US, who are working in Lesotho since 2007. As of 2013, the program employed 24 site coordinators and 82 Mentor
Mothers (Mothers2Mothers 2014). Thus, just one of these recorded 600 projects employed over 106 people. Economic statistics instead may suggest the large role played by “service” activities. More research is warranted to disentangle the actual amounts of money and goods provided by this vague category. Table 3 describes consumption by category end use. Given that 92.9% of consumption was by “household” and 34.4% by “government” a supposition would be that the economy is relatively healthy, seen by households who are “consuming” (CIA 2016). However, a closer look at who comprises “households” reveals that this includes resident households as well as “nonprofit institutions that serve households” and furthermore includes the consumption of both domestically produced and foreign goods and services. The negative -101% of imports of goods and services reaffirms the dependence on imported goods and services and the depth of debt overall. Considering, these expenditures and the unaccounted

<table>
<thead>
<tr>
<th>Consumption Category, by End Use</th>
<th>% 2014 est</th>
<th>Category Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Household consumption</td>
<td>92.9</td>
<td>consists of expenditures by resident households, and by nonprofit institutions that serve households, on goods and services that are consumed by individuals. This includes consumption of both domestically produced and foreign goods and services.</td>
</tr>
<tr>
<td>Government consumption</td>
<td>34.4</td>
<td>consists of government expenditures on goods and services. These figures exclude government transfer payments, such as interest on debt, unemployment, and social security, since such payments are not made in exchange for goods and services supplied.</td>
</tr>
<tr>
<td>Exports of goods and services</td>
<td>40.6</td>
<td>consist of sales, barter, gifts, or grants of goods and services from residents to nonresidents.</td>
</tr>
<tr>
<td>Imports of goods and services</td>
<td>-101.1</td>
<td>consist of purchases, barter, or receipts of gifts, or grants of goods and services by residents from nonresidents. Exports are treated as a positive item, while imports are treated as a negative item. A surplus of exports of goods and services over imports indicates an economy is investing abroad, while a deficit indicates an economy is borrowing from abroad.</td>
</tr>
</tbody>
</table>

employment category of NGOs, IGOs and churches may paint a very different picture of employment dynamics and in-country spending (CIA 2016).
3.1.8. HIV/AIDS Sector’s Role in the Economy

According to UNAIDS, in 1987, total official donor assistance for HIV/AIDS from 10 countries was approximately $59 million. Between 1996 and 2006, spending on HIV in developing countries rose by 2,900% while the number of people living with HIV rose by 38% (KFF and UNAIDS 2014). By 2007 the world was spending $10 billion US dollars a year on HIV in developing countries, the most that has ever been dedicated to a single disease. Yet, despite the vastly increasing quantity of money harnessed for the disease, in 2014 the WHO’s Global Summary of the Epidemic reports an estimated 36.9 million people were living with HIV; there were two million new infections in 2014 and 1.2 million deaths attributed to AIDS (WHO 2015a). Furthermore, the UNAIDS “Fast-Track Approach” to ending the epidemic by 2020 calls for a meager US $ 31.9 billion to be invested (UNAIDS 2015). It would appear that, regardless of the amount of money invested, the problem of new infections continues to grow.

Institutional discourse on HIV/AIDS funding repeatedly emphasizes the gap between what is needed and how much currently exists.

“There is no dispute that significant new resources are required to address the AIDS epidemic in developing countries.” (Jamison 2006)

“Resources, however, remain a critical question mark going forward, with UNAIDS estimating a continued gap between available resources to address HIV and the projected need” (KFF and UNAIDS 2014)

These types of mainstream voices within the response continue to underline the gap between the need and resources (Yu, Souteyrand et al. 2008; Smith and Whiteside 2010). Yet, there are some inherent problems where much funding is actually wasted, misdirected, and mismanaged by focusing the money in the wrong places. There are also loose controls for how the money is managed and spent, and in some cases that more could be done with less (Bishai, Paina et al. 2014). Furthermore, there is a steady increase in the money needed and funding given which is directly associated with the ever increasing costs of pharmaceutical treatments (NIH 2016). Treatment expenses continue to increase with the increasing number of people testing (be it by choice or part of standard health care services for example during
pregnancy) as well as in the increase in HIV negative persons starting on antiretroviral prophylaxis for prevention (Venter 2009; Smith, Powers et al. 2011; Macklin 2012).

Within the context of extraordinary spending for HIV, there is an ongoing discussion about targeting funds directly for HIV versus a broader health systems strengthening approach. Some argue that vertical programs, those focused on a specific disease, may be diverting funds away from other programs (Faragm, Nandakumar et al. 2009) and mechanisms that strengthen the entire health system (Shiffman, Berlan et al. 2009). Those supporting targeted programs highlight the need and potency for easier accountability, service specialization, and faster results within fragile health systems (Atun, Bennet et al. 2008; Global Fund 2008). They point out successes such as polio eradication, which met its primary objectives while producing multiple unintended positive consequences (Loevinsohn, Aylward et al. 2002). Another argument draws on the synergistic effect of combining vertical programs within existing health systems, arguing that the combined effect provides positive outcomes for both the specific health problem and the general health system (Buse, Sidibe et al. 2006; Ooms, Van Damme et al. 2008; Group 2009). The current trend for many funders is a shift towards a Health Systems Strengthening approach. Oftentimes, researchers present these arguments for vertical or horizontal funding only from the clinical and state level appropriation of resources. However, a missing perspective is how an extreme influx of funding, be it vertical, horizontal, or a mixed approach, influences people’s perceptions of health and disease at the local level. This dissertation demonstrates how this influence of an influx of funding is especially true in the case of HIV in resource unequal settings like Lesotho. Chapters 5, 6 and 10 provide examples of how investments of HIV targeted money influence the ways in which local leaders, and everyday citizens, define, communicate and conceive solutions to the problem of HIV.

With this influx of earmarked funding for HIV there is a troubling issue with the amount some countries spend on overall health versus HIV expenditures. Amico and colleagues (2010) found that Sub-Saharan African countries spent 19.4 percent of their total health expenditures on HIV-related activities, compared to Central and South America (CSA) spending less than 1.1 percent. The study did not include a few countries of high incidence and high receipt of funding that may have actually increased this
percentage such as Zimbabwe, Malawi, and Tanzania. According to the authors, the 28 SSA countries, included in their study spent US$ 2 billion on HIV health, but their total health expenditure was only US$ 10.56 billion (Amico, Aran et al. 2010).

Sub-Saharan Africa spent more per capita than any other region on HIV and less per capita than any other region on health. A sizeable divergence between the highest and lowest country-specific values for spending within SSA was apparent. Several countries, including Zambia, Uganda, Kenya, and Lesotho spent a significant portion of their total health spending on HIV, ranging from 42–64 percent. More specifically, Kenya and Lesotho were the highest spenders, allocating more than 60 percent of their health spending to HIV. Botswana spent almost US$ 118 per capita on HIV health compared to the average of US$ 9.34 in the rest of SSA. While there are high spenders, it seems that spending is often in proportion to the overall burden of HIV, as was suggested by the regression of HIV spending and prevalence. However, a few countries such as Burundi, Niger, and Rwanda spent relatively high amounts compared to their low burden of HIV. Burundi spent 28 percent of their health spending while having a prevalence of only 2 percent. Most countries follow rational spending patterns, while a few outliers' spending may be reliant on other unknown factors. (Amico, Aran et al. 2010)

Lesotho is one of these outliers, spending 64% of its health expenditure on HIV/AIDS in 2007 (Amico, Aran et al. 2010). The increased spending may be reflective of increasing access and paying for testing, infrastructure, and pharmaceutical treatment, however it also demonstrates the pervasiveness of silo funding in certain Sub-Saharan countries, particularly in Lesotho.

The high amount of spending for HIV in Lesotho is directly linked to its importance as a site to to explore HIV related health technology and innovations within the larger global AIDS Response. The country was the first in the world to initiate the “Know Your Status Campaign” a universal testing initiative with door to door testing providing researchers with learning about testing outreach and testing technology. In 2010, Lesotho was one of the first countries to revise their PMTCT policies, based on WHO recommendations, to providing antiretroviral treatment for all pregnant women regardless of their CD4 count or viral load—making it possible to implement in facilities stocked with the treatment (MoHSW 2012). Furthermore, in 2013 the government implemented option B+, providing life-long ART to all HIV+ pregnant women. Lesotho was one of the first countries in the region to pilot cash transfers for prevention (UNAIDS 2014). In 2015, it was one of the first countries to adopt the WHO recommended use of pre exposure prophylaxis (PRE) (WHO 2015b). In 2016, it was the first country in
the world to roll-out the UNAIDS, WHO, PEPFAR promoted, “Test and Treat” guidelines for HIV throughout the country, a guideline that instead of waiting for the standard of treatment of significantly decreased CD4 counts, starts treatment upon testing positive regardless of CD4 counts (see 2.3.6 Treatment for Prevention for more details).

None of these initiatives would have been possible without donor funding. All of these initiatives stimulated some employment for locals, however the imports of medicines and health technology contribute to the -101% imports of goods and services GDP and stimulate the export GDP for donor countries working in Lesotho. In other words, the medicines and technology flow through serving Basotho, but the net economic benefit goes to the donor countries. In fact, over the past twenty years, the health balance was heavily paid by outsiders, particularly US institutions, buying goods from “home” based industries or gaining needed product knowledge. For example, through PEPFAR funding, in 2015, 118,428 individuals received antiretroviral treatment, 7,452 pregnant women received PMTCT prevention, testing and counseling were carried out for 549,913, and care and support were given for 20,623 orphans and vulnerable children, totaling $39 million USD, nearly four times the $10 million given in 2007 (PEPFAR 2015). Other development partners prioritize biomedical projects or the physical construction of health facilities. For example, the UN allocates 25% of its $85 million towards HIV and AIDS priorities particularly for the provision of high quality ARVs. The US Millennium Challenge Account provided $362 million in 2007 for the construction of a new reference laboratory, blood bank and medical university. PEPFAR provided 29.2 million per year between 2010 and 2015 for testing, counseling, ARVs and TB treatment. Finally, the World Bank provided a second $5 million for a five-year technical assistance project to help NAC and MOHSW in expenditure tracking as well as strengthening compliance to PMTCT protocols at the community level. The Clinton Health Access Initiative (CHAI) is also listed as one of the eight significant development donors. Furthermore, Columbia University’s ICAP project, The Clinton Health Access Initiative (CHAI), Elizabeth Glaser Pediatric AIDS Foundation (EGPAF), and the Baylor College of Medicine/Bristol-Myers Squibb
Children's Clinical Center of Excellence (COE) not only sustain PMTCT, ART, and TB treatment, they have also collected large amounts of data for over ten years (MoHSW 2012).

Previously, I gave a simple example of one of the 600 HIV NGOs employing 106 people. Officially, the textile industry is the largest private employer in the country. However, there is no actual enumeration of the total persons employed in the HIV sector. The health care centers and medicines supported by outside funding are not simply points of care, but are settings of highly specialized research, which hire local employees or import personnel. For example, Elizabeth Glaser Pediatric AIDS Foundation (EGPAF), a particularly active and well-funded foundation, supported by PEPFAR, controls over 220 sites in all ten districts of Lesotho funded by CDC and USAID. The map below in Figure 5 shows their coverage in sub-Saharan Africa and Lesotho specifically. Since 2004, EGPAF has trained over 3,000 medical staff and served on various advisory boards (EGPAF 2016). EGPAF notes how they have “enrolled” more than 227,900 clients into HIV care and support programs, started 113,300 individuals on ART, provided PMTCT services to 183,000 women, screened 4,200 women for cervical cancer and treated 350 precancerous lesions (see appendix C) description of the types of HIV research conducted in Lesotho)

![Map of CDC and USAID funded EGPAF sites](image)

**Figure 5**: Map of CDC and USAID funded EGPAF sites, reprinted with permission (EGPAF 2016).
Like EGPAF, other health centers in Lesotho are supported by a mix of private and public funding, often in collaboration with pharmaceutical companies. Baylor College of Medicine Children's Foundation—Lesotho (BCMCF-L) operates the Baylor College of Medicine/Bristol-Myers Squibb Children's Clinical Center of Excellence (COE) in the capital, Maseru, and five Baylor College of Medicine/Texas Children’s Hospital/Bristol-Myers Squibb Satellite Centers of Excellence (SCOEs) (BIPAI 2016). The project is a private public partnership sponsored by Bristol-Myers Squibb and the Abbot Fund (from Abbot Pharma) in collaboration with the Lesotho national government. The project is one of eleven sites including, Houston, Uganda, Tanzania, Swaziland, Romania, Papua New Guinea, Malawi, Liberia, Colombia, Botswana, and Angola. The Baylor International Pediatric AIDS Initiative (BIPAI) which includes the Bristol-Myers Squibb pharmaceutical collaboration, states that it provides medical expertise, training and help with decentralizing health care outside the capital through outreach programs, teen clubs, and educational efforts. It has a Global Health Corp of physicians based in Maseru who spend 25% of their time outside of Maseru providing care, training, and health education. In 2014, Lesotho established its first medical school under the auspices of supporting “the professional development of future Basotho physicians and pediatricians” (BIPAI 2016). The BIPAI public (university) and private (pharmaceutical) collaboration also serves on relevant technical advisory committees to the Ministry of Health, providing a weekly continuing professional development course, journal clubs, case presentations, a monthly Learning and Sharing Forum as well as a one-month visiting scholar program for US medical residents. Clearly, there is a large investment in building up the biomedical capacity in Lesotho.

Since 2005, the Maseru Centers of Excellence (COE) have enrolled over 9,400 patients. As of January 2015, they reported 3,100 active patients, 92% receiving ART, while satellite COEs reported having 1,100 active patients almost all of which were on ART. BIPAI supports treatment for life, providing second and third line treatment options for those who have failed therapy (BIPAI 2016). Centers of Excellence have clinical-like trial practices, monitor treatment success and medication side
effects, and provide adherence counseling. The description of the centers patient home visits reads like trial follow-up standard procedures where “lost from care” substitutes “lost to follow-up”:

Patients who miss clinic appointments and fail to return for care are traced using a combination of phone calls and physical visits to their homes by a team of nurses, social workers, and trained volunteers. Over the last year, nearly 2,000 patients were called or visited to ensure retention in care. This resulted in dramatic reductions in patients who are lost from care and therefore receive inadequate treatment. The volunteers also visit households affected by TB to find additional cases. (BIPAI 2016)

None of the activities of EGPAF or BIPAI are mentioned in mainstream general descriptions of Lesotho’s treatment and care initiatives, while testing kit stock out, the need to increase coverage and healthcare access are all mentioned (MoHSW and WHO 2011; Lesotho Ministry of Health 2012; AVERT 2016). The types of research activities, however, are conducted as operational research under program delivery, and thus are exempt from “research” requirements such as informed consent, reimbursements, quality control and oversight (Resnik 2008). The basic or operational research categorization leaves these entities with fewer reporting and requirement constraints, applying the NIH 2014 definition of a clinical trial patients in Lesotho are “treated” and not “prospectively assigned”:

A research study\(^1\) in which one or more human subjects\(^2\) are prospectively assigned\(^3\) to one or more interventions\(^4\) (which may include placebo or other control) to evaluate the effects of those interventions on health-related biomedical or behavioral outcomes.\(^5\) (NIH 2014)

Thereby, it is possible to conduct operational research for over ten years of follow-up, without such research being considered a clinical trial. There is nothing illegal or ethically wrong, since all of the studies conducted by EGPAF and BIPAI have undergone IRB approval. However, it is interesting to note how much high level biomedical and technical work is done in Lesotho, yet how far behind the government of Lesotho is in building up its own pharmaceutical legislation (MoHSW and WHO 2011) (see appendix B 2011 Lesotho Pharmaceutical Country Profile). Thus, unlike what happens in other settings, institutions that provide pharmaceuticals in Lesotho are not legally bound and cannot face legal repercussions for their work or research. Over the last decade these entities have invested billions in goods and services to Lesotho’s HIV treatment and prevention efforts, however they have also gained a large amount of data that will inform future research and sales in biomedical medicine and technology.
Sometimes the juxtaposition of state of the art U.S. funded “centers for excellence” are in the middle of communities where a large number of people are “sitting”, as some say in Lesotho, having no employment opportunities. This juxtaposition of unemployment and poverty with large amounts of funding going towards specialized clinics and medicines for one disease inevitably provokes questions about health and development investment decisions. These questions are heightened when considering the wealth of data collected for the US government and private pharmaceutical entities at a relatively lower cost and less legally risky environment. It is not that the centers and medicines are not needed, the problem is instead the seemingly exaggerated investment in one strategy at the neglect of investing in other long-term prevention steps such as increasing the quantity and quality of work, strengthening relationships and social action towards specific behaviors fueling the epidemic in Lesotho. Yet, because HIV initiatives like EGPAF and BIPAI, and research projects like the case-study used for this dissertation, do offer employment, goods and services that otherwise would not be available, they have become an important part of the local economy, rendering their work immune to critical discussions about the balance in reciprocity between poor recipient country Lesotho and the possible benefits for international donor organizations working in Lesotho.

The average wholesale prices of HIV medicines range between $280 and $4,097 a month, per person (NIH 2016). The importing of medicines, accounts for a major part of the -101 % of Lesotho’s GDP for imported goods and services. Furthermore, the 92.9% household expenditure by resident households, and by nonprofit institutions that serve households, on goods and services that are consumed by individuals, includes consumption of both domestically produced and foreign goods and services. The six hundred HIV organizations, medical services and medicines, while not stated in “official” descriptions of the economy of Lesotho (CIA 2016) are indeed a significant component of the economy as they fuel a large part of GDP for imported goods and services and household expenditure.

Since 2010, Lesotho has been left without a National AIDS Commission or a specific body responsible for coordinating, monitoring and evaluating all aspects of the response—civil society, biomedical, SBCC. In this lapse the responsibility was given to the Ministry of Health, however there are
many aspects of the response that did not fall under their clinical and medical expertise. Further, compounding the problem, the periods from 2012-2015 were marked by political unrest, and there was a lag in the overall HIV Response. At the end of 2015, the government started rebuilding the NAC. A December, 2015 editorial entitled “NAC return: Time to roll up sleeves” discusses the “re-launch” of the NAC by Prime Minister Pakalitha Mosisili (the same who received the $250,000 in 2011 at the revitalization launch). The author notes:

We couldn’t agree more with Dr Mosisili that the bulk of NAC’s budget should be devoted to fighting the pandemic and not staff salaries. Lesotho can ill-afford bankrolling lavish lifestyles with money meant for stopping a pandemic that has truly become an existential threat. Instead of just sitting in plush offices in Maseru, NAC officials should be deployed in the districts where the pandemic is rearing its ugly head. According to recent official figures, 62 people are infected with HIV on a daily basis in Lesotho, while 50 deaths related to the Acquired Immunodeficiency Syndrome (AIDS) also take place every day in the kingdom.(SundayExpress 2015)

While there is a widespread perception of the mismanagement of funds by NAC, there is also a misperception that the “ugly head” of the epidemic is found in the districts and not in Maseru (SundayExpress 2015). This reflects, once again, the dominant rhetoric of poor rural non-condom using people feeding the epidemic and not the urban professionals, who actually have higher prevalence rates. Also important in this article excerpt is the popular perception that working in the HIV industry is a lucrative employment opportunity one that permits “bankrolling lavish lifestyles”. During the “relaunch” of the NAC, the US Ambassador to Lesotho, Matthew Harrington made the connection of the revival of NAC with the need to reach the Fast-Track 90/90/90 goals during the five-year window or having to face a reality where the expanding epidemic will, “outstrip the capacity of the country and development partners to respond”(SundayExpress 2015). This again shows the close link between the Fast-Track approach discussed in Chapter 2 and the lines of power and funding in local contexts such as Lesotho.

This brings us back to another dominant theme, the resentment of outside interference in the country. An editorial in late 2015 reflects the complex dynamics between identity, government rule, hegemony, and the growing resentment for the American presence in the country (SundayExpress 2015). In April 2015, the American government warned that it would withdraw aid to Lesotho should the
coalition administration fail to adhere to “democratic principles” and observe the rule of law as enshrined in the country’s constitution. The threat to pulling out aid has received split views within the country. On one side there are those urging the government towards a “paradigm shift” that is accompanied by structural reforms creating an “enabling business environment” that “attracts, not only aid, but investment and ensures growth” (SundayExpress 2015). Others instead see the US as “meddling” in internal affairs and argue for sovereignty from American and South African colonial usage of Basuto land, bodies, and industry for their own benefit and continual detriment of Lesotho’s development. Within this context, revisiting the map in Figure 5 of the splitting of Lesotho into CDC and USAID aid regions seems uncomfortably similar to colonial maps dividing territory for governing.

In 2012, while in Lesotho, my focus was on following up with the MCP research team and tracing how and where the findings went to affect change. The connection between employment, politics, inequalities, and pharmaceuticals was not part of my original study agenda, but became integral through the themes repeatedly mentioned by participants and the policy documents I reviewed. The below newspaper article shows the presence of these overlapping themes (Figure 6) the picture is small in order to visualize the three different sources sharing these intersecting connections, (appendix E) contains larger more easily legible version of the texts (Editorial 2012; Lekhetho 2012).

Within the same page, there is the juxtaposition of the sensation of being infused by the pharmaceutical industry seen in the cartoon, the need for decent work in the general population, and the contradicting presence of super wealthy politicians and elite alongside citizens vulnerable to starving or freezing to death, seen in the two articles, “Excesses of Democracy” and “Promises and Lies”. Journalists and intellectuals articulate well the situation. One author describes the frustration with politicians and structural adjustment programs in the country: “Years of aloofness and materialistic lifestyle have left people like him obsessed with huge sums of money and highways forgetting that millions go hungry everyday because they are broke….we are tired of a ruling class that is incapable of understanding roads are built to create jobs first and comfort next, in a country where the majority is unemployed” (Lekhetho 2012: 10). The editorial writer of “Promises and Lies” describes how further frustrations rear their head
with the apparent disjuncture between the rhetoric on creating employment and the lack of tangible detail about the logistics of generating work (Editorial 2012: 10). However, these frustrations actually conceal the overriding problem that a majority of the funds coming in are linked to bio-technology such as hospital and clinical structures, clinical staff, health technology and pharmaceuticals. These funds do generate some work in Lesotho but a large amount of the funding is consumed for services and goods that stimulate the economy of donor countries (MoHSW 2012; CIA 2016).
This chapter has shown how the local context within Lesotho is much more complicated than a “poor” HIV stricken country. Lesotho’s development is filled with contradictions. Lesotho is a rich source of diamonds, exports water and energy to South Africa yet suffers from droughts and poverty. Lesotho has had and continues to have one of the highest levels of inequality in the world (UNDP 2011; WorldBank 2016). Lesotho ranks within the top 50 highest of 132 countries in GDP percentage devoted to military use (CIA 2016). It invests the highest GDP percentage into education in the world (CIA 2016). Lesotho has high rates of literacy 79.4% of the population age 15 and over can read and write with females having higher literacy rates than men (70.1% of males and 88.3% of females) (CIA 2016). Since independence, the country is in cyclical political turmoil. More recently, freedom of speech is threatened, kidnappings and military force are utilized to maintain “democracy” (BTI 2016) (SALC 2016). Lesotho’s structural problems are closely related to a history of colonization/protectorate and economic development steered by outsider and local leader interests rather than towards providing sustainable employment opportunities allowing individuals and families to stay together, work, and invest in Lesotho. Furthermore, this trajectory of development and modernization has left distinct racial and class demarcations in a society that is often depicted as being ethnically homogenous.

This chapter also demonstrated that there are indisputably large amounts of money coming into the country for HIV aid and medicines. The health expenditure as a percentage of GDP spent by institutions or individuals for the application of medical, paramedical, and or nursing knowledge and technology for health was 11.6% in 2012, that is the tenth highest in the world (CIA 2016). Closely related to the aid and the medicines are the health and research infrastructure developed alongside this aid. International initiatives like the Fast-Track discussed in Chapter 2 are often implemented at the local level without much consideration for context specific complexity. Large funders have and will most likely continue to promote a more technological biomedical approach. However, biomedical approaches often need and seek out the expertise of social and behavior scientist to understand challenges to medicine adherence, issues of accessibility and also to understand the audience for demand generation. As mentioned previously the MCP 2008 project’s funding was partially part of funding allocated for site
identification for pharmaceutical research sites. Without this biomedical funding allocation, the social and behavioral MCP study would not have happened. Given the current trajectory of policies like the Fast-Track it is likely that more qualitative research will be commissioned as a complement to quantitative clinical studies rather than stand-alone projects (UNAIDS 2015: 19). Because the nature of qualitative research depends on the interaction of people, discussing, reflecting upon their reality issues surrounding the context specific complexity in social, political and economic factors will inevitably come to the fore. Within this context, it is important to consider what unique contribution a qualitative research experience provides to the capacity of individuals and to the long-term translation of research into tangible HIV prevention actions. And more importantly, how the qualitative experience contributes to HIV solutions while engaging with context specific realities. The next chapter further develops arguments on how ordinary on the ground practices in qualitative research and capacity building, can facilitate longer-term social changes and improvements in HIV prevention information diffusion.
CHAPTER 4: ON THE GROUND PRACTICES

The objective of this chapter is to present the concept of diffusion of information as it relates to translating knowledge into practices that help humans. In discussing health science approaches to the problem of diffusing research into practice, the chapter explores how elevating particular research practices to praxis, heightening awareness of everyday practices in qualitative research, and capacity building, can improve HIV prevention information diffusion.

4.1. Translational Research

Across the social and biomedical sciences, there exists a grave divide between the state of knowledge and the state of practice. Foundations, universities, health organizations, and hospitals have established centers for translational research in order to address this problem. The U.S. National Institutes of Health (NIH) has dedicated $500 million a year for 60 such projects through 2012 (NIH 2010). Translational research comprises a significant component of the European Commission’s $6 billion budget for health related research and the UK invested £460 million to establish its own translational research center. It would appear that the problem of translating science into use is being taken seriously, but by whom and for whom? Steven H. Woolf has pointed out that “translational research means different things to different people” (Woolf 2008: 211) and these differences have serious implications for health outcomes.

Within health research there are several competing understandings of what comprises translational research. The Institute of Medicine’s Clinical Research Roundtable made the distinction between two “translational blocks,” which some label as T1 and T2. T1 is “the transfer of new
understandings of disease mechanisms gained in the laboratory into the development of new methods for
diagnosis, therapy, and prevention and their first testing in humans” (Woolf 2008: 211). The second is T2
“the translation of results from clinical studies into everyday clinical practice and health decision making”
(Woolf 2008: 211). Both types of translational research are necessary to ensure that the findings of
science and research make their way to improve human lives. However, more attention and financial
resources are devoted to T1 (Moses, Dorsey et al. 2005). As a result, there is a proliferation in scientific
discoveries created in labs and controlled settings but the gap in health disparities widens, as the transfer
of these discoveries at the local level is not done with the same care or resources as in their creation.
Traditional means of dissemination of scientific findings are usually limited to manuscripts for
submission to academic journals and presentations at academic meetings. “Missing, by and large, are
plans, processes, and methods for focused translation and dissemination of discovered knowledge to
potential practitioner end users” (Arrington, Kimmey et al. 2008: 186). According to the U.S. National
Institutes of Health, “each year, billions of U.S. tax dollars are spent on research and hundreds of billions
are spent on service delivery programs. However, relatively little is spent on, or known about, how best to
ensure that the lessons learned from research inform and improve the quality of health and human
services and the availability and utilization of evidence-based approaches” (NIH 2010).

4.1.1. Dissemination and Implementation Research

Under the wider umbrella of translational research is the nascent area of dissemination and
implementation research, which intends to bridge the gap between public health, clinical research, and
everyday practice by building a knowledge base about how health information, interventions, and new
clinical practices are transmitted and translated for public health and health care service use in specific
settings (NIH 2010). However, like “translation” research, there is great variation in how these terms are
used. The NIH has provided the below definitions (emphasis added):

- Dissemination is the targeted distribution of information and intervention materials to
  a specific public health or clinical practice audience. The intent is to spread knowledge
  and the associated evidence-based interventions.
• Implementation is the use of strategies to adopt and integrate evidence-based health interventions and change practice patterns within specific settings.

The distinction between these two exists because interventions developed in the context of efficacy and effectiveness trials were rarely transferable without adaptations to specific settings (NIH 2010). Even in the case of situations similar to those in trials, the process of transfer has not been straightforward. In light of the need for applications at both the local and international settings, the NIH has made these terms distinct as a heuristic device for researchers to study how to make developed and tested information used in every day practice. Interestingly, while bridging the gap to every day practice is the goal, there is no mention of the involvement of policy and community level stakeholders or the general involvement of persons beyond the traditional public health and clinical audience. Yet, at the same time, in an effort to further ensure the return of investment on research dollars spent, requirements of “community engagement”, “multi-stakeholder partnerships,” and “capacity building” have become essential ingredients in project proposals from the NIH and other leading funding agencies (Viswanathan, Ammerman et al. 2004; NIH 2007; NCRR 2008; CDC 2010; Fund 2010; Gates 2010; USAID 2010).

There is a need for a broader conceptualization of how information is disseminated and implemented and who carries out the dissemination and implementation. Thus, while subtle, this omission of a wider target audience is reflective of a larger disjuncture between the desire of getting health information and interventions to the local level and that of the means of going beyond traditional health practice and research settings.

4.1.2. Translation, Dissemination, and Implementation and HIV/AIDS

For the past 25 years, the field of HIV/AIDS has been a microcosm of the wider trends in funding and prioritization towards laboratory and clinical approaches. Funding has focused predominantly on clinical research and pharmacological approaches to treatment and prevention (ARVs, PREP, vaccine) and less on the work with communities, partnerships, and laypersons (Campbell 2003). In order to move forward, the advances of T1 translational research—lab, clinically controlled findings—must now go
through the second type of translation into real world settings. For example, interventions like prophylactic antiretroviral therapy and replacement feeding of newborn babies to HIV infected mothers worked well in hospitals and clinics. Translating this evidence to low and middle-income settings of homes and communities that have limited access to clean water and formal health care has proved to be a serious challenge. The scientific community’s failure to properly invest in the translation of this type of T1 evidence into T2 real world applications in the early dissemination and implementation process, has resulted in the unnecessary morbidity and mortality of infants throughout the world (McIntyre 2010).

Similarly, clinical trials have shown that male circumcision is protective against HIV transmission for men (Green 2003). Yet, like the previous example, the investment in the type T2 work of understanding local conditions, resources, and challenges beyond the lab and clinic was much less, resulting in a much longer curve between known efficacy and on the ground practice.

In recent years, however, there has been a growing body of support for behavioral and structural approaches to prevention and treatment that break the traditional lab and clinical boundaries (Campbell 2003; CDC 2010; Fund 2010; PEPFAR 2010). There is a recognition that a combination of biomedical, behavioral, social, and structural responses that incorporate short, medium, and long-term solutions, is the way to move forward. For example, The U.S. President's Emergency Plan for AIDS Relief (PEPFAR) states that it “will not only continue quality delivery of HIV prevention, care, and treatment services, but will also create a durable response that will be sustainable long into the future” (PEPFAR 2010) The strategy was broken down into two phases. Phase one, during the first two years, entailed working with governments to collect evidence on what works and developing a road map for a basic package of prevention, care, and treatment services. Phase two outlined the subsequent three years and entitled countries to scale up the evidence-based approaches identified in the first two years.

Like PEPFAR, other funders are stressing the importance of making all decisions on policy and programming based on “evidence.” Evidence often refers to the important scientific findings of T1 lab and clinical findings. In formulating prevention strategies, policy makers often rely on T1 information and quantitative indicators as “evidence” such as incidence, prevalence, number of people who have access to
treatment, surveys on Knowledge Attitudes and Behaviors (KAB) that indicate condom use, transmission knowledge, number of sexual partners etc. In order to understand the specific nuances behind these numbers and trends, T2 qualitative studies are sometimes commissioned. In attempts to take a medium and long-term approach, there is a trend towards the inclusion of indigenous researchers and community stakeholders in the research process. The ultimate goal of local participation is to give ownership of the findings and to increase the likelihood of the findings being used (Callard, Rose et al. 2012). This combination of local involvement and qualitative evidence is intended to filter back into policy and programmatic decisions. However, wastes of time and money often occur because of our inability to translate results and local experience into practical use. Part of the problem may lie in the nature of translational research being conceived in a linear model where “non” experts are brought in only at the end of the research pipeline and qualitative research is either conducted at the end or often at the commission of studies linked to a specific product, that already has the weight of years and millions invested. Thus, the qualitative endeavor is often tagged on to help with approvals, acceptability and “demand generation”.

4.1.3. Non “expert” Participation in Translational Research

Collard and colleagues provide a critical review of existing literature on translational research and medicine (Callard, Rose et al. 2012). Taking two dominant frameworks, one from the US (President’s Cancer Panel) and the Welcome Trust in the United Kingdom, they point out how neither creates space for patients, or the public, in earlier translational phase but rather at the end when products are ready to be “disseminated” or ready for the market. The authors underline how, it is extremely rare for patients and the public to be positioned anywhere but at the end of the (translational) line (Callard, Rose et al. 2012: 391). Furthermore, they argue that this orthodox conceptualization renders invisible the growing body of research conducted by, or in collaboration with, service users and stakeholders. They demonstrate how the term “bench to bedside” and the dominant translational model described as a one-way pipeline starting from the lab and working its way down to the “people” is scientifically, ethically, and
pragmatically problematic. Instead they offer a re-conceptualized model of translational research as an interlocking loop rather than as a pipeline, one in which service users and other stakeholder involvement feed into each of its elements (Callard, Rose et al. 2012: 389). For some scientists, this seems like a logical and pragmatic way to further the depth and quality of patient’s/user’s knowledge and expertise in biomedical research (Grocott, Weir et al. 2007; Sha and Robinson 2007; Staley 2009; Callard, Rose et al. 2012). For others this approach runs counter to good science, service users and stakeholders lack the requisite objectivity and familiarity with high-level abstraction adequate to participate (Caron-Flinterman, Broerse et al. 2007; Baart and Abma 2010). Increasing “participation” earlier on in the pipeline or in more depth in later stage will inevitably slow down and dilute the quality of research. Even those who may be sympathetic towards increasing partnerships see the power imbalance between scientist and end users and perceive collaboration as an impossible task.

Thus far, the evidence based on the impact and benefits of service user and stakeholder involvement in research is not convincing for either of these two groups but is steadily growing for those who emphasize the pros of such endeavors. A recent study attempted to fill the gap between the increasing requirement for patient and public involvement (PPI) in research and the evidence to inform just how to implement this prerequisite (Buck, Gamble et al. 2014). They compared PPI plans extracted from 28 clinical trial grants in the UK between 2006 and 2010 with a review of implementation and qualitative interviews with researchers and PPI contributors. They found most (20/25) had been implemented exactly as written, but several researchers interviewed described the PPI as tokenistic and described the difficulty of finding “the right” contributors, advising caution in involving current patients. PPI contributors reported feeling constrained by their late involvement, lack of clarity in roles, limited confidence in interaction, and inadequate understanding of the technical language. Much of what these clinical researchers document is information well established in literature on community based research and action based research. There seems to be a lack of utilization of this wealth of knowledge from outside of the clinical paradigm. Nonetheless, the authors usefully highlight the importance for funders
and reviewers to allocate resources (human and financial) to pre-application reviews and to monitoring
PPI involvement before, during, and after trials while leaving space for ongoing flexibility.

Other bodies of evidence include patients’ organizations that have designed and led biomedical
research into rare diseases and setting up biobanks (Callard, Rose et al. 2012). There is also a growing
interest in using service users’ experiential knowledge of diseases and disorders to shape biomedical
hypotheses and research questions. Collard and colleagues present the following example using new
drugs for psychotic disorders within psychiatry:

…many service users find some of the side effects of current medication more troubling than
some of the symptoms for which that medication is prescribed. This opens up complex questions
in terms of how best to judge the therapeutic value of existing and yet-to-be-developed
medications—as well as how to determine which symptoms are most pressing when deciding on
priorities for drug development. Decisions over future drug design ought, we believe, to take into
account service user’s lived experience regarding which symptoms of the psychiatric diagnosis
are most troubling, rather than simply drawing on scientific and clinical expertise vis-à-vis what
kind of medication is likely to produce most therapeutic value. (Callard, Rose et al. 2012: 393)

The discussion of psychiatric drugs can also be extended to HIV/AIDS technologies. In the
various forms of PrEP, gel, pill, female condom, male condom, etc. the idea is to provide a menu of
options that can satisfy various prevention needs. If one does not work, the person can try another
method. Rather than involving people early on to understand how they experience the problem, or even
during clinical trials, the focus is often on adherence to prove efficacy rather than adherence linked to a
person’s ownership that the new technology is a sensible solution to a problem they cannot resolve by
other means. Energy, emphasis, and resources are placed in the “marketing” to convince the target
audience that this is indeed the best solution to their problem. We often take for granted the simple reality
that, “Any approach to health improvement carries assumptions about what health, disease, and disorder
are, and how best to intervene” (Callard, Rose et al. 2012: 396). By providing expert solutions we side-
step the messy work of collaborative problem definition. This is not applicable to clinical research alone,
but also to behavioral studies; we increase understanding of the social and cultural contributing factors
but rarely is the public brought in to identify what is the right angle or action step to use what we have
learned. For example, multiple studies were conducted in Lesotho to confirm the reality and uncover the
nuances surrounding the practice of having multiple and concurrent partners, but little was done to ask people the right angle to change behavior regarding MCP. Little public consultation was done to involve traditional healers, to ask how the MCP behavior agrees or conflicts with religious and cultural teachings, to identify if partner reduction education is needed, if strengthening the message of using condoms with all partners all the time is the priority, or to simply explain how MCP increases transmission.

In conclusion, nowhere in translation and dissemination descriptions of increased participation are the research team members discussed, as if research is produced by robots and not by humans who along the way have their own observations and experience with the problem and the proposed solution. The authors who call for a change in the way knowledge is created, advocate for greater involvement of the public and stakeholders in the knowledge creation loop. I would argue that there is another blind spot which is the inclusion of “implementers” of research beyond that of the principal investigators: the research staff.

4.2. Diffusion of Innovations

Closing the gap between research and practice is a longstanding complex process that has motivated the development of several frameworks and models (Greenhalgh, Robert et al. 2004; Fixsen, Naoom et al. 2005). One of the most influential theories is Everett Rogers’ (2003) ‘Diffusion of Innovations’ (DOI) for the adoption of innovations among individuals and organizations. The DOI theory has its roots in several different disciplines, the most important including anthropology, early sociology, rural sociology, education, industrial sociology, and medical sociology. Today, the DOI theory is one of the most interdisciplinary frameworks used in economics, development, communications, political science, and public health, among others. In fact, based on the number of diffusion study publications over the past four decades, the field of diffusion studies represents more scholars from different disciplines and different nations than any other field of behavior science research (Rogers 2003).

In fact, the previously discussed terms of “dissemination” and “implementation” have their history in the older concept of diffusion. These terms were conceived as ways to break down the concept
of diffusion into smaller organizational components (NIH 2010). Diffusion itself is defined as “the process in which an innovation is communicated through certain channels over time among the members of a social system” (Rogers 2003: 5). An innovation is defined as “an idea, practice, or object that is perceived as new by an individual or other unit of adoption” (Rogers 2003: 12). A communication channel is "the means by which messages get from one individual to another" (Rogers 2003: 18). The concept of time is broken down into two components. "The innovation-decision period is the length of time required to pass through the innovation-decision process" (Rogers 2003: 21). While the "Rate of adoption is the relative speed with which an innovation is adopted by members of a social system" (Rogers 2003: 23). Lastly, a social system is defined as "a set of interrelated units that are engaged in joint problem solving to accomplish a common goal” (Rogers 2003: 24).

As evidenced the theory of DOI is quite extensive. Rao and Svenkerud (1998) have identified six DOI concepts that are most relevant to HIV/AIDS prevention: communication channels, the innovation-decision process, innovation attributes, adopter categories, homophily, and opinion leaders. The innovation-decision process is an over-time sequence through which a person or organization passes and includes five stages: awareness, knowledge, persuasion, adoption, and implementation. The innovation itself is also comprised of attributes or the characteristics of the innovation that may be perceived either positively or negatively. The concept of adopter categories is basically a categorization of individual groups based on the relative rate at which they adopt a new idea, technique, or process (Rogers 2003).

Homophily and heterophily are key principles within this theory. Rogers defines homophily as "the degree to which pairs of individuals who interact are similar in certain attributes, such as beliefs, education, social status, and the like" (Rogers 2003: 19). The theory posits that when given the choice, individuals tend to interact with someone similar to themselves. In the context of knowledge gain and attitude or behavior change, homophilous individuals have more effective communications because their similarities facilitate the exchange of information. It is argued that the most ideal situation for diffusion is where two individuals are homophilous in every aspect except for the knowledge of the innovation (Rogers 2003).
Another principle of the theory is the role of opinion leaders within a social system. This can be understood as either a strong naysayer or a champion for the cause. They are particular individuals who have greater influence on spreading either positive or negative information about an innovation. Rogers (2003) describes these individuals as usually having greater exposure to mass media, as being more cosmopolitan, having greater contact with change agents, having more social experience and exposure, having higher socioeconomic status, and being more innovative (Rogers 2003). In other words, those that have enough capital to take a risk and not care what other people think.

4.2.1. Limitations of Diffusion of Innovation Research

In 2004, Gary Meyer argued that a vast majority of the thousands of diffusion studies that have been conducted across disciplines in the past 60 years have been driven by a methodological approach that has become institutionalized in diffusion research (Meyer 2004). The approaches consistently rely on quantitative data, investigate only one innovation at a time, collect information from adopters, describe only a single point in time, and typically the study is conducted after a widespread diffusion had already taken place. Meyer questions:

When considering the methods that have become institutionalized in diffusion research, one cannot help but wonder whether the research questions asked over time have limited the methods selected, or rather if the methods established early on have restricted the research questions asked (Meyer 2004: 68).

Meyer’s main argument is that, in order for the collective knowledge on the process of diffusion to move forward other methodologies and questions must be asked. He suggests consideration of the following methodologies: panel, archival, quasi experimental, point of adoption, and an integration of qualitative methodologies (Meyer 2004). Of particular importance is Meyer’s argument that qualitative methods, such as in-depth interviews, written journals or logs, and tape-recorded conversations, allow the researcher to get “close enough” to the process permitting the researcher to explain why certain events unfolded as they did or specify more precisely the relationship between independent and dependent variables than do traditional DOI methodologies.
As mentioned previously, Rogers model has and is being used all over the world. His book alone, synthesizes research from over 508 diffusion studies. Yet, Rogers himself has noted that there are several areas still in need of research, including: the consequences of adoption, resistances to adoption, prediction of how the diffusion process will occur, and better ways to track how an innovation spread through a system via social networks (Singhal and Law 1997). According to Rogers (2003), there is a tendency towards documenting only the positives in the adoption of an innovation, rather than the real picture that encompasses both the positive and negative outcomes for an individual or organization. As a result of this positive attitude bias, Rogers has outlined three categories of consequences that need to be explored: desirable vs. undesirable, direct vs. indirect, and anticipated vs. unanticipated (Rogers 2003: 470).

Much attention has been given to the actual spread of an innovation without looking at factors of resistance. Obviously, with the failure of many attempts to diffuse an innovation it is key to understand the nature of resistance in order to overcome it.

Rogers has also identified the need to more efficiently track how an innovation spreads through a social network. Rogers describes one study of the Tanzanian HIV/AIDS educational soap opera, “Twende na Wakati” where people that were only exposed to the show but did not have an opportunity to talk with other people did not adopt the family planning or HIV/AIDS prevention messages. Rogers concludes that:

communication networks are important in the diffusion process, yet they are invisible-we often cannot see them. We need new methods of obtaining communication network data so that we can better understand how innovations diffuse… we need to know who talks to whom and what they say to each other about the innovation (Singhal and Law 1997: 46).

The importance of communication networks in behavior change strategies and the need to study them are echoed by several other researchers in the field (Auerbach, Wypijewska et al. 1994; Kelly 1995; Morris 1997). The value of not only the message but who transmits the message and the context of the transmission is a thread that runs through both individual and social models of behavioral change. Furthering our understanding of communication networks using a particular theoretical lens like ‘Diffusion of Innovations’ has been, and will be, applicable in other theories, models, and research traditions.
4.2.2. Anthropology and Diffusion Research

Diffusion research’s intellectual roots can be traced back to European beginnings of social science, over a century ago. In his influential book *The Laws of Imitation*, Gabriel Tarde, one of the forefathers of sociology and social psychology, makes some general observations about the diffusion of innovations. Tarde explains the reason for his investigations, was “to learn why given one hundred different innovations conceived at the same time—innovations in the form of words, in mythological ideas, in industrial processes, etc.—ten will spread abroad while ninety will be forgotten” (Tarde 1903/1969). Another forefather of sociology, Georg Simmel’s, defined the concept of the “stranger” as an individual who is a member of a system but who is not strongly attached to the system (Simmel 1908/1964) and influenced later concepts such as social distance, heterophily, and cosmopolitiness (contacts outside the “normal” social system of individuals). Simmel also fostered an interest in studying communication networks to understand diffusions within a system. Simmel describes that, “the groups with which the individual is affiliated constitute a system of coordinates, as it were, such that each new group with which he becomes affiliated circumscribes him more exactly and less ambiguously” (Simmel 1908/1964: 140). One root of diffusion research is traced to the early anthropological work of British diffusionists and the German-Austrian diffusionists. Their basic argument was that social change can be explained by the introduction of innovations from one original source. Although today this is a rather antiquated idea, since social change occurs both by invention and diffusion, at the time the model was important in bringing the idea of diffusion to other social scientists (Kroeber 1937). Thus, in the 1920’s American anthropologists, like Boas and Kroeber, were the ones to most directly expound and challenge the work of European diffusionists pointing to how the same “innovations” can come about and spread by a variety of reasons including trade, diffusion, environmental conditions, historical accidents, and psychological factors. In fact, anthropology was the first research discipline to take up the study of diffusion. It was followed by other traditions, such as sociology, education, public health and medical sociology, communication, marketing and management, and geography.
Over the years, anthropology has offered several unique contributions throughout the growth of the diffusion paradigm, especially through the methodological approaches of investigating a subject over time and doing participant observation, where the researcher attempts to build up a relationship and share in the every-day experiences of respondents. This combination of time and local proximity results in a process of immersion that attempts to allow the story of a diffusion to emerge from the change receiver’s perspectives and not just from that of the change agent. Furthermore, the American anthropological tradition of a “holistic” perspective brings together the lifestyles, worldviews, economics, and social relationships to understanding the process of diffusion. As a result, the anthropological tradition has helped the diffusion paradigm to be aware of the pro-innovation bias and to pay more attention to the broader consequences of an innovation (Rogers 2003). Many anthropological studies have documented how planners and officials in charge of diffusion programs failed to account for the cultural values of the adopters of an innovation which resulted in either the failure of projects or led to a series of unanticipated consequences (Sharp 1952; Wellin 1955; Pelto and Miller-Wille 1972; Harding 1973; Havens and Finn 1974; Dewees and Hawkins 1988; Carter 2001). Several studies have highlighted the importance of understanding culture and intercultural interactions and the significance of indigenous knowledge systems in the acceptance or dismissal of innovations (Hawley 1946; Linton and Kradiner 1952; Cancian 1979; Lansing 1991; Sommers and Napier 1993; Mensch, Bagah et al. 1999).

Anthropology has contributed much to the micro level details of diffusion. However, some see this as a trade-off between the rich contextual details these studies have provided and their overall generalizability. I believe that due to constraints on anthropologists to perform primary research rather than study what has been done and analyze for larger patterns and generalizations, meta-analysis rather than literature review, there are probably more generalizations than we realize. Nonetheless, anthropological theory and methodological approaches have in the past, and continue, to both gain much from and contribute to the diffusion paradigm.
4.2.3. Clinical and Public Health Models for Dissemination and Implementation

The most dominant models in the health domain for dissemination and implementation include those of the Institutes of Medicine’s model and the Public Health Model (Wandersman, Duffy et al. 2008). In 1994, the Institutes of Medicine released a report on prevention research in mental health that outlined a five step model for assessment, intervention and dissemination (IOM 1994) (see Figure 7). Similarly, the public health model for developing interventions also includes a linear process (Mercy, Rosenberg et al. 1993) (also presented in Figure 7). These models, like the diffusion of innovations, can

**Public Health Model 4 Stages to Develop Interventions (Mercy et al. 1993)**

1. Define the problem
2. Identify risk factors
3. Develop and test interventions
4. Ensure wide spread use

**The Prevention Research Cycle (IOM 1994:362)**

![Figure 7: Public Health model 4 stages in developing interventions (Mercy et al. 1993). And the Institute of Medicine (1994:362) model of the prevention research cycle reprinted with permission by the National Academy of Sciences, Courtesy of the National Academies Press, Washington, D.C.]

broadly be understood as source based models (“science push” or supply centered) which are based on the perspective of the innovation developer and trace the creation of an innovation to its transfer to an end user. These models are unidirectional with a feedback loop and seem to assume that effective
interventions will naturally flow from arrow to arrow without taking into account what happens in the space between steps.

Building upon this weakness, in collaboration with Divisions at the Center for Disease Control (CDC), Wandersman and colleagues (2008), developed the Interactive Systems Framework for Dissemination and Implementation (ISF) which draws upon aspects of research to practice models, like those previously described, as well as upon community-centered models. The model was developed and utilized to bridge the gap between research and practice and to support evidence-based practices. The ISF describes an innovation as new knowledge or information that could be useful to prevention efforts in the field (Wandersman, Duffy et al. 2008: 174). In this framework, prevention innovations can be categorized as programs, policies, processes, and principles. What is different and significant about this model is that it looks specifically at the systems and processes involved in the development and testing of innovations. It takes the arrows within the other two models and explicates how the movements from one stage to the next can occur. Other models describe the functions (e.g., exposure, selection, adoption), this model takes into account the systems and infrastructure necessary to carry out these functions. Since the focus is on the infrastructure needed to carry out various activities in the implementation and dissemination process, a key component of this model is the notion of capacity. The authors divide capacity into two domains—innovation specific capacity and general capacity. Innovation specific pertains to the capacity necessary to complete a specific present objective. While general capacity is intended to enhance the infrastructure, skills, and motivation of an organization but it does not specifically focus on an innovation.

Within the ISF model, a system refers to a set of activities that may vary in the degree to which they are systematic or coherently organized. The framework presents three systems: the Prevention Synthesis and Translation System (which distills information about innovations and translates it into user-friendly formats); the Prevention Support System (which provides training, technical assistance or other support to users in the field); and the Prevention Delivery System (which implements innovations in the world of practice). Both the prevention support and delivery systems take into account general capacity building/use and innovation-specific capacity building and use (Wandersman, Duffy et al. 2008: 179).
The creators note that the model is intended to be used by different stakeholders: (e.g., funders, practitioners, researchers) who can use it to see prevention not only through the lens of their own needs and perspectives, but also as a way to better understand the needs of other stakeholders and systems. It provides a heuristic for understanding the needs, barriers, and resources for the different systems as well as a structure for summarizing existing research and for illuminating priority areas for new research and action (Wandersman, Duffy et al. 2008: 171)

Unlike the other frameworks so far described, the ISF does not take the primary perspective of the researcher, practitioner, or community. Rather, it lays out the relationships between all of them, looking at all perspectives and leaving space for the user to decide where to begin and end in the framework. As a
result, the emphasis of the framework is on collaboration and communication among all stakeholders, and not on a unidirectional flow of an innovation. The creators of the framework note:

We are unaware of any research or systematic efforts to examine or strengthen connections among these systems. The amount of interaction currently taking place between the Systems is not known. Likewise, we do not know how best to promote interactions between the Systems. While these interactions were not the primary focus of the development of the interactive systems framework, it may be that the greatest contribution to enhancing dissemination and implementation may lie in these interactions. (Wandersman, Duffy et al. 2008: 179).

4.2.3.1. Interactive Systems Framework for Dissemination and Implementation (ISF)

Public Health models and the Diffusion of Innovations theory tend to take a linear approach from the maker of an innovation going straight to the “target” population. These models are unidirectional and seem to assume that effective innovations will naturally flow from step to step without taking into account what happens in the space between steps. I argue that it is in this space between the steps, the interactions that take place between those who create a prevention innovation and those who will get it to the “target” population, that there is a critical point to the success or failure of getting a health prevention innovation into practical use. It is much easier to focus only on the subjects or targets of dissemination than to turn the lens to include those who create and disseminate a health prevention innovation. The ISF provides a means in which to include multiple perspectives and interactions.

For this dissertation, the new ideas, knowledge, or information to be studied are the actual study results as well as the indigenous researchers’ experience (knowledge gained, lessons learned) while participating in the research process. As mentioned previously, the creators of the framework note the need within the scientific community of health implementation and dissemination research for more systematic efforts to examine or strengthen connections among these systems. They specifically state that, “while these interactions were not the primary focus of the development of the interactive systems framework, it may be that the greatest contribution to enhancing dissemination and implementation may lie in these interactions” (Wandersman, Duffy et al. 2008: 179). This research responds to this scientific need by studying connections among these systems.
The interactive systems framework for dissemination and implementation provides a structure for what may seem, at first glance, disparate subjects within this critical space between steps. The framework, unlike other dissemination models, provides a means to look at the processes involved in the development and testing of innovations. Furthermore, it takes into account the infrastructure necessary to carry out the functions (e.g. exposure, selection, adoption) to move an innovation through different stages of dissemination and implementation. By applying the framework to this research it allows us to take a small piece from different parts of the innovation creation and dissemination process, to create a more realistic perspective of the multi-dimensional and interactive nature of getting research into practice. Using this framework also connects this project to a larger initiative by the Centers for Disease Control and others working in the field of Implementation and Dissemination research.

Since its introduction in 2008, the ISF is building a body of practice and theory work demonstrating the utility of the approach; including a Rhode Island project with 13 community substance abuse and mental health assistance programs (Florin, Friend et al. 2012), a teen pregnancy and STI prevention intervention (Lewis, Lesesne et al. 2012), and an analysis of post-trauma school-based mental health services after Hurricane Katrina (Taylor, Weist et al. 2012). Wandersman and colleagues (2012) note that literature on the support system, those who support an individual or organization to implement an innovation, is under-researched and underdeveloped. They emphasize the importance of strengthening the science and practice of support in order to enhance the capacity within the Delivery System to implement with quality and achieve outcomes (Wandersman, Chien et al. 2012). Fundamental to this logic model of evidence-based system of innovation support are tools, training, technical assistance, and quality assurance/quality improvement. A central aspect of the research used for this dissertation study was the tool—qualitative research and the training, technical assistance and quality assurance —provided by FHI360 and UNAIDS.

Turning back to the goal of ensuring that the lessons learned from research inform and improve the quality of health and human services, the next section explores concepts related to qualitative research, capacity building, and “participation” that provide means of translation and dissemination
beyond traditional means (papers, presentations) and “end users” (clinical and public health practitioners). Using the ISF, two points of interaction within the model serve as a conceptual guide for studying how qualitative prevention information is created and diffused in this case study. The first points of study are the “Synthesis and Translation System” ↔ and the “Prevention Support System”, which distill information about innovations and translate it into user-friendly formats, in this case translating qualitative findings into policy and practice. The second point of study focuses on the indigenous research team as a site to look at the interactions between the “Support System” ↔ and “Prevention Delivery System”. Looking at the indigenous research team from a support system perspective, I try to see the way in which they internalized and transmitted their new knowledge about HIV/AIDS and the practice of multiple concurrent partners to the “Prevention Delivery System” which in this case include their personal networks and national and community stakeholders in Lesotho.

4.3. Trustworthy Qualitative Research as an instrument for Dissemination and Implementation

Qualitative research is a methodological tool in research as well as a means of dissemination and implementation. Like quantitative methods, qualitative methods result in a data set that researchers must rigorously analyze, interpret, and put into use. Quantitative methods try to minimize the presence of the researcher and avoid the introduction of bias by minimizing interactions (with researcher and between participants); quantitative methods are intended to extract information that easily and directly can be made numerical (Punch 2005). In contrast, qualitative methods such as interviews and focus group discussions imply an interactive process between the researcher and participants. In the case of focus group discussions (FGDs), these depend, and are enriched by, the interaction among the participants themselves (Krueger and Casey 2000). For example, seven individuals sitting in the same room filling out a survey do not experience the process of research in the same way as those talking and interacting in an FGD. A researcher conducting a qualitative interview uses “probing” techniques to quickly assimilate
what has been said and attempt to dig deeper for understanding. These approaches depend and are enriched by the interaction whereas traditional quantitative methods do not depend on and often view interaction as a source of contamination.

Health science researchers utilize qualitative research to inform prevention and intervention development as well as aid in the process of dissemination and implementation of biomedical, behavioral and social change strategies. Some argue that qualitative data provides a window into the hidden complexities, answering the “why” behind and often speaking with quantitative findings to give a more holistic picture of an issue (Schensul, Schensul et al. 1999). Qualitative results illuminate social, cultural, economic, and political factors influencing individuals and communities (Secker, Wimbush et al. 1995). Many researchers have found the input invaluable in the design and adaptation of research instruments to make the tools user friendly, applicable, and culturally appropriate (CCPH 1998; Estrella and Gaventa 1998; Scharff and Mathews 2008). Qualitative results can also help to determine the validity and cultural sensitivity of measures. In the translation of information and data, qualitative methods can inform how to adapt, contextualize and make relevant and understandable research innovations. Furthermore, they can help researchers identify the most appropriate dissemination strategy as well as point out potential roadblocks.

When executed by well-trained professionals, the process of implementing qualitative methods such as interviews and focus group discussions can have consequences beyond traditional scientific study objectives. Some argue that using qualitative methods itself becomes a trust-promoting activity that is useful throughout the translation and dissemination process (Scharff and Mathews 2008). Others have noted the almost therapeutic value in the process of talking, not only to be heard, but to be listened to with genuine interest (Butterfield, Borgen et al. 2009; Clark 2010). On the flip side, others have documented the various impacts on researchers who systematically listen and document people’s stories of trauma, struggles, and injustice (Gilbert 2000; Goldenberg 2002; Rager 2005; Blackman 2007; Wray, Markovic et al. 2007; Dickson-Swift, James et al. 2008; Watts 2008). This interaction between and amongst researcher
and participants is especially heightened in the context of work with HIV/AIDS, sexual behavior, and social change.

### 4.3.1. Increasing Local Capacity Through the Inclusion of Well-Trained Local Researchers

With the trend for increasing stakeholder and community engagement in health research comes the heightened desire for the inclusion of local researchers. In the relationship between researchers, practitioners, and policy makers the inclusion of local researchers appears to benefit all parties. Principal investigators gain easier access for the recruitment of participants as well as the “on the ground” perspective of local researchers that increases research validity by incorporating indigenous theory and interpretation into the findings (Isreal, Schulz et al. 1998; Minkler 2000; Wallerstein and Duran 2003; Scharff and Mathews 2008). By advocating for the use of local researchers, practitioners and policy makers can add to their portfolio the building of sustainability, capacity, and employment.

As mentioned above, Wandersman and colleagues (2008) usefully divide capacity into two domains: innovation-specific and general capacity. The former pertains to the capacity necessary to complete a specific objective, while the latter aims to enhance the infrastructure, skills, and motivation of an organization, without focusing on a specific innovation (Wandersman, Duffy et al. 2008). With fixed budgets, outcomes, and timelines, innovation specific capacity is more routinely used in the form of trainings, technical assistance, and coaching. In contrast, general capacity is more difficult to justify, and harder to implement and measure in terms of success. Relatively little empirical research has examined the effectiveness of training methods for disseminating prevention innovations (Wandersman, Duffy et al. 2008). Yet, with the little empirical evidence making a direct link between general capacity and increased ability to implement innovations, some studies suggest that such efforts have beneficial effect on organizations and communities (Altman 1995; Arthur, Bennet et al. 2003; Chinman, Hannah et al. 2005; Fixsen, Naoom et al. 2005). What is anecdotally established is that training and giving experience to locals help to develop expertise and local capacity to investigate their present and future issues. As health research leaves the controlled environment of labs and hospitals and spans out into communities, the
importance of incorporating locals and capacity building becomes increasingly evident. With this, so does the need to measure more explicitly the associated consequences between training and building local capacity in qualitative research.

An excellent example of the practical and deeper vision for developing specific and general capacity is in the training tools and approach of FHI social and behavioral researchers. In 2005, when qualitative research methods were gaining popularity outside of traditional academic realms, FHI published a Qualitative Research Methods: Data Collector’s Field Guide, funded by the USAID. The guide is a tool, written primarily for training research staff members of multisite and team-based public health projects, that can be applied by various disciplines and scales of research. It is a simple, effective manual on how to do systematic and ethically-sound qualitative research. The material presented is accessible for beginners, yet incorporates important methodological nuances and details that can affect the quality of a project. It provides a structure for guiding interaction between trainers and research teams that provokes collaborative experiential learning for both parties. The acknowledgements of the book highlight Woodsong as the “originator and inspiration” where she “sought to prepare teams for the immediate while equipping them with skills to collect data for other research projects in the future” (Mack, Woodsong et al. 2005: v). The authors of the manual also describe Woodsong’s “vision for capacity building in developing country settings” as a collective purpose for the guide. With each training project Woodsong built upon recurring needs and lessons gleaned only through experience. In the case of the manual, Woodsong developed much of the materials over several years with considerable funding from the U.S. National Institutes of Health. Oftentimes, method manuals have co-authors who worked together on similar projects in similar settings but this manual includes five authors who bring diverse perspectives and experience. Thus, what distinguishes the book from many methods manuals is that it is laden with insights gained over years of research and training experience across multiple settings all around the world.

Trainers and research teams implementing trainings based on the guide open a rare space for co-learning of theoretical, practical, and ethical dimensions that traditional academic learning environments
cannot provide. Even the most practice-based academic experiences are usually constrained by an individualistic or small group approach and do not have the benefit of a team of “teachers” joining the group and ensuring quality, personal ongoing feedback, and progression towards perfection. Furthermore, these trainings provided as part of employment offer an opportunity to demonstrate abilities and acquire new competencies that foster motivations other than a grade. Applied researchers like MacQueen, Woodsong and Guest may not have students in the academic sense, but they have guided, mentored, and shared their expertise with thousands of individuals in developing countries who went on to lead and teach others. In turning the lens towards the long-term investment that individuals make through training and capacity building, this product of a manual diffused all over the world has its roots in the funding mechanisms that supported the previous work of each of the authors. No evaluation could capture the long-term and cumulative impact on the projects and individuals who benefit from these investments. In fact, since its publication in 2005 the tool has been part of projects in over 85 countries and cited in 1,248 publications (FHI360Communications 2016; Google 2016). The actual number of projects who have used the tool since 2005 is unknown but tracking data on the downloads from the internet indicate that in the period of July 2013 through July 2016 a total of 13,105 training manuals were downloaded (FHI360Communications 2016). This total does not account for the actual projects where the printed manual was taken to the field by the project implementation team, nor does it account for other versions of the manual adopted for various audiences. This manual is an example of long-term sustained capacity building that is often left unmeasured by organizations and policy makers.

Symbolically, donors acknowledge the long-term value in high quality training of researchers and project staff; however when it comes to budgeting the necessary time or expertise needed to implement high quality oversight or the funding necessary to evaluate the value of this investment, there is often less substantial support. For example, a 1992 project in South Africa, based on “training of trainers” initiated by the AIDS Control Prevention project funded by USAID and administered by Family Health International, trained an initial 28 traditional healers in preventing AIDS and STI’s and these healers trained an additional 630 additional healers (the second generation). By the end of the 10 months, 1,510
healers had been trained, and it was estimated that over 200,000 patients and clients may have benefited from AIDS education as a result of the training. AIDSCAP supported workshops and sessions financially, but the training was left to the healers who had been previously trained. An internal evaluation was conducted as part of the program and found that the second generation appeared to be as well-trained as the first, based on measures such as reporting correctly how HIV is transmitted and different ways HIV transmission can be prevented. Despite program implementers and researchers asking for an external evaluation, the evaluation was never funded (Green and Herling Ruark 2011). It was not in the funding priorities of anyone at the time.

This case study of the MCP project offers an ideal opportunity to study the associations between the consequences of training and building local capacity in qualitative research and the diffusion of this information for behavioral and social change. The principal partners in the MCP project hired a local team of researchers with little to no practical experience in qualitative research. The team members, like the previous two examples were trained in ethics, qualitative research, collaborative analysis, and HIV/AIDS and MCP by FHI, using the Field Guide and ongoing training and expertise from a highly experienced Social and Behavioral Scientist and a team of Research Associates. The obvious benefits of this approach included more accurate and appropriate translation of research tools, sensitivity to cultural norms and expectations, facilitation of community engagement, theme identification, attention to linguistic nuances, local perspectives on interpretation of findings, and much more. However, this approach was extremely time consuming and expensive. Was it worth it? The easy answer is yes, “capacity” was built. But, how can we further our understanding of just how far the investment in the capacity of indigenous researchers went? In the next sections I explore some of the ground practices in implementing qualitative research for HIV/AIDS, sexual behavior, and social change in order to highlight the link between building the specific and general capacity of local researchers and the resulting consequences for disease prevention—individually and communally.
4.3.2. Interaction between and amongst researcher and participants as an HIV/AIDS Intervention

Several successful communication and education interventions utilize qualitative methods in various ways such as adapting interventions to local settings, increasing cultural appropriateness, adapting FGD methods for educational meetings, or using in-depth interviews to evaluate change (Minkler 1997; Schensul, Schensul et al. 1999; Krueger and Casey 2000; Buller, Woodall et al. 2001; Studies 2001; Silverstein and Auerbach 2009; Urban and Trochim 2009). In addition to these benefits, I would propose that the long-term benefit of the “capacity built” in carrying on conversations and getting people to talk about the problem of HIV goes further and perhaps “flies” under the radar for the changes provoked in the lives of the researchers and that of participants. The act of implementing, and the results of qualitative research in the realm of HIV/AIDS, has the potential to raise problem consciousness which lives on in conversations about AIDS and a heightened awareness of how particular sexual behaviors increase risk.

Rock Hudson’s public admittance of AIDS in 1985 provoked much sought and needed media attention in the United States. However, this unbalanced media attention, focused on celebrity cases, schoolchildren, innocent blood recipients, laboratory breakthroughs, and the inevitable apocalyptical spread of AIDS to the heterosexual population. The media paid little attention to the federal government’s role in addressing the epidemic. In fact, Shilts recounts how in 1986, eighty-five of the top AIDS experts tried to turn the gaze “to the more significant story: the message that the AIDS challenge still was not being met” (Shilts 1987: 586). Unfortunately, the media ignored the message from experts calling for massive public education, better coordination, and more acute devotion to the amount and strategic deployment of money for research and treatment. Shilts argues that the real game changer that “galvanized the media and allowed AIDS to achieve the critical mass to make it a pivotal social issue”(588) was in 1987 when Surgeon General Koop released his report on AIDS. Koop, elected in 1981, was known by the public as a conservative religious fundamentalist, yet he unlikely, was the first to treat AIDS as a public health problem, recommending education, widespread use of condoms, and going against the then largely conservative movement for compulsory identification and quarantine. Shilts
points out that Koop was able “to talk in a way that made sense” and that the impact made by Koop was attributed to the “archetypal juxtaposition” that it:

Took a square-jawed, heterosexually perceived actor like Rock Hudson to make AIDS something people could talk about. It took an ultra-conservative fundamentalist who looked like an Old Testament prophet to credibly call for all of America to take the epidemic seriously at last (Shilts 1987: 588).

From 1981 through 1986 Koop had done nothing significant for the cause of HIV. Only until asked by President Reagan to prepare a report on AIDS did the issue become part of the surgeon general’s agenda, despite the fact that 27,000 Americans had already died or were dying of the disease” (Shilts 1987: 587). Koop undoubtedly knew about the statistics, knew about the latest published facts about the disease. What could make a man whose nomination liberals, feminists, and gay leaders fiercely opposed in 1981 morph into a “scientific Bruce Springsteen,” as Shilts questions, thus speaking the truth about AIDS and acting fearlessly in opposition to his ideological and political core. Part of the answer may be in the seemingly inconsequential sentence by Shilts describing how Koop came to his conclusions, “Koop spent much of 1986 interviewing scientists, health officials, and even suspicious gay community leaders” (Shilts 1987: 587). Somehow in the process of asking questions, listening, carrying out dialogue, and the process of implementing qualitative research he discerned what he had been blind to for the five proceeding years. While this was not his intention with these interviews, it does demonstrate that when done well, the act of conducting interviews can change a person’s perspective and thereby their realm of influence.

In the previous example I tried to bring to light the way the research interaction may have helped people to open up and talk. In my own experiences, in working with qualitative research teams in Lesotho and South Africa, researchers often noted after interviews or focus groups discussing sexual behaviors and AIDS that people seemed almost relieved to have the opportunity to talk and desired to continue the conversation. In several of the hyperendemic zones, there is a reliance on mass-media campaigns, the distribution of condoms and other commodities, and hospital-based services (Low-Beer and Stoneburner 2004). These services undoubtedly benefit many individuals. However, without the chance to interact, ask
questions, or talk to someone the ownership, the individual consciousness and social responsibility for prevention, is not triggered. As demonstrated in the results in this dissertation the opportunity to talk is not only that of the participants but also the researchers who go on to have conversations in their personal and professional networks. This consequential effect is not something easily measured. Anthropologist Edward Green, in his book *Evidence Based Prevention* argues that the most success in prevention in Africa is in the absence of donor-funded programming. He also supports the argument that Uganda’s early success was centered in communities and neighbor-to neighbor communication and not because of any high funded, high-tech effort from the AIDS industry. He points out that Kenya’s success was off the radar in terms of what can be measured and attributed to professionally organized efforts. Likewise, he cites Zimbabwe showing a decrease in infection rates as the country was in turmoil and Western funded organizations were leaving. Green argues that more energy needs to be given to understanding and evaluating, communities, cultures, and indigenous responses:

> There is a critical need to better understand and monitor exactly those things that do not fall under the purview or radar of any particular program, but that may have more to do with the long-term trajectory of AIDS than all AIDS-industry programs put together. (Green and Herling Ruark 2011: 249)

Because qualitative research fosters conversations at both the primary point of researcher participant interaction as well as secondary conversations, it may be important to re-conceptualize the purpose of research. For example, maybe we “already know” information based on previous research or surveillance but the action of letting people do science and discover for themselves what is known may have more long-term success in creating change than in “programs” using what is already known.

### 4.3.2.1. Stop AIDS Campaign

One famous example of the utility of trustworthy qualitative research as an instrument of dissemination and implementation is the STOP AIDS campaign in San Francisco, which drew upon Kurt Lewin's small Group Communication Theory and the Diffusion of Innovation Theory (Singhal and Law 1997). STOP AIDS began by conducting focus groups to learn how much gay men already knew about
HIV/AIDS (Wohlfeiler 1998) as a basis for designing effective interventions. However, as the investigators implemented the study, they realized that the focus groups were actually having a strong educational effect, as men shared information about HIV prevention. STOP AIDS then transitioned to employ a group of outreach workers from the gay community to conduct small group meeting in homes and apartments throughout the gay neighborhoods, which launched the diffusion process. From 1985 to 1987, STOP AIDS reached approximately 30,000 men in San Francisco through its various outreach activities. Related or unrelated, the proportion of gay men in San Francisco reporting multiple anal-sex partners fell by 60% between 1984 and 1988 (Winkelstein, Wiley et al. 1988). This example, demonstrates the utility of combining qualitative approaches and the inclusion of local stakeholders in the research process. The process increased health researchers understanding about the local situation and created a direct link between problem definition and discussing what to do to take action for care, treatment, and minimizing risk. Perhaps some of the reasons for why we are seeing increasing levels of risky behaviors in the community of men who have sex with men, is related to the way we “know” everything and do not engage people in research, defining and discussing the problem but deliver pre-packaged messages and solutions.

4.3.2.2. Maxine Ankrah Uganda

Another often described and debated success story is that of Uganda where HIV prevalence declined from 21% to 9.8% from 1991 to1998. There are many factors debated as having contributed to this decline from partner reduction, increase in condom use, fear messages, social cohesion, end of war, faulty surveillance, to the cumulative effect of death after death, all of which most likely played a role in varying degrees to the reduction in transmission. I would also like to propose qualitative research as a possible co-facilitator. Similar to the STOP AIDS campaign’s inclusion of outreach researchers, in the late 1980s the World Health Organization’s Global Program on AIDS conducted a giant “Kinsey-like” project. The objective of the study was to investigate sexual behaviors in different populations around the world with particular attention to determine the types of behaviors that fuel the spread of HIV and thereby
predict the future course of the epidemic. Sociologist Maxine Ankrah and colleagues conducted the study in 1989 when Uganda had the highest HIV infection rate in the world. “Ankrah’s research assistants fanned out into villages throughout the country and interviewed thousands of people about their sexual behavior: they asked them how many partners they had, whether they used condoms, and what they were doing to protect themselves from HIV” (Epstein 2007: 173). One of their main findings was that many people had more than one partner at a time and condom use was low. In 1995, the same study was partially replicated. Since Ankrah’s study was conducted during the peak of the epidemic and the second after the decrease in transmission levels, the data sets were compared to understand the types of differences in sexual behaviors. UNAIDS published an article comparing the two pre and post peak data sets and attributed the difference to a rise in condom usage and age of sexual debut (UNAIDS 1998), an argument consistent with their past and current policy and programming support. As mainstream researchers from UNAIDS and USAID were arguing for “high-risk groups” interventions and condom use in the late 90s, Ankrah maintained that based on her findings, and locally informed experience, the problem was not “high-risk groups” but rather ordinary people. For her, it was clear that prevention of HIV transmission was the responsibility of every sexually active person and partner reduction and changes in gender relations at the core (Epstein 2007). In fact, later analysis of the two datasets demonstrated significant changes in the proportion of people with multiple partners decreasing their number of partners and less attribution to condom usage (Low-Beer and Stoneburner: 2003; Epstein 2007).

I am not arguing that every sexual health survey has a dual prevention role. Instead, I would like to point out important characteristics about the way this study was conducted and who it was conducted by that enhanced its role as a consciousness raising exercise-giving people a chance to talk, ask questions, and define and discuss the problem of HIV/AIDS and thereby contribute to the positive changes of higher condom use, decreasing partners and higher age of sexual debut. First, as stated above, the researchers went out into villages and spoke with thousands of people. The action of going to the villages from the intellectual center created an opportunity of exchange between what is known in the village and what is
known from the scientific biomedical realm. Researchers facilitated participants’ reflection on their own personal sexual behaviors and provided an opportunity to talk about them and ask questions to a third party external to their village. This may have been an occasion, as Roger’s discusses, where the agent of change meets a person who is similar in all aspects except for what they know about the innovation and where the recipients of new information are given a chance to interrogate verbally the messages they were hearing in mass media campaigns and consequentially more likely to change. In addition to the possibility of increasing their risk awareness, the interview encounter opened space to talk about sex and the disease, letting the words escape from thought and into reality, making it easier to give voice in other contexts.

The next important aspect of the research involves the who and the level of quality maintained in the research. The principal investigator Maxine Ankrah had a strong commitment to the well-being of people in Uganda, and held a position of influence, teaching and training at the University. She established the Makerere women’s studies program and helped lead the women’s movement of the 1980s. At the time of the sex study, Ankrah was the head of the department of social work and social administration at Makerere University. She trained thousands of Uganda’s managers, NGO officials, and researchers. This means that she had multiple opportunities to communicate what she learned through research experience to others who went on to fulfill positions of power and influence. Her general capacity could be said to continuously flow between synthesis, prevention support, and prevention delivery. Ankrah is often described as an activist. For some people, the term “activist” research evokes associations of bad science and bias. However, for many researchers, like Ankrah, the sense of activism inspires methodological perfection and strength to stand by your findings. Ankrah recalls in a discussion with Epstein, “I was so careful. Some researchers just sit in their offices and shuffle papers, but I went out into the field to check on things myself all the time” (Epstein 2007: 183). For those who conduct fieldwork, this statement reflects an awareness of how difficult field team research is and how easy it is for research assistants to cut corners on recruitment or falsify where they went, with whom they talked, and what was said. Obtaining high quality data means conducting high quality research with highly committed researchers.
4.3.2.3. Who Implements the Research is Important

Epidemiologist Elizabeth Pisani had over ten years of experience in surveillance, monitoring, and intervention programming at the time of writing the *Wisdom of Whores*. She describes well the importance of “who” conducts field research about sexual behaviors and AIDS. She underlines that there is a popular assumption that people automatically lie about their sex lives and drug abuse. In contrast to this assumption, she argues that if you ask the right question correctly and get the right person to do the asking, a researcher can elicit reliable information on sex and drug behavior. At the heart of this is the important issue of hiring and training the right people to conduct the research. In an almost reactionary, reflex, manner getting the “right person” and local “participation” for research assistants has morphed into the practice of hiring “peers” and NGO workers as research assistants. Pisani underlines that this does work in some cases, but can backfire in others. NGO workers are associated with the goods they bring to the community, consequentially participants may not answer honestly but give the response that will please the agency. Other times, NGO workers and community “leaders” so connected to their particular advocacy can be biased towards asking questions and hearing what supports their vested interest (Pisano 2008). In other cases, peers such as sex workers or school class mates provoke resistance to recruitment and noncompliance in participation, whether that be out of jealousy that they got the research job, an underlying knowledge about the other (prophet is not a prophet in his own home,) or individuals hesitating to share personal information with a peer. Pisani makes the argument for still using local researchers but using middle class civil servants to do sensitive research noting that “with a bit of training, most seemed able to morph from wide-eyed innocent to seasoned observer in remarkably short order” (Pisani 2008: 101). She proposes the model of co-opting peers not to act as interviewers but to help with mapping, questionnaire design, and field supervision. She describes how the model has made for some unlikely friendships “it has been fun to watch stuffy civil servants loosening up around blatantly gay co-workers …seeing screamingly camp rent boys adopting a new ‘grown-up’ persona as they give presentations at meetings in government departments” (Pisani 2008: 105). While Pisani does not mention
it, there are multiple implications for the translation of research into action. Tapping into the middle class may aid recruitment across class differences, if the hired research assistants are perceived as not too far from the poor and not too far from the rich. Not only does the knowledge gained cut across social classes, but the knowledge gained by the middle class can then travel with the middle class who are more likely to flow between urban and rural settings. Civil servants and University graduates conducting research as “strangers” provide an opportunity for the participant to divulge sensitive information in the security of a “non-relationship”. If the research assistants are permitted by the principal investigators to answer questions and correct misconceptions, the interview interaction can also serve as a prevention interaction. Civil servants and university graduates from the middle class are more likely to go on and fulfill positions where they can use the specific and general capacity gained in multiple contexts. They also have relatively more power to support research transitioning into tangible actions. Middle class actors have more chances to recreate themselves, and have the concepts and language to combine indigenous and biomedical explanations. Pisano (2008) describes Mr. Eko, a man she met ten years previously, who worked for the government and was a waria (biological male, dressed as woman, who has sex with men) by night who later left his government position, opened up a salon, became an activist and joined Pisano’s surveillance research team. The importance of “who” conducts the research is not only relevant to the specific capacity and single research job but to the future lives and experiences of the researcher.

4.3.3. Capacity, Stakeholders and Community Engagement: For Participation or Retention?

In efforts to make sure that the results and experience of research are efficiently and effectively utilized for disease prevention, organizations and funders are favoring the use of “Community-based participatory research,” “community engagement,” “multi-stakeholder partnerships,” and “capacity building.” These are paradigms that have historically evolved within the context of activism and development but are now being employed within the contexts of clinical care and public health. The concepts, seemingly straightforward, are laden in their own sets of complexities, especially for researchers and professionals whose training and infrastructure do not give much attention, if any, to what
these terms mean or how to use them. Funders, researchers, partners, and participants may all be using the same terms but their conceptualizations are often different. Expectations are built from one interpretation and actions are fostered by another (Macaulay, Commanda et al. 1999; Minkler 2004; Kerner 2008). This sometimes results in conflict that presents challenges, and sometimes failure, to the process of conducting research as well as dissemination and implementation efforts.

One might ask, if it is so complicated, why is the approach being mandated by funders and applied by persons who traditionally have not needed or used “community engagement,” “multi-stakeholder partnerships,” and “capacity building”? Some argue that Community Based Participatory Research (CBPR) is increasingly being used because traditional research methods have failed to address complex health disparities (Group 2006; Colditz, Emmons et al. 2008). Previous paradigms are inadequate to account for multi-level social, cultural, and economic forces motivating individuals’ and families’ behaviors. Moreover, it is suggested that using this approach not only helps to answer complex social questions, but also makes it a priority for the results to provide information that can be used by the community to develop its own solutions (Studies 2001; Minkler and Wallerstein 2003; Group 2006; Colditz, Emmons et al. 2008). A more pragmatic argument for the recent popularity of CBPR is that researchers are finding it difficult to recruit research subjects. Some potential research participants refuse to take part because of a history where trust and respect have been violated by researchers. This is particularly so for minority populations in the U.S. as well as in multiple economically impoverished international settings (Gorelick, Harris et al. 1998; Sharp and Foster 2002; Weijer and Anderson 2002; Barlett and Steele 2011). Community members refuse to participate because of previous experiences where they have felt used when results were taken and never seen to directly benefit their situation (Gbadegesin and Wendler 2006; Williams, Willging et al. 2010).

While at one time researchers could more easily navigate work in the “community” as negotiating directly with participants or clients in a prescribed area, today stakeholders and gate-keepers include more powerful entities such as government officials, institutional review boards, private sector, industrial representatives, mayors, chiefs, etc. The notion of community is becoming more and more complex and
contested. The recognition that geographical areas are home to a range of different stakeholders with varying degrees of power and often competing interests has led to the adoption of the concept of ‘multi-stakeholders’ (Campbell 2003). Negotiation of what will be researched and how it will be conducted is no longer solely the responsibility of the researcher but now must be seen as a larger process of engaging the “community” and its “stakeholders.”

The NIH Director’s Council of Public Representatives (COPR) work group for the role of the public in research defined community engagement as:

a process of inclusive participation that supports mutual respect of values, strategies, and actions for authentic partnership of people affiliated with or self-identified by geographic proximity, special interest, or similar situations to address issues affecting the well-being of the community of focus (COPR 2008:7).

There is a broad spectrum of how this definition is applied (DSE 2011). For some researchers, authentic partnership means the active participation of community members from the conception of the idea throughout the entire process. Others go further, arguing that only if the need is identified by the community itself should a project be designed. While some see engagement as a means to “foster collaborative research partnerships and enhance public trust in clinical and translational research, facilitating the recruitment of research participants from the community.” (NIH 2007) quoted in (Woolf 2008: 212) So, while researchers may all be doing “community engagement” there is a range in the interpretation of participation from an active decision making role to engagement and participation as a process to ensure the enrollment and retention of participants.

The use of this process of negotiation of community engagement has important consequences for how research is conducted, with whom, and what will be done with the findings. Given the record of medical ethical abuse and the amount of profits being made, having doubts towards the nature of “community engagement” could be considered adaptive (Skloot 2010). Informed consent is required for sampling, but storing tissues from diagnostic procedures for future research does not legally require consent (Skloot 2010). As of today, samples given for routine procedures or research can be used later for any type of research—racial differences, nuclear weapons, abortion, intelligence, anti-aging as well as
go on to contribute to commercialized profits—yet there are no laws requiring permission or guidelines about who gets the profits and how they are spent (Skloot 2010). Yet, patent laws protecting the property and commercialized rights (and profits) of researchers and the research industry is expanding, contributing to increasing competition, secrecy, and increases in the costs for licensing samples for research and testing. Thus, the sticky issues of permission and profits are being negotiated for professionals but not for those who supply the raw materials. These are the conversation that are right below the surface, affecting daily research practices like consent, engagement, profits, and the good of knowledge. Engagement with participants and community forces the research community to face hard questions about profits we prefer to ignore. Enrolled participants spend hours being educated about how to read clocks, adhere to medicine, and communicate to partners about methods, but we need to be aware of how little time is spent on collaboratively understanding the disease, how it is spread, the cultural and social nuances, communication skills, and the many options they have to decrease their risk of transmission.

Many women, for instance, have for years used birth control drugs for fertility, yet they have never been taught about how the human body works and when they are actually fertile. Instead, understanding how fertility works your own sexual practices, and making educated decisions on the right reproductive and HIV prevention plan for their lives and bodies could be more efficacious. In the same way, perhaps adherence and recruitment would be easier if people, rich and poor, educated and uneducated are given a chance to understand, learn, talk, argue and believe in the solutions proposed.

All of this takes us back to “non-expert” participation in research. One typical argument is that there are certain realms that should be left to “experts” and involving “non-experts” is unproductive and a waste of time and money. Anton van Niekerk in his paper on the moral and social complexities of AIDS in Africa begins with a question from Virginia van der Vliet:

How do you reach a poor, isolated, illiterate rural or urban woman, who is not at school, at work, or at church or a clinic attender? (Van der Vliet 1996: 97) One has to go further to ask if you reach her, how do you start communicating the complexities of HIV to this woman? How, first of all, do you explain that she might become devastatingly ill simply by having sex with her husband, who is a migrant labourer, and that it is best to have them both tested…might already be
ill, not know it, there are drugs but she can’t afford them….that she can infect her husband or lover….the point is: understanding and explaining the phenomenon of HIV/AIDS is a complex matter. This woman will, in all probability, either not understand what is being communicated to her, not believe it, or shrug it off as just one of the many hazards that she has to face in order to continue her struggle for survival….Most rural Africans lack the material, social and educational resources, even to understand, let alone to foster, their interests in a way even remotely comparable to what happened in the US in the eighties….The solution to this complexity is not self-evident. Clearly more and better education is needed. But that will mainly benefit the younger generation, not the adult population referred to above. Adult education is, therefore, also clearly required, but the resources for that, and the motivation of the people who stand to benefit from it, are limited. It may be that the sheer brutality and extent of suffering and death that people from these communities experience in the near future will cause an outrage that provides the opportunity for education that focuses the mind. However, by then most of the damage will have been done for the foreseeable future. On what exactly to do about this problem, the jury is unfortunately still out. (van Niekerk 2005: 61).

The assumption that non experts lack the ability to comprehend, or know what to do to solve, their problems proliferates the norm that outreach and access will follow the same trajectories promoted by experts in the AIDS industry, typically biomedical interventions—clinic, school, and “community leader” approaches. As van Niekerk argues, adult education and participatory action as a philosophy of practice, and not just for short-term programming, are key to creating the supporting environment for long-term social change (van Niekerk 2005: 61). Further problems, as well, with the lucrative nature of the AIDS industry makes it increasingly difficult for individuals to “participate” without demanding something in return. Participation may be seen as unprofitable, communities may not have enough resources, or payments may be seen as coercive and actually undermine the capacity for self-reliant and sustainable change (Cromwall, Musyoki et al. 2001). Finally, HIV/AIDS is a complex matter; and we need deeper understanding of what constitutes adult education, “participation,” and “engagement” to retain, make adhere, or “generate demand.”.

4.3.4. Key Concepts and Practices in “Participation”

What is echoed in all sources supporting participation is the importance of not just extracting and copying best participatory practice from other settings but to focus on creativity and the process. For example, The International Food Policy Research Institute (IFPRI) reviewed five community-driven
development (CDD) projects in Zambia, Malawi, Kyrgyz Republic, India and Nepal, examining conditions for success. They concluded that capacity is not just resources but involves motivation, commitment, and appropriate incentives at all levels. An upfront and ongoing investment in capacity, with particular attention to facilitators and local leaders, is vital. “Learning by doing,” as opposed to mere replication, should be fostered at all levels, with time horizons adjusted accordingly. A “learning by doing” culture values adaptation, flexibility, and openness to change. Ultimately, the study found that success hinged on processes and principles that are anchored in national policy frameworks and embedded within the country’s social, cultural and institutional fabric (FANTA 2007: 148).

In 1997, Robert Chambers published Whose Reality Counts?, which reflected the insistence internationally by donors, governments, and NGOs on participatory approaches in assessing needs and in implementing programs. The basic doctrine is to start with people’s knowledge as the fundamental basis for planning and change (Chambers 1997). Stating it is one thing, however, monitoring and evaluating the outcome is quite another. Estrella (1998) points out that “as institutions became more inclusive in the ‘front-end’ of project development, that is, in promoting participation in appraisal and implementation—then questions of ‘who measures’ results and ‘who defines’ success become critical. ‘Who Counts Reality?’ may prove as significant a question as ‘whose reality counts?’” (Estrella and Gaventa 1998: 3).

These theoretical considerations sparked the merger of the “people’s knowledge” and enumeration of reality which is known as participatory monitoring and evaluation (PM&E). PM&E is part of a wider historical process emerging over the last 40 years of participatory research, drawing on various participatory research traditions, from participatory action research (PAR), spearheaded by the work of Paolo Freire (1979), Orlando Fals-Borda (Fals-Borda 1979) and Rapid Rural Appraisal (RRA) and later Participatory Rural Appraisal (PRA) (Chambers 1997). The broad participatory framework combines visuals, tangibles, and numbers to facilitate the creation of a group-visual synergy, a democracy of the ground, representations of the complex realities and relationships, instruments of empowerment, and participation and participatory numbers. Over the past forty years researchers (Chambers 1997) have demonstrated that local people themselves can make maps and diagrams, and especially when they
worked in small groups, demonstrated a complexity, diversity, accuracy and, for many purposes, relevance far superior to anything that could be elicited or expressed using earlier extractive or observational methodologies. This led to the practical principle that ‘They can do it’ applied to activity after activity, recognizing that local people had far greater abilities for analysis, action, experimentation, research, and monitoring and evaluation than had been supposed by outside professionals or by themselves (Chambers 1997: 10).

Practitioners of participatory methods recognize practical issues concerning standardization and ethical issues on ownership and use. The underlying premise is that numbers generated by local people through participatory methods and processes combine accuracy, authority, and utility (Chambers 1997: 23). In the Philippines, for example, statistics aggregated from village health workers replaced less accurate and less relevant top down government statistics; insights led to policy changes that reduced deaths (Nierras 2002). Whiteside and colleagues overlaid bereavement notices in Swaziland, from 1994 to 1999, in local newspapers with mortality data and deaths predicted in models. The visual consistency of the two sources graphed together provided needed power in demonstrating the magnitude of the problem of AIDS related deaths helping policy makers, politicians, and people to come to grips with the reality (Whiteside, Desmond et al. 2001).

Being guided by a philosophy of participation does not mean that the label of “participation,” “engagement,” or “community based” must be an explicit objective of the research. Participation as a concept is broken down into various levels and in practice spans across a spectrum of intensity (FANTA 2007: 141). The highest level of participation is self-mobilization, without external actors serving as catalysts of change. In this level, communities or local partners take initiatives, independent of external institutions to change systems. Interactive participation includes partners and communities coming together to analyze for the purpose of leading to action. In this framework, there is often the formation of new local groups or the strengthening of existing ones; local stakeholders take control over local decisions, giving them an incentive to maintain structures and/or practices. Functional participation arises when communities form groups to meet a program’s pre-determined objectives, driven by external
stakeholders. Such involvement tends to occur after major decisions have been made; such groups may be dependent on external initiators but can also become self-dependent. Consultative participation occurs when communities are consulted by external stakeholders to consider their knowledge and interests; outsiders define both problems and solutions but may modify these based on local people’s responses. Communities do not make decisions, and outsiders are under no obligation to act on local people’s views. Information-giving participation involves communities answering questions posed by external stakeholders or program staff, but without an opportunity to influence decision making because findings are not shared. Passive participation involves only external stakeholders in making decisions, with local communities simply being told what is going to happen or has already happened. (FANTA 2007: 141)

Most funded HIV projects at best involve functional participation but lean more heavily towards information-giving participation and passive participation. Obviously, there is a reporting bias towards the projects that actually get written up, published, discussed being outsider driven. The lack of “evidence” may actually reflect the lack of access to resources for recording and dissemination of “home-grown” best practices.

Within the dominant realm of clinical and biomedical approaches to HIV prevention, “participation” is sometimes viewed as lacking substance and practical and easily measurable outcomes. Preferred measurements of change required by funding agencies are easily quantifiable indicators how many patients on treatment, how many condoms distributed, how many people counseled, how many orphans fed, how many people tested, and how many people attended training. While the fruits of participation and engagement are desired, the ratio of work involved against the lack of effective measurability lend themselves to avoiding participatory practices or adapting abbreviated versions. At the core of the issue of what practices are implemented is “the problem of what the data will be used for and who will use it” (Eele 1994). The answer/justification typically found is that the “need” determines the type of information collected. We need to pay attention to who is determining the “need”, whose end does it serve, and does it justify spending. And furthermore, encourage communities to own the information and act on the research results.
4.3.5. The Problem of Measuring “Success” in HIV Participatory Approaches

As discussed in Chapter 2, a current global trend in the AIDS industry is to increase the number of people who know their status through testing and ensure that these people are on medicines to keep their viral load low enough to decrease chances of transmission to others or to defend against the virus upon its entrance to the body. These policy documents, such as the UNAIDS Fast-Track to End the Epidemic and the US National HIV/AIDS Policy, stress the need for creating a positive structural environment for prevention, yet they highlight social and behavioral approaches with skepticism because of the lack of “hard” evidence demonstrating their efficacy in lowering HIV incidence (ONAP 2015) (UNAIDS 2015). In fact, one of the main “social and behavioral” strategies suggested is the use of cash transfers, that are easy to measure in terms of short-term efficacy, but are sustainable only as long as someone is willing to supply the cash. Little is known about the long-term consequences of the “cash transfer” approach on the individual or the broader social system. For example, what does it mean for the individual and family when a person receiving cash transfers for prevention sero-converts to being HIV+? Again the approach is reinforced by the need to demonstrate a quick measurable change in HIV incidence and not for social conscious awareness about the disease. In this section I briefly present one of the most famous participatory approaches towards social change and HIV prevention. I contrast what participatory monitoring has said about the program with that of a controlled randomized effectiveness trial. The objective of this section is to demonstrate how “evidence” is presented for what works and does not work in projects targeting larger social change and HIV prevention. A critical awareness of how evidence is presented is helpful to both entities that genuinely want to combine biomedical and social interventions as well as for educating individuals about the types of strategies that may help a community without the dependence on large institutions or the state.

One of the widest known participatory approaches is Alice Welbourn’s Stepping Stones (Welbourn 1995) first implemented in Uganda in 1994. It consists of an approach and methods to facilitate experiential learning concerned with social awareness, communication, and relationships. The
program draws upon participatory learning approaches including critical reflection, roleplay, and drama based on the everyday reality of participants. No literacy is needed. Stepping Stones is based on the principle of having people reflect, discuss, and analyze their own problems and rehearse scenarios to improve the situation. In contrast to passive learning, the objective is to utilize aspects from Bloom’s taxonomy of higher level thinking where people conduct research on their own lives. Stepping Stones advocates contrast their interactive method against “petrol pump” behavior change approaches of pouring information into an empty head (Figure 9).

Instead, groups of people in communities meet for a sequence of interactions and reflections with particular emphasis on the inequalities that govern gender and other social relations—not necessarily about—but in the context of HIV/AIDS.

People have implemented Stepping Stones (SS) all over the world and in diverse settings. Tina Wallace (Wallace 2006) conducted an assessment of several participatory monitoring and evaluation reviews and reported that SS had been adapted and used in over 100 countries. Wallace’s review found: almost universal support for, and appreciation of, SS as a change process from those with firsthand experience of using it or seeing it used’ including ‘better inter-generational communication, more openness about discussing sex, less stigma and more care for those with HIV and AIDS, and a willingness of PLWHA [People Living With HIV/AIDS] to be open (Wallace 2006: 20).
In 2004-2006 Rachel Jewkes and her team from UKZN implemented a randomized cluster control study in rural South Africa in order to assess the impact of Stepping Stones on the incidence of HIV, herpes simplex type 2, and sexual behavior (Jewkes, Nduna et al. 2008). Participants included 1,360 men and 1,416 women ages 15 to 26 from 70 village clusters in the Eastern Cape province of South Africa. Evaluation included a baseline measurement and follow-up at 12 and 24 months. The conclusion reported in the British Medical Journal, “Stepping Stones did not reduce incidence of HIV but had an impact on several risk factors for HIV---notably HSV-2 and perpetration of intimate partner violence” (Jewkes, Nduna et al. 2008). Some may read this and understand the message as no effect demonstrated on incidence of HIV. The abstract findings note female participants actually having no desired behavioral changes and increasing transactional behavior, while men reported less depression, intimate partner violence, transactional sex, drinking, and drug use as a consequential finding. Unfortunately, for studies like this, the sexual partners of the men were not included in the analysis. The authors acknowledge:

Our South African adaptation has a slightly different content from the Welbourn original and was not used in a community development context. Welbourn recommended working with older men and women in each community as well as young people and suggested that peer groups be encouraged to continue to meet after the end of the workshops. We did not implement either of these components as it would have added greatly to the cost and we wanted to test a delivery model that we thought could be more easily funded for roll-out. (Jewkes, Nduna et al. 2008)

While they note in the article many of the limitations for why effect may not have been documented, it is clear that the constraints of “cost” and what they determine as a more feasible delivery model greatly influenced the results. The differences in how the approach was implemented and by whom for the purpose of research inevitably changed what could be said about the effectiveness of this approach. In all reality, it is a social and behavioral change approach, but the model implemented is only behavioral. The “costs” of testing materials, professionals for testing and counseling, incentives for a population big enough to measure effect, and salaries for the large research staff altered the very nature of what they set out to measure. For example, the original model is structured around intergenerational involvement in a series of meetings within peer groups (older men, older women, young men, young women) and larger intergenerational and gender workshops over an extended time period. The trial did not tap into pre-
existing groups or any type of social cohesion that could further short-term support for change as well as foster the ability to meet up afterwards. They did perform “community engagement” by informing chiefs and community leaders about the study. However, similar to many clinical and biomedical approaches, “engagement” involved informing them of the study and seeking permission as opposed to actually including them in some form of the intervention. This is especially so for the Stepping Stones, whose success is closely linked to building intergenerational understanding and solidarity.

The authors report that in the intervention arm women may have shown less behavioral change difference out of initial reporting bias when they were less likely to report negative behaviors. They also discussed the possibility of the way:

Group discussions might have inadvertently encouraged transactional sex by reflecting it as at least common, if not standard, and an effective way of acquiring desired items. The attempts of facilitators to avoid being moralistic in discussions about transactional sex might have meant that the negative impacts were insufficiently emphasized. (Jewkes, Nduna et al. 2008)

Other aspects not considered for the lack of measurable effect is the fact that during the study period the government extended public access to antiretrovirals to all in South Africa. As discussed in Chapter 2, knowing that HIV is treatable, sometimes decreases the fear impact and lessens protective behaviors. Another difficulty, is that this trial recruited predominantly from high school students. The facilitators, around the same age as students (16 to 23), conducted three-hour meetings at schools after the school day finished. It is possible that students who were allowed to participate in workshops, hosted by Planned Parenthood, after school hours may have differed from those not participating in the research and the control group. The after school schedule and the monetary incentives to participate may have inadvertently furthered risky opportunities for young people having an excuse to be out and the means to do things they otherwise would not have had. Later focus groups with research staff of the Stepping Stones trial revealed that facilitators conceptualization of “successful” facilitation may have actually undermined dialogue and critical consciousness—they emphasized the importance of discussion but also highlighted success as securing high levels of attendance, ensuring answers provided by participants were “right”, and that they were “achieving” behavior change. The investigators conclude that the facilitators
feeling the tension to conduct “rigorous” research may have unintentionally undermined the participatory educatory element of the design. The trial investigators, echoing the ISF framework, suggest the need for delivery system support in high quality training and ongoing skill building for facilitators if participatory structural interventions are to be accurately delivered to scale (Gibbs, Willan et al. 2015). Initial findings of no “effectiveness” were quickly diffused after 2008 and the authors themselves later wrote about the need to understand the challenges in translating these interventions into studies and larger initiatives. These factors in various ways, impinged on the ability to create a safe social space to implement participatory learning (Gibbs, Jewkes et al. 2014). These same factors are repeated in trials and interventions across sub-Saharan Africa; they are symptomatic of approaches that continue to treat lightly inequalities and the social-economic reality of these populations.

Another challenge to measuring change in these types of interventions may be the standard basic HIV education used in controls. For the SS trial, for example, the control intervention was a single three hour session on HIV, safer sex, and condoms based on the Stepping Stones material. The authors note, “given the difficulties researchers face in showing impact from behavioral interventions, it would be surprising if the control intervention had a substantial impact” (Jewkes, Nduna et al. 2008). However, it is possible that even a three hour participatory conversation, not a passive reception of information, can plant a seed of change or inquiry in a person. Given that the opportunity to engage, talk, and interact with people on the topic of HIV is an exceptional event, even this small encounter may have had an impact. Perhaps having had a different team facilitate the control intervention, or the quality or quantity of meetings, different control for HIV baselines, or rerunning the statistics could have influenced a different result.

Many times researchers implementing structural interventions inadvertently undermine the effectiveness of the approach because of research and evaluation driven constraints. In 2008, I discussed the difficulty in implementing a randomized trial design to demonstrate the effectiveness of combining food security, economic empowerment, and participatory HIV education with that of implementing a more inclusive non-randomized design (Watson Lai, Mpemi et al. 2008). Community members rejected
the idea of the randomization of households, preferred a more equitable solution, and insinuated the consequences of jealousy on the people chosen to participate and consequently on project outcomes. In determining eligibility criteria, researchers often create injustice and inequalities that alter relationships. Another collaborative team of researchers from the University of Zimbabwe and the University of San Francisco highlight this difficulty. They designed the ‘Shaping the Health of Adolescents in Zimbabwe’ (SHAZ) program conceived as a structural approach to HIV prevention (Dunbar, Kang Dufour et al. 2014). It was originally envisioned as a large effectiveness trial, but due to various challenges, transformed into a smaller randomized controlled trial (315 young females) of a combined intervention package including life-skills, health education, vocational training, micro-grants, and social supports compared to life-skills and health education alone package. The intervention arm participants showed statistically significant differences from the control arm during the two years of follow up including; reduced food insecurity and having their own income, lower risk of transactional sex and higher likelihood of using a condom with their current partner over time compared to baseline, and fewer unintended pregnancies among intervention participants. The project provides a wealth of lessons learned in attempting to merge vocational training, micro-loans, and HIV prevention; however, it did not include biological outcomes. Epstein independently interviewed some of the participants and those implementing the program and identified some of the unanticipated consequences of project implementation. She found that in some cases, business activities actually increased participants’ exposure to risk as well as eroded relationships between elders and partners not included. Epstein interviewed one woman who briefly worked for the program who criticized the design, “In Africa, you can’t empower women and girls in isolation. African society isn’t individualistic. When the Western people promote ‘empowerment,’ they just end up promoting the breakdown of families (Epstein 2007: 251). Interestingly, one of the success stories highlighted by the program was a young girl who used the money to support her family’s already existing business to expand. In this case the money helped to build solidarity within the family.

In 2001 South African University of Witwatersrand Public Health and London School of Hygiene in collaboration with the Small Enterprise Foundation implemented the same approach of combining
microfinancing, business, and life skills but differed in a few fundamental aspects (Pronyk, Hargreaves et al. 2006). Unlike SHAZ, the program recruited older women, many of whom were grandmothers, and utilized pre-existing groups who were already meeting to repay loans and discuss business plans in which to implement the project. Locals were trained in “Sisters for Life” participatory methods using drama, song, and facilitation techniques for open-ended discussions about sexuality, relationships, the different roles of men and women in daily life, and the effects of culture on the treatment of women. At first, women were uncomfortable with the sessions arguing that it was culturally inappropriate. However, as the sessions progressed, women opened up and talked about sex, domestic violence, and AIDS. A review of the program two years post-intervention found women’s risk to domestic violence half that of women who had not participated in the program. The rate of divorce and separation did not increase; instead, women reported their partners showing greater respect and appreciation of their financial contributions to the family. However, researchers were unable to measure an effect on HIV incidence, which may partially be due to sample size and person years contributed to the cluster randomized trial design. The research team described a key component to the project’s success as the collective social energy that brought women together to deal with issues that they could not resolve on their own. The women also went on to talk about issues beyond the borders of the intervention group and their families to other social settings including churches, schools, and soccer clubs.

A majority of public health interventions and studies tend to control for indirect variables rather than attempt to study the possible interactions between indirect factors. Part of this is related to the expertise, interest and weakened ability to demonstrate association. For example, most home-based care programs would evaluate the effect on the patient’s health, or the families ability to provide care. However, in 2005, Busiswe Ncama a researcher in the School of nursing at the University of KwaZulu-Natal in South Africa, measured the effects of a home-based care program on sexual behavior. She found that where the services were provided, people spoke more openly about the disease and patients disclosed their status to more people (Ncama 2005). Furthermore, the social contacts of the patients—their friends, relatives, and coworkers—were more likely to say they changed their sexual behavior and were now
being faithful, compared to the social contacts of patients on a waiting list for the services. By expanding her design beyond the individual patient and even the household to the friends, relatives, and coworkers, Ncama demonstrated the indirect benefits of home based care for HIV prevention. Likewise, secondary indirect benefits to the partners of males participating in these types of interventions as well as to the children are typically left unmeasured. In the case of Lesotho, the rates of HIV are higher amongst divorced, separated, and widowed women. Additional indirect benefits are possible through supporting married couples. Take for consideration, John Gottman’s research on marriage which found that couples who had a ratio of five positive interactions for every one negative interaction their marriages succeeded, whereas couples who had ratios approaching 1 to 1 tended to “cascade to divorce” (Gottman 1994). To test the predictive value of this finding, Gottman collaborated with mathematicians to test the model. They recruited 700 couples, videotaped a 15 minute conversation between husband and wife, and counted the number of positive and negative interactions. They then predicted divorce or togetherness. At ten years follow up, they had predicted divorce with 94% accuracy. If this negative discourse exchange could predict, with this level of precision, future divorce, it begs the question on the value, worth, and long-term investment in implementing social and behavioral interventions, like these examples, that help individuals, couples, and families improve communications.

Studies and interventions linking structure and social and behavioral outcomes are a good example of practice and theory feedback. The researchers of the Stepping Stones Trial reported in 2008 went on to use the lessons learned from their own study and that of other interventions to try another iteration of the intervention (Jewkes, Gibbs et al. 2014). The researchers combined a broad economic empowerment intervention which focused on livelihood strengthening (helping to find work or set up a business) that did not give out cash or make loans, using the Stepping Stones curriculum. They recruited 232, out of school men and women between the ages of 18 and 30 from informal settlements outside of Durban. Building on lessons learned, the project maintained single sex small groups (rather than mixing), provided the sessions sequentially (social and behavioral program first and then livelihoods training), and twice a week sessions for a twelve week period (six hours a week intensive). In comparison to the first
trial, facilitator descriptions seems to reflect a higher level of quality; they were similar in age but slightly better off materially, had completed high-school, and some had previous facilitation experience. Facilitators were trained on gender attitudes, norms, and inequalities, HIV and AIDS, sexual and reproductive health, and facilitation skills. They were also co-trained, managed and supervised throughout the study by the Project Empower local NGO.

The researchers found many positive results: men’s earnings increased by 247% and women’s by 278%, reduction in reports of intimate partner violence from 30.3% to 18.9%, a decrease in controlling practices in relationships, severe depression, and suicidal thoughts for men; a greater proportion of men reported their main partner as their sexual partner, women and men scored better on quantitative assessments of gender attitudes, women reported less quarrelling over drinking, but more heavy drinking, and women showed a significant decrease in their experience of sexual and/or physical intimate partner violence (Jewkes et al 2014). Jewkes and colleagues (2014) also found that in comparison to the first trial, women in this combined intervention did show a statistically significant decrease in their experience of sexual and/or physical intimate partner violence. This supports a growing body of evidence that suggests women require change in their material circumstances in order to be able to use knowledge from gender-transformative programs, especially those aimed at reducing intimate partner violence. Biological, sexual, outcomes such as STD and HIV incidence were not measured.

The qualitative evaluation included a longitudinal cohort study dyadic pairs of interviews with a partner selected by the male participant (Gibbs, Jewkes et al. 2015). The study investigated two major claims that dominate justifications for male involvement in reducing risks for women in partner violence and HIV. One is the idea that interventions should “reconstruct” masculinities—implying a type of replacing the old with a new form of masculinity. The second is that the success of any intervention hinges on its ability to address male exclusion from the economy. As discussed above, the men did have marked improvements in livelihoods, health, and relationships—however the qualitative component captured the limits to changes from their social context. The researchers describe:
Rather than reconstructing masculinity, a more subtle shift was seen with men moving away from 'harmful' aspects of a dominant youth masculinity towards a form of masculinity whereby male power is buttressed by economic provision and attempting to form and support 'households'. Working with men on their livelihoods at an instrumental level encouraged participation in the intervention. Beyond encouragement, men's improving livelihoods afforded men the opportunity to materially demonstrate the social changes - in the form of shifts in masculinity--they were seeking to enact. (Gibbs, Jewkes et al. 2015: 208)

In consideration of the justified angst by many men, feeling forced into adopting Western conceptions of masculinity and relationships, this linkage of livelihoods with shifting gender norms and expectations creates space for an organic shift in masculinity not imposed but created. A study of men in 15 sub-Saharan African countries discussed the importance of men’s control of economic resources and freedom from social control mechanisms that may be more important than their authority over their wives in promulgating multiple sexual partnerships (Bingenheimer 2010). These are significant findings not only for reducing partner violence and HIV risk, but for broader visions of social change.

In conclusion, qualitative research and participatory approaches to eliciting information provide serious implications for the diffusion and translation of HIV prevention knowledge. However, these implications are often not measured because of the indirect interactions and need for long-term observation to detect the extent of changes. The primary method to show effectiveness for structural and participatory approaches for HIV prevention is to demonstrate the difference in HIV incidence between the control and intervention. Using the golden approach of a randomized trial participatory structural interventions show little effect on HIV incidence. Consequently, the lack of evidence supporting the effect on HIV incidence in contrast to more easily scientifically measured prevention methods, such as drugs and condoms, are deemed less efficacious and receive less attention and funding for HIV prevention. However, there are several challenges to measuring change that the scientific community (and donors) may not be taking into consideration.

First, many assumptions go into the analysis to show effect. It is accepted practice that accounting and controlling for sexual activities is as easy as accounting for age and gender. This may be an oversimplification. Two groups can be sampled from clusters, but within those clusters the sexual lives of
individuals can vary considerably. HIV risk and incidence are related to the number of partners an individual has, the number of partners that the partner has, the frequency of sex, the exposure to the virus, the health and nutrition of the individuals having sex, the probability of being raped, and the type of sex—oral, anal, vaginal, dry, wet, pulling out, condoms no condoms—all have varying degrees of risk. These factors need to be part of the equation used by statisticians in measuring effect differences.

Secondly, for ethical purposes, most trials provide a minimum intervention for the control group. Considering that this type of participatory dialogue opportunity is a rare life event, the effect on some participants may be greater than assumed. This larger effect may in fact diminish the difference observed between the control and intervention. Thirdly, most trials do not measure the ripple effect on the partners of participants or on other members of their family or social network. Furthermore, these studies attempting to measure the effectiveness of structural, social, and behavioral interventions sometimes undermine the effectiveness of these interventions by implementing them in a purely individualistic manner. As for the effect of the qualitative research encounter of talking about HIV and AIDS, sex, and personal behavior little is known. In practice, agencies and funding organizations commission the research to learn about the behaviors. It is no one’s interest to turn back and measure if the research experience had an effect on the participant’s perspectives on risk and sexual practices. Despite living within a deluge of campaigns and messaging, the qualitative research encounter is a rare event for people in high prevalence zones of Africa to talk about sex and HIV; principal investigators instruct their research teams to refer participants to professionals and not act as counselors or educators. This practice, while good for research purposes, may need further attention and discussion by researchers working on HIV in the hyper-epidemic zones.

4.4. Praxis the Bridging of Theory and Practice.

“These experiments in action research were not always coherent and suffered from inevitable errors; they generated failures, misunderstandings, polemics, and reflections. The problem of linking knowledge and action—theory and practice—is permanent and never ending effort to understand, revise and overcome an unending and difficult uphill (I will not say Sisyphean)
struggle; one which is lined with obstacles. This has been the human struggle since the beginning” (Fals-Borda 1979: 34)

Being a scientist is a human activity. Humans throughout history systematically observe, make predictions, experiment, and practice science. In the early days of the epidemic in Uganda, people observed that couples would get sick and die but not the children; through this observation, they knew that something about the disease was related to sex. Experts actually retard the diffusion and translation of research by first, considering non-experts as incapable of understanding the complexities of HIV prevention knowledge and secondly, treating research assistants as outside the diffusion process. This perspective leads to a lack of investing in the capacity of non-experts and research assistants as agents of change and educators about the disease and its prevention. While public health reading lists expand to include the works of Paul Farmer (1992, 1999) and other structural perspectives on the history and spread of HIV, formal clinical and public health education give little attention to the concepts of praxis and pedagogy. Praxis, while variously defined, has the common thread of linking with human freedom. It is the process of acting on theory. Brazilian educator Paulo Freire and author of Pedagogy of the Oppressed defines praxis as reflection and action directed at the structures to be transformed (Freire 1979: 72). For the most part, traditional pedagogy is employed using the “banking model” treating students as empty vessels to be filled with knowledge like a piggy bank. According to Freire (ibid), this approach is dehumanizing to both the students and the teachers and leads to oppressive attitudes and practices in society. There is a need for conscientization, or the use of education as a means of consciously shaping the person and the society, and the learner should be treated as a co-creator of knowledge. While perhaps not intentional, or perhaps intentionally, using a solely biomedical clinical approach to HIV prevention actually impedes dialogue and dehumanizes the way people talk and respond to the epidemic. Freire (ibid) describes this process as antidialogics which uses conquest, manipulation, cultural invasion and the concept of divide and rule. All aspects that may not have been intentional but are part of the AIDS industry’s approach to HIV prevention are consequences of particular institutional practices. As this dissertation illustrates from the case in Lesotho---conquest can be seen by the presence of large foreign
donors steering the ship, *manipulation* of the elite to join, “AIDS is everybody’s business,” wealth building, and employing manipulative advertising rather than education and dialogue are also observed. The concept of *cultural invasion* is evidenced in the way in which Western definitions of the HIV problem and its solutions are imposed upon the local population. Lastly Freire’s (1979) notion of *dividing* society is seen in the way AIDS industry outsiders hold the purse strings and provide employment, economic means and social support—furthering “development” but exasperating inequalities on multiple levels.

Acknowledgement of these detrimental approaches is the first step in moving forward in humanities based research. The next chapter highlights how a middle ground can be achieved through translating raw data and scientific approaches into useful information that can be easily understood and put into practice in the field.
CHAPTER 5: ORGANIZATIONS: WHERE DID THE MCP KNOWLEDGE GO?

As seen in the previous chapter, there is some discrepancy between how research is conducted and how this information is then translated and put into practice by those in the field. In Chapter 4, this dilemma is tackled by looking into the inner workings of the Prevention Synthesis and Translation System, which distills information about innovations and translates it into user-friendly formats that can be easily used by prevention delivery organizations. The findings of this chapter address specifically objective 2 of the research, the identification of how research results are integrated or rejected by local change agents. In order to contribute to this objective, this chapter details what we know about MCP in Lesotho, how this wealth of information gets integrated into local initiatives, and what factors affect (either facilitating or preventing) their adoption. A review of recent primary research based on MCP is presented, followed by the results of how interviewed organizations described how they learn about research and/or “evidence” in HIV prevention. A shift is then made to highlight how these organizations...
knew specifically about the MCP study of the present research. Once it is established how organizations and policy makers learned about the study, we can then explore how the research findings were used (or not) in prevention efforts. There is also some need to look at how the broader body of evidence about MCP and HIV made its way into policy and national prevention initiatives. Applying Rogers’ (2003) Diffusion of Innovations theory, particular attention must be paid to points of resistance to the diffusion of information into action as well as to those champions, individuals and entities, that were key in translating research into programming. I use his concept of the difference between homophiliac and heterophiliac interactions in the transmission of an innovation to see if those who self-identify as being indigenous (Masotho) or expatriates display any differences in their reception and application of the MCP research results (Rogers 2003). In order to make this comparison clear to the reader all quotes from expatriates are demarcated by the prefix X_.

5.1. Existing Research and Theory: The Evidence Base of MCP in Lesotho

In 2006, the Southern African Development Community (SADC) held an expert think tank meeting focusing on the regional nuances of the AIDS epidemic. One of the meeting’s main conclusions was that having multiple and concurrent sexual partners is one of the key drivers of the epidemic in the region (SADC 2006). Previous to the SADC meeting numerous social and behavioral studies documented the practice of concurrent and multiple partners in Lesotho (Spiegel 1991; Romero-Daza and Himmelgreen 1998; Magrath 2005). Quantitative studies and statistics from Lesotho seemed to support the connection between the cultural and behavioral dimensions of MCP and the spread of HIV. A WHO publication, *Sexual Behaviour and AIDS*, using data collected in 1989-1990, found that 55% of all men and 39% of women in Lesotho reported having had more than one regular partner in the previous year (Caraël 1995). The FHI 2002 Behavioral Surveillance Survey (BSS) targeted specific risk groups in the population. While the population sample was not representative, it still provided insight into the prevalence of multiple sexual partners in sexually active populations, where 32% of miners, 54% of soldiers, and 59% of taxi drivers reported having had multiple partners in the year; 41% of those reporting
multiple partners were married. Over the past ten years, other quantitative studies documented the same risk behavior (FHI 2002; LDHS 2004). The 2004 DHS, which is based on a representative population sample, found that 11% of women aged 15-49 and 29% of men aged 15-59 reported two or more sexual partners in the previous 12 months. While the evidence for the practice and its relationship with HIV in Lesotho seemed well established, it was only after the 2006 SADC meeting, that stakeholders prioritized the need to understand the nuances of the behavior and the need for building a current research base for decisions and policy construction. Several studies between 2007 and 2009 filled this lacuna.

One of these studies was the MCP research used as a case study in this dissertation, and implemented in 2008 by the National AIDS Commission, UNAIDS and FHI in order to fill the gap in understanding perceptions of risk of HIV infection in stable relationships and to explore current norms and practices concerning multiple concurrent sexual partnerships in Lesotho (Khobotlo, Hildebrand et al. 2009) (described in detail in section 1.2.1). The research, conducted in five districts of Lesotho, with 92 individual interviews and 30 focus group discussions, revealed rich insights into the social, economic and cultural considerations that influence individuals’ decisions related to sexual partnerships. The main themes brought out by participants in interviews and focus group discussions are listed below:

MCP (Khobotlo, Hildebrand et al. 2009). Qualitative Main Themes

- the role of money, initiating sexual relationships to overcome a hardship
- the consequences of mobility,
- alcohol’s facilitating role,
- the dynamics of sexual relationships where men and women instigate an additional partnership,
- the dynamics between intergenerational relationships between not only men and girls but also women with younger men,
- the way that the sentiment of dissatisfaction be it sexually, financially, or affective provokes the need for another partner,
- the sheer “greed” for more sex, the ways in which family and peers influence decisions to engage or not to engage in sexual relationships,
- the nonsexual benefits of partnering with a married person,
- the role of traditional medicines and potions in relationships
- participant perspectives on the spread of disease as a result of sexual relationships
In addition to thick descriptions of these themes the study also reconfirmed that concurrency was still a common practice with about half of the male and a third of the female study population reporting concurrent partnerships over the last year recall period. And those reporting concurrent partnership having on average 3.1 partners, with no one person reporting more than ten partners in a year. Over the one year, recall period of the study 42 (17 men and 25 women) of 91 reported having only one sexual partner, 47 out of 93 individuals recounted one new sexual partner from the previous year, reflecting a high rate of new partnerships. More than half of the participants reported believing that at least one of their current partners had other sexual relationships. Thirty of the 90 participants stated that one of their current sexual partners was either HIV positive or suspected to be infected.

As discussed in Chapter 1 the research team worked collaboratively to create presentations of the study findings adapted for meetings with national, district and community stakeholders that included participatory feedback and ranking activities to both help stakeholders engage with the results and to “member check” if what was found in the study reflected the reality. The national/international stakeholder dissemination meetings (500-600 participants), included government representatives, NGO’s and international organizations, the topics that generated the most discussion in these higher level meetings was the finding that both women and men express dislike for condoms, the finding that younger boy’s chase women, and that dissatisfaction in a relationship leads to having more than one partner. Whereas the participatory validation meetings with stakeholders and community members from the five research communities (128 participants) found that the image of the “epi-curve”, in combination with the representation of a sexual network generated the most discussion in the community meetings. Figure 11 and Figure 12 demonstrate the images used to translate the scientific explanation for the increased risk of transmission in concurrent sexual partnerships. Figure 11 slide is taken from the dissemination stakeholder meeting presentation “Gender and Multiple and Concurrent Sexual Partnerships in Lesotho Preliminary Findings 30 October 2008”. While Figure 11. is an image from the Relationships: Intimacy without Risk Facilitators Guide to MCP community dialogues(C-Change 2010; C-Change 2010). Depicts the translation of the same scientific explanation for the increased risk of transmission in concurrent
sexual partnerships into everyday language and images making scientific discoveries easily accessible and understandable.

One conclusion drawn by the community members from the visuals was that: “even though I stick to one partner, and I stay safe, I am still at risk if my partner has other partners, as I am connected to a larger network” (Khobotlo, Hildebrand et al. 2009: 13). There was also extensive discussion and agreement on the finding that both men and women have more than one partner. Additionally, the finding that respondents in concurrent relationships spent on average three months in such relationships, six months monogamous and three months without sex engaged the community members. Meeting participants were curious as to why someone would not have sex in those three month periods if they had more than one partner, even expressing disbelief in this finding. In both district and community meetings some participants argued that there have always been certain prominent diseases, and so HIV is nothing new, or that it is not as serious as it is made out to be, since it is not the first, nor will it be the last sexually transmitted disease. Others made implications
about cures found for other illnesses such as “mokaola” (syphilis) which was previously thought to be incurable (Khobotlo, Hildebrand et al. 2009).

Figure 12. Translation of scientific explanation for the increased risk of transmission in concurrent sexual partnerships into everyday language (C-Change 2010: 39). Copyright 2010 FHI 360 (Communication for Change Program) reprinted with FHI 360 permission.

A total of 89 individuals from four out of the five districts were asked to choose from a list of nine key drivers, identified by the preliminary analysis of the data, and to individually identify the most important factor that leads to the formation of multiple concurrent partnerships. The top driver cited in this ranking exercise was the Desire for Money (34%); followed by Economic Need (18%) and then Alcohol (13%). While there was some variability across the four districts in the rankings, the top three drivers, out of the nine, were the same across all four districts. At the end of the dissemination sessions the closing question, “If you had one minute to address members of your community what would you advise them to do to prevent the spread of HIV” was asked. Suggestions included:
Employment, life skills and empowerment were highlighted, including government interventions to reduce poverty “give us jobs, so we can get out of economic need” (Khobotlo, Hildebrand et al. 2009: 67) in order to avoid economic reasons and provide disincentives by giving people work, confidence and self-esteem. Religious leaders were also called upon to take action. Interestingly, none of the sites brought up partner reduction. At one site a research member asked “What about partner reduction in stable relationships, why don’t we talk about it?” Stakeholders stated, “Re thibele mohloling!” or ‘Stop it at the source’ meaning that if you take care of the factors leading to concurrency, concurrency will decrease (Khobotlo, Hildebrand et al. 2009: 68).

Another study commissioned under the USAID, C-change umbrella, specifically to inform prevention policy and programming was A Baseline Survey of Multiple and Concurrent Sexual Partnerships among Basotho Men in Lesotho conducted in 2009 on 1,643 urban and rural Basotho men (Volle, Foreit et al. 2009). In the survey men were defined as engaging in MCP if they reported having more than one sexual partner at the time of the interview. Based on this single item, 43.9% of the men in the study were classified as engaging in MCP. Among the 722 men engaging in MCP, the median number of concurrent partners was three, with over 30% having more than three partners, pointing to the reality that concurrency is not only frequent but involves a large number of partners.

The 2009 DHS reconfirmed the high prevalence of concurrency with 45% of all sexually active adult males reporting sexual contacts with more than two partners in the past year, with men between the ages of 20 and 30 ranging between 40-60% (Lesotho Ministry of Health and Social Welfare (MOHSW)
During the same year, for sexually active adult women, 25.9% reported multiple sexual partners, between the ages of 20 and 30, the proportion ranged from 20-36%. Within the group of married men reporting multiple partners, 80.1% were married and of the women, 93.8% married. Yet, a statistic less diffused, 64.5% of married or cohabiting couples surveyed, both partners were HIV-negative. As for the remainder, in 18.9% of relationships, both partners were positive; in 16.6% one or the other partner was HIV-positive (in 9.2% discordant couples it was the female and in 7.4% it was the male). Married men surveyed were 30.7% HIV-positive, while among married women, 26.4% were HIV-positive. Divorced and widowed men and women had the highest prevalence. It is 30.8% for divorced men and 62.0% for widowed men. For divorced or widowed women, 59% of both groups were HIV-positive. As documented in other research, HIV-prevalence increased for both men and women in parallel with the number of lifetime sexual partners. Overall, women report an average of 2 lifetime sexual partners and men report an average of 8. The increase in HIV prevalence with number of partners is most dramatic for women going from 18% for those with only 1 lifetime partner, to 32% for those with 2, to 41% for those with 3 or 4, to as high as 66% for those with 5 or more lifetime partners. For men, the increase in prevalence over this same range is from 13% to 33% (Lesotho Ministry of Health and Social Welfare (MOHSW) 2009).

In the end, MCP as a driver in the Lesotho epidemic produces a wealth of evidence, in terms of quantitative information of who and how many people and qualitative information about the why behind these numbers. In fact, it is noteworthy that 87% of men and women, regardless of social status, identified that limiting sexual contacts to one uninfected partner reduced the risk of acquiring HIV (Lesotho Ministry of Health and Social Welfare (MOHSW) 2009). The information is well documented; there seems to be a high level of general awareness about MCP and HIV risk, or at least enough to regurgitate the right answer, but it begs the question why after all these years is MCP still so high? How have local change agents integrated or rejected these results? In order to answer these questions the next section presents responses from ten individuals (representing 15 different organizations) working on projects targeting social and behavior change and HIV prevention (as described in section 1.4.1). The
questions asked to participants concern how they learn about research in general, about the MCP research and how the MCP research results were integrated in their own work or in policy.

5.2. Organizational Learning About Research in HIV Prevention

When asked about how their specific organization learns about research and evidence in HIV prevention participating agencies reveal that organizations in Lesotho do not use a central source for receiving and exchanging information. When probed about the role of the Ministry of Health and Social Work (MOHSW) as a central source for information one participant noted:

ORG_07_3: whenever you need something from them you'll be pointed to different directions…Oh that you can get from Disease Control….oh that one you can get from such and such… there is no one place. So I think...we do need a resource center.

Another participant described the problem of not having a centralized point to access research creating a default mechanism of focusing only on what they need for a current specific project rather than what others have done, or what “evidence’ has demonstrated:

ORG_03_1: I think everybody is just focusing on what they are doing, for us here we are just focusing on our support groups…the problem here is that we do not have an institution where we can say we will find all the research works. Everybody is doing research for her or his organization.

The instability of NAC has eroded attempts to create a one stop source for national coordination and a reservoir of information. Some respondents noted that the previously existing NAC library and website were useful for finding the reports that NAC chose to publicize. However they noted that it was not an organized catalogue of all the reports that have been done on different aspects of HIV/AIDS, but tended towards self-reference, “they publicize the findings, like the MCP, the Modes of Transmission...but then the studies there were only the ones that were done by NAC...” (ORG_03_1).

The coordinating role of NAC served to facilitate both formal and informal network opportunities for sharing information and resources. Formally, NAC established a listserv for the exchange of information. They also sponsored different national meetings for stakeholders some directly focusing on research
exchange and dissemination and others, like Monitoring and Evaluation Meetings, that indirectly created space for organizations to network. As a result, even after NAC ceased to provide this central coordination, mini-networks continue to exist and exchange information. However, what information an organization could access depended on with whom they had partnerships or good working relationships.

In a resource competitive environment, without a coordinating independent body, the exchange of information turned into isolated silos.

**ORG_04_3**: maybe you won't even be aware that there's a certain study … I'm saying that if PSI has carried out a study, maybe during our prevention meeting PSI will tell the stakeholders, I'm carrying out this study which has this and this and this. Then when the study goes out we will be able to share that, as all the stakeholders. But currently what is happening is that PSI will share the study with the people it is already working with not necessarily that whole group….they will share it with who they think cares the most, rather than it being available to everyone. That’s a challenge …I think they should re-establish NAC…. Maybe not the old NAC but something a coordinating body. We need a coordinating body that is certain.

On a similar vein, another participant stated that there is a dire need for a central organization to capture, publish and be a data resource point:

**X_ORG_07_4**: well first of all the dissolution of NAC has to come as a primary reason. I mean there, there is a reason that a National AIDS commission was set up ten years ago or even fifteen years ago. I mean just the idea that we need a multi-sectoral, independent body that is going to really capture and publish data and be the clearinghouse for HIV programming. And it’s gone now and not only is it gone but it had its legs cut out from under it as early as 2010 so it’s been defunct for at least two years.

Several sources indicated that NAC had actually ceased coordination activities in 2010. In 2012 attempts were being made to create a resource center by a consortium of NGOs. In fact several organizations had identified the gap in research coordination and were in the process of writing proposals for support in establishing a resource center. **PHELA Health and Development Communications** (PHELA) one such organization, described how they and others go about implementing an evidence-based approach they noted:

We rely mainly on the strategic plans, the DHS and research that has been carried out by other organizations but not many organizations carry out research. For us we rely mainly on the research that we undertake so that we use to inform our product our programs. And we think that some organizations might be doing a bit of that but they do not call it research. So we want to get
all that information that is why the research center we are going to get all of that information even though it is taking us more, we want to be the place. ORG_07_3

However, even if the resource center gets started it would not have the “authority” of a government body to mandate all bodies to notify and submit reports for cataloging. Furthermore, the success and sustainability of the resource center is dependent on donor funding. In December of 2012 the PHELA website showed an initiated resource center. Unfortunately, by 2015 the link to the resource center did not seem to be working any longer.

Another problem is that there is no official information center at the Ministry of Health. There does seem to be a resource center (physical room), but it is not functional as there is no staff hired for the purpose of creating, maintaining, cataloging, filing, creating copies, responding to questions or even a system for research and information management. The MOHSW has some record of HIV related studies through the Ethics office but it is limited. One, it is not offered as an electronic database, two, often researchers do not submit studies upon completion, and finally, many studies are conducted without IRB approval. In fact, several respondents noted that many people did not consult the Ethics committee due to long waiting periods. While the Ethics Office personnel were judged to be timely and helpful, the actual wait for committee meetings, approvals, signatures, and further approvals of revisions were a deterrent to compliance. After all, there are no legal sanctions for lack of compliance. Of special note, the 2008 MCP research project received ethical approvals from both the Lesotho MOHSW and US based ethics committees.

Despite the study having been reviewed within the ministry there appeared to be a gap between studies processed in the Ethics office and those that make their way to the desks of interested department divisions. The lack of a central coordinating body for information was confirmed by a representative from the Division of HIV in the MOHSW when asked whether they were aware of the MCP 2008 Project conducted by NAC, FHI and UNAIDS (the case study of this project):

ORG_07_1: I think there is plenty of research out there but it’s not as yet properly coordinated. Some was under NAC some was under Ministry of Health like I am saying this study that you
just mentioned. I was not aware of it but… I think just that we were not properly coordinated that's the problem. There's nothing more that I can think of.

Interviewer: And for the future is there any kind of movement to have some kind of coordinating body for all research?

ORG_07_1: Yes, there has been one good move just about two weeks back … there was the research symposium, several researches it was very informative of all the researches that are going on.

Interviewer: But as of now, there is no central place that I can say I'm doing research on HIV prevention I go here and I know that all of the materials are there, I don't have to like knock on every door

ORG_07_1: No not yet.

In this exchange it should be noted that the representative within the Division of HIV at the Ministry of Health was “not aware” of the MCP research (none of the three conducted in that period) which demonstrates the limited utility of a “research symposium” or one day research conference. Individuals from other government ministries reported the same reliance on informal networks and physically having to go from office to office or just conduct research on their own. One individual from the Ministry of Science, Information and Technology discussed how challenging it is to access reports:

…you know the government and how it works, the red tapes, the hierarchies and everything… information is not readily accessible, you can't get so much anything you want, you still have to go through the NGO's and parastatals, but what's through the government than it's quite limited information. So I wouldn't really lie to you and say that is how we do it (gain access to research and information). Cause even in our department we are still using researchers from NUL, the National University, mostly for some of the projects that we're carrying out. We are still using the students from NUL, you know. ORG_08_1

This points to the possibility that instead of accessing what has been done, practitioners just answer the question that they need to know—begging the questions of quality, expertise and building on what is already known or has been done.

5.3. Organizational Uptake of 2008 MCP Research Findings

One of the main critiques of the utility of qualitative research for policy and action is that it is cumbersome and takes too much time to conduct and synthesize (Rist 1994). As a result, qualitative research has often taken the form of simpler Knowledge Attitude and Practices studies or rapid appraisals when informing policy makers and practitioners who are often working on tight timelines (Estrella and
Gaventa 1998; Chambers 2007). However, this original 2008 MCP research was created with and for policy makers in an effort to be relevant and timely in disseminating findings (Khobotlo, Hildebrand et al. 2009). Therefore, it offers a unique window into the potential of making complex large qualitative data sets user friendly. Additionally, organizations are increasingly commissioning qualitative studies, similar to this one, in order to inform as well as adapt studies, clinical trials, and interventions. This section presents an example of how the diffusion and uptake processes occurred within target audiences. The aim of the section is to improve our understanding of the dissemination process and increase the likelihood for other studies to have a greater impact for the resources invested.

When asked how they knew about the MCP research findings, a large majority (70%) of respondents connected their knowledge of the MCP research to a first-hand encounter with members of the original research team—whether from attending one of the original dissemination meetings or through a personal relationship. These respondents claimed to have read the original report and could cite ways in which they have seen the information used in different settings. Two expatriate respondents, who came to Lesotho after the original research, noted that they learned about the MCP findings during their orientation period. Both responded that they knew of the research, though had not read the report themselves, but had seen it referenced in reports and proposals. Two Masotho representatives from the Ministry of Health and Social Welfare in the Division of HIV and AIDS interviewed noted that they had not seen or read the original report/presentations, whereas representatives affiliated with NGOs or National AIDS Commission all reported having seen a presentation or read part of the original report/presentations, including those who were not present during the original dissemination.

5.4. Applications of the MCP Research Findings

This section provides examples described by organizational representatives about the way in which they either used the original 2008 MCP research or how they saw it applied by other agencies or in policy documents.
5.4.1. National AIDS Commission (NAC)

According to several participants the National AIDS Commission, one of the primary partners of the study, went to great efforts to disseminate and share the 2008 MCP research study findings. One participant described how:

NAC took the MCP PowerPoint and presented it EVERYWHERE. I believe it was the most disseminated research I have ever seen. The MCP results were very visible. The PowerPoint was very well developed and NAC used it everywhere. Everyone heard MCP, MCP as a key driver but in terms of actually communicating what that meant got lost. The advocacy tools were needed and never established. X_ORG_02_2

The NAC used the study results to inform the review of the National Strategic Plan 2007-2011 and in the development of the 2011-2016 National Strategic Plan. The NAC planned to use the qualitative data to make advocacy tools. The NAC was given the responsibility and the funding to create a dialogue toolkit. The intended toolkit on MCP was to be combined with that for Male Circumcision (MC). However, in 2008-2009 the MOHSW did not want to be involved with “ANYTHING to do with MC” as one respondent indicated (X_ORG_02_2). It is unclear if the toolkit was blocked formally or informally but progress came to a halt. Reasons given for the rejection of MC by the MOHSW were reported as a “mixed bag” involving cultural reasons and lack of local scientific evidence. However, MC received support from outside the Lesotho government, through USAID programs supported by PEPFAR and the WHO. Funding for MC programs sidestepped the NAC and MOHSW and went to the “ground level” involving traditional schools and other organizations. During this period of friction several individuals in different organization were taken out of their positions, supposedly, for having worked with MC. Thus, according to respondents, between the NAC moving slowly and the MOHSW’s resistance to having MC propagated, money was allocated, but the toolkit was not produced.

5.4.2. United Nations Agencies

In addition to UNAIDS active involvement in implementing and disseminating the MCP research results to external stakeholders, UNAIDS focused internally. The MCP study results were quickly
integrated into the Modes of Transmission Study (Motlalepula, Tsehlo et al. 2009). Results and discussion were taken to the Joint United Nations Task Force on HIV/AIDS a committee consisting of representative from all the UN agencies working in Lesotho in order to brainstorm and increase focus on integrating MCP into current prevention activities. Disseminating the MCP results and gaining buy-in was stated as a significant motivator for the UN’s advocacy efforts in working with the MOHSW to institutionalize the National HIV/AIDS Prevention Symposium. UNAIDS worked closely with the implementation of the Essential Service Packages decentralized response to HIV at the community council level ensuring that the topic of MCP was one of the priority area options.

5.4.3. Lesotho Ministry of Health and Social Work

During the time of these interviews, the results were taken into consideration for the Behavioral Change and Communication strategy but there was no direct programming for MCP prevention associated with the MoHSW. Interviews from organizational experts highlighted that the results and discussion of the MCP research helped to call for more precise indicators and ways of measuring MCP in Lesotho and in the region. For example, informed by these study results the 2009 DHS included more specific measures on concurrency.

5.4.4. Non-Lesotho Government and International Organizations

The German International Development (GIZ) program Essential Services Package within the national HIV and AIDS response supported decentralization and local government structures to take an active role in the response. Anthropologist Kenworthy explores in great detail this initiative (Kenworthy 2014a; Kenworthy 2014b). GIZ provided financial and technical support to helping local governments prioritize HIV and AIDS within their community development and poverty reduction plans. The program helped communities to facilitate the identification of their own needs and priorities, and then provided a basic package of responses that the community could adapt to address their needs and context. Those working for the Essential Service Package project noted that they were given directives to integrate MCP
into their HIV prevention work. MCP as a problem needing to be addressed was quite popular at the community level, according to one participant who worked for the project, “…the community counselors were given a number of activities then they were to choose five, I think five, from that list. And most of them chose MCP” (ORG_03_1). Two researchers from the original MCP study were hired to serve in management and support positions at the district level for the ESP program. Both of them described how the skills and knowledge gained from the MCP research and dissemination process continued through their next assignment:

I used to meet with some of the people from Leribe, Maputsoe the ones we interviewed during the MCP. While I was working with GIZ. And I think what we did as MCP is marvelous they remembered me from MCP not GIZ and they always connected me with MCP…not that other organization I was working for and they would talk to me, I mean they would TALK to me, TALK HIV, TALK, TALK SEX, TALK everything you know. TALK, TALK. Just talking. I was like I am not with MCP anymore and then they were like "no we can just talk, we can do, we can continue the talk, continue educating." I remember telling this other one she told me she had another boyfriend, they are stable but she is HIV positive and she said, “No he doesn't know” and I said, “do you think it is better if you tell him? That you are HIV positive?” We talked, we talked and talked she told me she was afraid but then at the end of the day she said, "I am going tell him today. That I am HIV positive, thank you." That, that MCP WOW. It was very fulfilling. You sleep at night you feel so relaxed, you feel so fulfilled, you feel so happy that you are changing lives. It was one of its kind. IR_ORG_02_1

This is only one example of the way in which the capacity built into one funded project spilled into other contexts. Furthermore, this type of informal communication would not have been enumerated by anyone but is efficacious, possibly preventing transmission in a discordant relationship. Another MCP research team member went on to be the Executive Director at the Lesotho Network for People Living With HIV and AIDS (LENEPWA) he also discussed the ways in which he shared the knowledge from the MCP study in his work at this other organization and in larger national strategic planning meetings:

To a large extent there has been a connection. Let me take the connection at the work level setting. Where I am now, we are working on HIV and AIDS interventions and the link that comes clearly is on the fact that HIV prevention in Lesotho centers around addressing issues that came up out of this study as a national study. We are having the national strategy plan, behavioral communication plan which is also directed towards addressing the issues that came out from this study. So this means that in my daily work when we are talking prevention, planning implementation and so forth our mind is fully focusing on MCP which is something that I personally was able to engage in coming up with these issues and putting them together. Fully understanding what they really mean. So it’s directly having a link with my work…Now I can proudly say I have been part of that team that conducted the MCP because it is the same study
that is helping the country towards eradicating, it’s actually the reference for Lesotho to say MCP is talking to this, this is a challenge and this is the thing we are addressing. We are targeting so much of this for the challenges that came out with the MCP study. IR_ORG_04_1

The effect of the study was not only felt and maintained by the ex-MCP research team members but also continued when team members were not present and after the initial dissemination process. As one expatriate organizational representative from Population Services International (PSI) describes his engagement with the study results:

I probably just read summaries of it...but I know that...based on that...the modes of transmission study for PSI was a ground-moving study. We literally turned the ship in a different direction because of the information coming out. A lot of that information was concurrency it was, who are the drivers and what are the behaviors that are driving the epidemic and who are we currently reaching. And we weren't reaching the right people. We weren't having the impact that we need to and so we made different decisions…based on data …and we're in arguments now about our decisions based on that data because, what happened is that we had these programs that were targeting mass general populations. And we've gone now to what we consider to be the misbehaviors. PSI divides the world into behaviors and nonbehaviors when it comes to health and men 25-39 they are the nonbehaviors and they are driving the epidemic, their behaviors are driving the epidemic. X_ORG_07_4

This excerpt indicates the trail the MCP research took between the original report, feeding into the Modes of Transmission Study and making its way into prevention target groups. While subtle, the representative reveals the arguments going on in 2012 about which direction prevention programs should go. PSI supporting targeting the “nonbehavers” (non-condom users) men aged 25-39 and others who saw the need to address MCP as a general population problem. In addition to arguments about how to translate what was known about MCP and HIV transmission into “target groups” there was a lack of clarity of what was considered behavior change communications. Three messages were clearly diffused in the general population, MCP linked to AIDS, use a condom every time, and try to have one uninfected partner, yet, all the way into 2012 there was still few organizations dealing with communications and education of the local nuances of concurrency as it relates to HIV transmission, individual and social change. The next participant commented on how surprised they were by the lack of programming on MCP:
We found that the main driver of HIV in this country was MCP. According to my expectation, I thought many of the organizations would become interested in addressing MCP. However, there are so few organizations that deal with MCP directly only. PHLEA, NAC was trying by the time it was still there. You know there are so many organizations (targeting behavior change)…you find that they talk about prevention in most cases…they mainly talk about HIV testing, as for behavioral change you'll find that there are not so many NGO's that deal with MCP…That is why I think we still need to focus more on that one.

In order to validate and quantify the participant’s perception that there was very little programming specific to MCP I reviewed 250 organization self-identifying as working in prevention. To gather the base number of organizations I used organizations listed in policy reports, Letsema/Sentebale’s website, and a draft list of SBCC organizations from the Lesotho John Hopkins Communication Change 2012 mapping exercise. Based on the project descriptions written in reports or on their website I categorized the organizations and found that 30 explicitly self-identified as working on Behavior Change and Communications, and eight of these organizations mentioned one of the words MCP, dialogues, life skills, community mobilization, education or Sex/STI. Confirming what the participants had said in interviews, only one organizational project description clearly associated their work with the aim of targeting MCP. The next section looks specifically at this one organization, to explain how MCP research was integrated into their prevention efforts and highlight some of the ways research knowledge and capacity translated into practice.

5.5. Targeting Multiple and Concurrent Partnerships Research Translated to Practice

2008-2012

The 2008 MCP study for this case study was a joint initiative between NAC, UNAIDS and FHI. The support from FHI was part of the USAID-funded Site Identification and Development Initiative (SIDI). At the same time that the MCP project began in 2008, C-Change communication managed by American Education for Development, funded by USAID collaborated with the local arm of CARE Lesotho on an initiative on education and communications regarding sex and HIV. The broader goal was to support the NAC and MoHSW in reducing MCP behavior by promoting open dialogue about HIV and
MCP, while educating and mobilizing communities to implement further interventions to lower MCP prevalence. Their strategy consisted of a short-term MCP communications campaign using mass media and community based outreach in early 2009 and a longer-term campaign for the middle of 2009. As part of this project, US sources helped with funding two additional MCP studies. Within the research partnership, C-Change collaborated with two Lesotho-based research agencies, Phela Health and Development Communications and Sechaba Consultants.

One of the studies, *The Baseline Survey of Multiple & Concurrent Partnerships (MCP) in Lesotho*, used a three stage random cluster sampling design, surveying 1,643 Basotho men from 55 urban and rural areas between March 2-12, 2009 (Volle, Foreit et al. 2009). The objective of the study was to collect population-based data related to MCP knowledge, attitudes, and practices of Basotho men. The second study was a formative study, *The language of multiple Concurrent Partners, Sex and HIV and AIDS: Opportunities for dialogue promotion*, designed to understand how culturally embedded communication about HIV and AIDS and sexual behavior links to the unrelenting practice of MCP in Lesotho (Sigamoney 2009). The study conducted 24 in-depth interviews with key informants identified from six categories: traditional healers, youth leaders, health care workers, volunteers involved in HIV and AIDS and reproductive health work, local area chiefs, and church leaders. The study yielded information on the communication processes surrounding sex, MCP, and HIV and AIDS, as well as on the socio-cultural contexts of these communications. Based on the findings the study team concluded that there is actually a certain amount of dialogue, but the dialogue is not apparent to cultural outsiders. They argued against the notion that Basotho are silent, secretive, and non-communicative about sex but rather that secrecy and silence are part of culturally appropriate communication used to talk about sex, MCP and HIV (Sigamoney 2009).

From the inception, the C-Change project had the objective of transforming into a larger MCP communications campaign. All three MCP study findings went on to inform the programming for the C-Change project. As one practitioner describes the integration of research studies into outreach:
…we conduct research to find out how Basotho perceive MCP. We did that and it gave us information. And around the same time you were doing the study as well. So we used the findings from our study and from your study which we call the NAC study. We use it to inform our content so we have developed materials like multi-media materials to support our outreach programs that supported and we have used the people that are in our outreach programs to model in our multi-media, like for example a person who is well respected and has attended all of our trainings and is now doing some work for ONE LOVE. That we use them to be models in our billboards and in our booklets. ORG_07_3

The example above also highlights the interactive process of identifying leadership over time rather than based on pre-existing criteria of “leadership”. For example, multi-media uses of well-respected politicians, musicians, or athletes who may have multiple current partners, use the “find the leader” diffusion effect but undermine the overall message. Another practitioner for the same project describes the iterative process of integrating research findings into programming and the progression of co-learning. When asked how helpful they found the MCP research project in informing their own work, the respondent stated:

ORG_04_2: It was so helpful because first of all we used its findings to come up with our own project. For example, we also realized that one of the drivers was alcohol abuse so we try to make people drink responsibly. And also the communication part we realized that a lack of communication also causes MCP so we tried to come up with ways that would encourage communication within partners. Such things from the research, all those different drivers of MCP were highlighted and that is where we got them and use them. We also have research within PHELA here and go to people there and try to ask questions from them so that we could see what is it that they themselves think would help them come up with solutions. Because one other thing that we do, we don't come up with solutions that these people have to use them, we try to make it as participative as possible, we go to them we ask questions that will help them, help themselves. Will help them to come up with solutions that will help them… that information helps us to come up with activities, programs that will address those drivers.

While the C-change Communication initiative promoted participatory and evidenced based practices, often described as the “ideal” for this type of intervention, the collaboration experienced several challenges slowing down project progression and perhaps retarding the potential fruits of the approach. In considering the challenges of translating research into program realities we see how the 2008 original research themes made their way into programs still existing in 2012. However, there were several points in between 2008 and 2012 that these programmatic initiatives almost failed. For example, the initial project collaboration between C-Change and CARE Lesotho was short staffed with only two paid team
members juggling other projects. Then in 2010, CARE Washington came into conflict with AED and the C-change group. The partnership ended, but fortunately the project went on. C-Change and AED collaborated with PHELA who had experience in HIV and sex communications and media with financial support from SoulCity and UKAID. Under this partnership, AED increased funding and the project scaled up. However, AED at the central institutional level faced charges of "serious corporate misconduct" bringing to a halt all AED contracts in December of 2010 (Dilanian 2010). In 2011 AED, contracts, programs and employees were transferred under the FHI umbrella, creating the new FHI 360.

All of these conflicts and funding constraints from outside funders were happening alongside previously described conflicts between the MOHSW and the NAC on the MCP combined Male Circumcision project and the virtual dissolution of the NAC. The project was hampered by these administrative, staffing and funding issues. Even if the project continued, the insecure work environment effected the growth and spread of the intervention.

Another clear theme in answering the dissertation study question about the factors that affected (either facilitating or preventing) the integration of the 2008 MCP research results by local agents was the important role of human and organizational capacity. During the 2009-2010 period, the project had a fortunate wealth of human and structural capacity rendering the project resilient despite the challenges. C-Change, AED, SoulCity, PHELA all came to the table with unique experiences involving MCP in Lesotho and in the region. During this period one of the research assistants from the NAC MCP 2008 research project volunteered with the group. Her description exemplifies the informal ways through human capacity that research results are synthesized and translated into prevention products. The excerpt initiates with her explanation for choosing to offer her volunteer services to the C-change project instead of accepting a paid job offer:

IR_ORG_06_2: I wanted to know where they were going with that information (MCP research results). What were they going to do? What is happening? I wanted to be part of that. If you are going to use this and do anything about it...then this is mine, this is me, this belongs to me… I went from collecting the data, to looking at MCP and the impact of MCP where and why, what’s happening, correlating the relationship between MCP and HIV, then we went through the data collection then the dissemination of the data. After the study, I went to volunteer on a project that
was funded by the C-change group that was a behavior change communications strategy it was a pilot at the time. Implementing a strategy that was a direct result of our MCP study (the 2008 MCP study). That's how fortunate, I was like, it’s ok you can't hire me, you don't have the budget yet and this is a pilot I will volunteer. I spent the whole year working for nothing. Literally nothing. Not even taxi fare or lunch money, I would wake-up in the morning, go to work five days a week I would travel, I would go out into the field, to the districts, we traveled all over Lesotho implementing the strategy and working on the manual and stuff like that, like that's where I started working on the manual …MCPs like all the stuff that we used it was the codes (from the original 2008 MCP study), it was the definitions that came out of our MCP study. It was seriously, we just took out these core areas, we need to talk about alcohol, lack of communication in sex, sexual dissatisfaction, money... like ALL those things that came out of our study that’s what went into informing the strategy… Instead of somebody coming with a tool and saying ok here it is go do this…I had an opportunity to actually start working on developing stuff. That process, the brainstorming, the sitting together, the coming up with stuff, like during the study (the 2008 MCP project) but even, especially after like during the dissemination. Getting a chance to apply different skills, different tools and that had such a HUGE impact on me…I'm glad I had that experience because it has helped me in my work, today. Do you know that I co-authored a communication manual? A manual that's being used like the C-change communication manual it’s an eleven week program for communities on behavior change. I co-authored!

One of the products of this collaboration, mentioned in the above example as the communication manual, was the *Relationships: Intimacy Without Risk* dialogue kit including a facilitator’s guide, a training manual and communications materials (C-Change 2010). The intervention consisted of 11 sessions including: HIV basics, relationship between HIV and MCP, sex and sexuality, facts and myths around HIV and AIDS, problems and pleasures of MCP, couples communication around love and sex, gender and culture, real men and real women, stages of behavior change, and “I can change my behavior.” Based on community feedback, later revised versions also included sessions on alcohol and general communications. The manual is similar to the Stepping Stones approach, but different in that all the content, messages, language had its roots in the locally researched reality and metaphors of Basotho. As the participant above mentioned the manual was directly based on the 2008 MCP research findings as well as the C-change MCP research projects, this was confirmed in two other interviews with Basotho staff members involved in the creation and implementation of the communication manual. Instead of being adapted, the collaborators mentioned above (C-change, CARE, AED, Soul City, PHELA) created it with and for Basotho. The team, using the materials, implemented the project, in six districts, trained 350 facilitators, utilized 150 pre-existing community based groups and included over 689 participants in the
dialogues. Each of the groups participating in the dialogue were encouraged to host an outreach event in their community to continue the learning chain. The outreach activity options included screening of the MCP Drama, ‘Monna oa Motsamai’ developed by Phela, discussions at local bars, and health talks on concurrency and HIV with health care providers (Meyanathan and Rogers 2012).

Simultaneous to the implementation of the community dialogues the project complemented and reinforced the larger OneLove regional campaign to address concurrency. During this period PHELA collaborated on two synergistic and reinforcing projects targeting MCP. The OneLove, was part of the Soul City Institute for Health & Development Communication financially supported from 2009 to 2011 by Soul City and UKAID. The campaign included booklets, flyers, posters, billboards, radio talk shows and public service announcements. This overlapping presence of the larger mass media campaign and the dialogues provided community members an additional opportunity to discuss and interrogate norms about MCP facilitating the spread of HIV.

Unlike many projects that implement and leave, the C-Change project team fostered sustainability by continuing to make themselves available to troubleshoot problems, visiting groups conducting follow up training, awarding participants with certificates at completion of the program and providing additional materials such as the community conversation toolkit (Meyanathan and Rogers 2012). These activities demonstrate well the fundamental role of the intermediary prevention support system. At the time of the interviews in the spring of 2012 the project continued, but instead of expanding the program, due to funding constraints, it was downsized, staff reduced, and the toolkit abbreviated.

In September 2012, C-Change published a qualitative evaluation of the community dialogues. They commissioned the Health Sciences Research Council (HSRC) to conduct in-depth interviews (IDI) and focus group discussions to assess how the dialogues had affected participants and the community as a whole (Meyanathan and Rogers 2012). A sample of 158 women and 107 men ages 18 and older from all districts where the dialogues took place participated. Most participants perceived that the dialogues had a significantly positive impact on both their communities as well as their sexual relationships. Documented perceived positive effects included:
• improved sexual behavior (reduction in concurrency practices, increased practice of protected sex, and reduction of transactional sex);

• more open communication about sex and other sensitive issues in communities and with sexual partners, spouses, children, parents, families, and peers;

• improved relationships with sexual partners, including strengthened emotional ties, trust, and commitment, improved sexual techniques and altered gender norms relating to women taking the initiative in sexual relationships;

• increased information dissemination and knowledge about HIV and AIDS;

• improved health-seeking behavior, including increased uptake of HIV testing;

• increased acceptance of one’s own HIV status; and

• increased sense of personal contribution and empowerment in the community. (Meyanathan and Rogers 2012)

During the project the main measurement indicators were quantitative numbers of how many people trained, attended dialogues, or outreach events. Unfortunately, much like many of these community dialogue/participatory-based interventions, post-project evaluations measuring impact is extremely constrained. First, in order for the evaluation to fall under the project-funding umbrella, HSRC conducted the assessment shortly after the program making it difficult to determine if changes were sustained over time. Secondly, the program was well informed by formative research but did not include a baseline of MCP or HIV/STD biomarkers in the specific communities that could be compared over time or against other groups. Nonetheless, the perceived positive effects addressed exactly the needs identified from the SADC 2006 meeting as well as the points identified by several formative Lesotho epidemic specific studies. The evaluation also noted criticisms from participants, particularly when dialogues were culturally inappropriate and/or fostered conflict between individuals and the community. The criticisms of the project identified in the evaluation could provide special insights to the implementation of future dialogues in Lesotho and abroad. Of note, we may ask, who were the people who felt the discussion of sexual practices and concurrency were culturally unacceptable? Where dialogues were said to lead to conflicts, what were the sources of conflict?
5.6. Tracing the MCP Findings in Practice 2012 to 2016

In 2012, the funding for the Relationships: Intimacy Without Risk community dialogues discussed in the previous section was nearing an end. Despite its success and lack of coverage throughout the country. NAC was no longer coordinating and monitoring prevention. A new group of stakeholders, heavily supported by US funding sources PSI and John Hopkins University coalesced under a partnership called LETLAMA. PSI took the lead in designing and implementing the New Revitalized and Energized Prevention Response. Under this umbrella, LETLAMA had a five-year project (2011-2016) with the aim of reducing HIV infection incidence through the promotion of protective behaviors and support for healthier social norms in young people 15-24 and adults 25-35. This new group was given responsibility to develop a Behavior Change Communication Program. They were also given the “mandate to develop a national brand that can be used to promote health behaviors, products and services”(Letlama 2012: 1). Using delta strategies and consumer research “The Pusha Love” brand was developed. Pusha Love is funded through a grant from USAID and works in partnership with the Lesotho Ministry of Health. This brand was again an important attempt to resolve the communication problem between HIV prevention information and its real world applications.

The new campaign launched on January 21, 2013. I analyzed two sources describing the new campaign, one of which was the public profile descriptions and the other a creative brief. The creative brief, focuses on the marketing of a brand, an idea of the “good life” and the services that can help you get there such as, using condoms, HIV testing and starting treatment (treatment if positive and PrEP if found negative) (Letlama 2012). The creative brief spells out detailed branding marking requirements for use of the Pusha Love logo including specifics such as “a tagline and space for up to two donor logos and a project logo” which may unintentionally send the message that HIV prevention should be officially sanctioned, for professionals and dependent on donor funding. Whereas the USAID description stresses dialogue and creating community support for change (Phomane 2013), lessening its commercialized tone and describing Pusha Love less as a brand and more like an organic movement by local organizations, frustrated and exploring completely new prevention approaches. In this description, Pusha Love uses
stories “to invite Masotho to discuss their own dreams, what they are doing to achieve those dreams and how as a community they can better support each other to stay healthy” (Phomane 2013). Unlike previous campaigns that funded leadership, the movement exploits volunteer ambassadors to share their stories, demonstrating that “these are real people who are so invested in the movement that they’re sharing their stories only because they want to make a difference” (Phomane 2013). In addition to the stories and the characters used, drawn from the various MCP research studies, including the 2008 MCP of this case study, there is also evidence that the community dialogue approach continues. For example, the NGO Kick4Life, working under the Letlama Pusha Love umbrella, uses Chromees, or coaches, to facilitate ten week participatory education discussions with young people (Hall 2014). Similar to the research results in this dissertation study, they discuss how “the most powerful and lasting effects of the program is the change the coaches see in themselves” (Hall 2014). Unlike other stand-alone curriculum often implemented by people who do not practice what they teach, the social commitment of representing a brand and being part of a movement is depicted in the article as helping these chomees towards the type of praxis discussed in Chapter 4, of putting the theory they are teaching into practice in their own lives. As a researcher looking from the outside in, it appears that capacity has been achieved, the 2008 original MCP research findings and the subsequent dialogues continue to “live-on”. The original MCP research team member from the 2008 study, (IR_ORG_06_2) quoted previously, is still very much involved in targeting MCP and is featured in the 2013 Pusha Love kick-off news brief saying, “We informally call ourselves the ‘House of Pusha Love’ because just like a family living under one roof, we couldn’t have done something this big or this ambitious alone…But in the end, it’s the Basotho who join the movement that make it what it is” (Phomane 2013).

While success is easy to convey on donor websites the real work on the ground of building knowledge and changing social norms and behaviors is another story. It is difficult to tell how much of the campaign is molded by Western biomedical imperatives or indigenous leaders. We know it is funded by international donors and some of the indigenous leaders behind the project were professionally raised by the AIDS industry. Pusha Love messages such as ‘Sex is part of the “good life,” just use a condom’ is
a high stakes message. If the message is successful, there is sex without fear and condom usage increases. If the message gets distorted, sex is part of the good life, having a really good life means more sex, one may inadvertently increase the perception of sex and achieving the good life as being one in the same. If condom usage does not match the increase in “the good life” sex, then we are increasing opportunities for transmission. The campaign, on paper, ignores evidence that shows delaying sexual activity reduces risk of transmission as well as overall number of partners, even if not achieved by all, and can still reduce transmission frequency in the general population. This is not an argument about sexual education, (the old if you teach about sex or provide condoms then people will do it), rather a huge national bombardment campaign, well-funded, studied to market an idea of the “good life” associated with no fear sex, condoms, testing and PrEP. Alternative traditional practices such as non-penetrative sex, disciplines taught in initiation schools, serial monogamy, mutual fidelity, partner reduction, abstinence, marital counseling, sexual education are not associated as part of the “good life” as depicted by funding websites associated with the Pusha Love brand.

The problem in Lesotho is an individual and social phenomenon. In the case of MCP in Lesotho there is a real tragedy in the lack of translating research into programming practice. While local newspapers note “official records” of 62 people being infected daily (Matope 2014), we still find that the elements used to produce the culturally specific behavior change discussions and even messages used by the latest campaign Pusha Love, were present since 2009, yet scale up and wider coverage of outreach did not happen. Even after Pusha Love campaign kickoff in 2013, it is not clear how many groups are going through the longer participatory educatory process of action, reflection, observation and action and how many of the billboards, PSA’s, radio shows, events, outreach activities and youth centers “generate demand” for services and technology and do not educate for individual change and social action.

5.7. Prevention Innovation Synthesis and Translation

The previous sections discussed ways in which research and experience moved (or did not) through the organizations tasked with behavior change and prevention. In this section I present the
context of what may be contributing to the overall resistance of disseminating what is known about MCP and HIV transmission in the Lesotho epidemic. I focus on two interacting factors of resistance, funding and the professionalization of HIV prevention. First, I show the ways that MCP is present in policy documents. I then present evidence about funding allocations and how these allocations influence the definition and implementation of prevention programming. I then shift to highlighting how deeply embedded MCP is as a practice rendering it easier to “professionalize” in policy and research but much harder to target for individual and social change.

5.7.1. Macro policy: MCP Presence in Policy

The National Behavior Change Communication Strategy 2008-2013 in the second paragraph of the executive statement states:

The HIV prevalence rate in Lesotho is holding steady at 23.2%. This elevated rate is a result of high risk sexual behaviours including the following: multiple concurrent partnerships; casual sex; intergenerational and transactional sex; the inability of couples to use condoms; lack of mutual monogamy within long term relationships and marriages; and the inability of men and women to share power and speak openly with each other and their children/youth about sex and sexuality.(GoL/MoHSW/NAC 2009: 6)

The National Strategic Plan for HIV and AIDS 2008-2011 and 2011-2016 (NAC 2011), 2009 Lesotho HIV Prevention Response, Modes of Transmission Analysis (Study) (Motlalepula, Tsehlo et al. 2009), Know Your Epidemic exercise, Lesotho Demographic Health Survey (2004 and 2009)(LDHS 2004; Lesotho Ministry of Health and Social Welfare (MOHSW) 2009) all state that the first objective is to reduce the sexual transmission of HIV and identified Multiple and Concurrent Partnerships as a main driver. In fact, in all of these documents multiple and concurrent partnerships is listed first in the sequence of drivers. For example, the 2011 National HIV Prevention for a Multi-Sectoral Response calls for a reinvigorated response to HIV prevention:

First and foremost is the need to focus on the main drivers of Lesotho’s epidemic: multiple and concurrent sexual partnerships. The strategy underscores the need to address the complexities of the motivations, behaviours, and social norms that shape these deeply rooted practices(NAC 2011: 5).
Based on policy documents the drivers, the problems, and the solutions seem extremely well articulated and specific. For example, a product of the national HIV Prevention Symposium held from November 29-30, 2011, at the Manthabiseng Convention Centre in Lesotho, brought together 300 delegates from public and private sectors, including faith leaders, traditional leaders, political leaders, people living with HIV and AIDS, women’s groups, young people, academia, civil Society, people with disabilities, and a generic category of “most at-risk population” signed a statement of commitment.

The Statement of Commitment from the HIV Prevention Symposium of 2011 demonstrates that stakeholders are very much aware of the local epidemic and its nuances. The points they support are specific and targeted. The problem may be more along the lines of prioritization among these points and funding allocation for prevention. Moreover, within the limited funding for prevention, we should look at which types of activities receive more resources.

5.7.2. MCP Prevention Programming

5.7.2.1. Coordination: “I thought you were doing that, no I thought you were doing that”

The 2011 National HIV Prevention Strategy posits that there are “numerous initiatives” in Lesotho addressing the reduction of the sexual transmission of HIV. They discuss the particular attention paid to social behavioral change communication programs including mass media campaigns, life-skills curricula in schools, peer education, and community engagement activities implemented by “a range of CSO’s, NGO’s, PLHIV support groups, faith based networks, and private sector” (NAC 2011). Yet, there is no listing of these initiatives and their specific activities to addressing sexual transmission. In fact, a mapping survey of prevention services is listed as a key activity (NAC 2011: 93) and the prevention concept note roadmap budgets $50,000 for a mapping of HIV prevention interventions and programs at the community and district council level (Team 2011: 7). This reflects that perhaps who was doing what and where was still not a coordinated and well-monitored effort. Civil Society Organizations have also complained that their contributions to addressing HIV and AIDS were not recognized or adequately
documented within reports or other activities. This was both in terms of what they gave in resources and in the support they felt they were not getting from the National Response (MoHSW 2012: 69).

The Prevention Concept Note is transparent about the programmatic challenge of having “limited available resources for periodic strategic information management that informs policy formulation, analysis, and implementation” (Team 2011: 4). This is despite the fact that between 2004 and 2007 the NAC developed a costed National M&E Plan (2006-2011) and established an M&E unit, finalizing the Lesotho Output Monitoring System for HIV and AIDS (LOMSHA in 2009) (MoHSW 2012: 73). However in 2010, “restructuring” of NAC put a halt to implementing the system. In the meantime the Lesotho Council of NGOs, in 2010 supported by a five year $5 USD million to assist stakeholders seemed to fill in the gaps identified with respect to M&E processes. Unfortunately, after the NAC went down in a flurry of accusations of mismanagement and corruption, the LCN tasked with the specific objective of capacity building of NGOs ended up in rumors of mismanaging funds. In both cases no final verdict was given, rumors left as rumors, no money was restituted. The main point being the continual problem of coordination, monitoring, expenditure tracking identified, funding allocated to address the problem, funding misused and the problem left unresolved. Not only unresolved, but with no consequences for misuse, neither the individuals responsible in international funding mechanisms nor the organizations and individuals profiting in the country.

5.7.2.2. Funding: Prevention Resources Dictate Prevention Programming

The Lesotho National Prevention report notes the continued success in resource mobilization in Lesotho, stating that “since 2007 resources for the national HIV and AIDS response have increased by 140% but only 12% of the national budget is allocated for HIV prevention and prevention is in 4th place in terms of funding by thematic area (1. Treatment, care and support, 2. Orphaned and Vulnerable Children, 3. Program Management) (NAC 2011; MoHSW 2012: 74). Figure 13 and 14 demonstrate the relatively lower allocation of funding towards prevention. The 2009/2010 increase in prevention spending is partially attributed to the roll-out of post-exposure prophylaxis in medical facilities for occupational

Figure 14. Bar chart of proportional HIV & AIDS expenditure from all sources by thematic area from 2005 to 2010 from the Lesotho Global AIDS Response Country Progress Report (MoHSW 2012: 76). Reprinted with UNAIDS permission.
safety as well as protocol for victims of sexual assault (NAC 2011: 93). This is an example of the delicate way in which “prevention” is conceptualized as a social and behavioral outreach or as a biomedical intervention, more similar to what the average person may categorize as “treatment”.

The funding increase and allocations represented are only those donated and reported to the national government. Based on the challenges in monitoring, these numbers probably do not reflect the true overall amounts in the country. Nonetheless, this partial picture reveals a clear discrepancy between the prioritization for prevention and the funding for prevention.

In the late 90’s and early 2000’s foreign donors have carried more than half of the total HIV/AIDS national budget. In 2008-2009 this shifted and the government of Lesotho took up more responsibility for the national budget averaging between 50% and 60% of the total HIV budget (MoHSW 2012). It is also not clear if the amount paid by the government is sourced from money generated by in-country taxation or the result of loans and grants to the government that enable the government to invest the 50-60% towards the AIDS response. What is clear, according to the Global AIDS Country Progress Report (GAPR) report is “the GOL invests most is in the provision of ART. Funds from international sources are largely directed towards prevention” (MoHSW 2012: 76). Thus, the government covers treatment and funds from international sources are more heavily concentrating on prevention. Policy documents and funding records demonstrate that the bulk of funding for “prevention” goes towards, testing, PMTCT, condom provision and promotion, male circumcision, and health systems strengthening (MoHSW 2012: 75).

Appendix F: lists a summary of excerpts taken from the Lesotho Global AIDS Country Progress Report documenting 8 significant development partners, the types of activities they were supporting and the financial commitment reported. Of these big funders only Irish Aid, GIZ and Canada specifically indicate non-clinical community-based projects. Only Irish AID mentions the word “sexual”. The other development partners prioritize biomedical projects or the physical construction of health facilities. The UN allocating 25% of its $85 million towards HIV and AIDS priorities particularly for the provision of high quality ARVs. The US Millennium Challenge Account providing $362 million in 2007 for the
construction of a new reference laboratory, blood bank and medical university. PEPFAR providing $29.2 million per year 2010-2015 for testing, counseling, ARVs and TB treatment. And the World Bank providing a second $5 million for a five year technical assistance project to assist NAC and MOHSW in expenditure tracking as well as strengthening compliance to PMTCT protocols at the community level. The Clinton Health Access Initiative (CHAI) is also listed as one of the eight significant development partners, the actual amount of funding is not listed, but it too focuses on HIV treatment, better laboratory systems and increasing operational research capacity in the country (MoHSW 2012: 77).

The GAPR makes a comparison of the 2009/2011 achievements and the ongoing challenges of the Lesotho National Response highlighting the awareness that there is an “inconsistent alignment of interventions with national prevention strategies and operational plans” (MoHSW 2012: 77). It is a fact that a large majority of prevention money is allocated towards technical and clinical solutions while very little is given towards non-technical solutions. This is especially true for HIV knowledge or education building, despite the identified need to target behavior change as it relates to sexual transmission and the social reality of multiple concurrent partnerships.

5.7.2.3. Prevention Programming for Social Change?

While there are fluctuations in prevention intervention funding year by year there is a clear trend on more funding going towards service delivery of condoms, HIV Testing and Counseling, and PMTCT. The 2006/2007 NASA reports only 2% of prevention funding going towards communication for social and behavioral change (NAC/MoHSW/UNAIDS 2009). While officially we can say that more money is going towards “prevention” the definition of “prevention” must be understood as promoting the solution of condoms, HIV testing, ARVs and PMTCT and not critical thinking, problem identification, or solution generation by individuals or social units. Even after money is taken out of the budget officially for condoms, PMTCT, and HTC what is left in the budget is actually heavily related to these solutions. For example line items separated as “mass media” in Lesotho are heavily biased towards PSI, PMTCT, and HCT messaging than to small NGO messaging about sexual behavior change—partner reduction,
intergenerational sex, long distance relationships, communications, satisfaction in relationships, or economic stability (abstinence went out with the Bush Administration). The problem is not only the subject material but also constricted formulations of target audiences and forms of “education”. Education in practice is translated into life skills curriculum in schools, formalized peer education (usually by youth), and mass media messaging. Most of this did not capitalize on what we know works and does not work in these approaches (Randall 2009). Little is based on participatory action research methodology or adult based education (Bulled 2012). For example, only one case was identified in which “mass media” was coordinated with behavior change dialogue and social support construction (not financial support but social). Funding mechanisms continue to require “priority populations” targeted for prevention activities. In the case of Lesotho, a generalized epidemic, where inter-generational sex is a research evidenced based problem, “youth”, “prisoners”, “people with disabilities”, “herd boys”, “sex workers”, “women and girls” are considered priority populations but not men (NAC 2011: 98). Despite high unemployment and a large number of people working in the informal sector, formal workplace programs receive almost seven times as much funding as community mobilization (NAC 2011). Table 4 from the National HIV Prevention Strategy (2011/12-2015/16) demonstrates the financial prevention priorities bringing to light many of the financial discrepancies between what research has identified as a problem, what policy believes should be targeted, and what types of programming interventions will be funded and implemented. Between 2011 and 2015, $112.9 million US dollars were spent for the provision of condoms, that is nearly half of the entire $241 million prevention strategy (NAC 2011: 98).

5.7.2.4. Prevention Programming Top Heavy

Of the funding that makes its way to behavior change communications much of it is spent on research, planning, and administration. Not only is money wasted at this level but years are also lost. For example, for the National BCC strategy, first national and international stakeholders commissioned several studies to inform the strategy, then it was written, then it had to be approved and disseminated to

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<td>10.14</td>
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all stakeholders before beginning implementation activities. At the research and policy levels outside consultants and technical advisors wrote-up tools, reports, concept notes, and even National Strategies. Multiple advisory boards, committees, and leaders are listed on budget line items making it unclear if they are being financially reimbursed for their specific involvement or if the funding is allocated to them to implement a specific task. For example, appendix G taken from the draft roadmap for the implementation
of the 2011 Revitalized and Energized HIV Prevention concept note details the activities of various committees and exemplifies well this ambiguity (Team 2011).

To ensure “effective implementation” of the Revitalized Prevention plan seven different individuals/committees are listed, TWGs, Committee of PSs, Senate and Parliamentary committee on HIV and AIDS, High Level steering committee, Cabinet Committee on HIV and AIDS, the Minister of Health & Social Welfare, the PM, and His Majesty. Particularly noteworthy is the line items of $25,000 for identifying and empowering champions and the $200,000 budget to the Prime Minister for the “launch of the revolution” (Team 2011). Are these champions and the Prime Minister budgeted this amount of money for their “leadership presence” or to implement specific activities that have specific expenses? Also striking, is the asterisks highlighting social/community mobilization activities happening concurrently to the listed activities, yet, there is no mention of the “responsible” parties or the funding, perhaps another reflection of the rhetoric of commitment for this type of practice without the will or financial support for implementation.

In this chapter I presented the context of what may be contributing to the overall resistance of disseminating what is known about MCP and HIV transmission in the Lesotho epidemic. First, I have shown the ways that MCP is present and highly prioritized in policy documents. I then presented evidence about how funding allocations influence the definition and implementation of prevention programming. In Lesotho there seems to have been a large investment in research about the MCP phenomenon and how to talk about it and create tools, but when it came to programming, implementation at the community level was hampered by relatively little funding support. This is in comparison to the funding allocated for initial MCP research and toolkit creation (pamphlets, billboards, radio clips, film series, dialogue guide) as well as in comparison to biomedical and technical solutions. Furthermore, funding for MCP prevention and community level work was sporadic and lacked full country coverage. In contrast biomedical interventions have been sustained, with high foreign funding especially that of the U.S., regardless of macro policy shifts, political instability or a local climate that tends to professionalize the HIV response. The below timeline overlays the key events for national MCP research, interventions,
policy issues, funding dynamics and biomedical innovations. The timeline features predominantly initiatives supported heavily by U.S. sourced investments. I do not claim the timeline to be comprehensive of all events but rather a snapshot of the dynamics between the macro-policy, funding and general climate influencing the translation of MCP knowledge into prevention programming. See appendix J for expanded descriptions of items 1-53 in figure 15.

5.7.3. Resistance to Change

2011 interviews for this study confirmed the difficulties of ownership and credibility provoked by the financing and management of the HIV Response in Lesotho by outsiders. According to several respondents, the division between the MoHSW and the NAC had its roots in the attention and funding given to NAC from outside the country. Credibility from NAC was undermined by years “where everything was done by UNAIDS and everyone knew it. Unfortunately when reports were submitted to Ministers, Parliament, or the Senate, they were seen as something done by “those” people and there was no ownership” (X_ORG_02_2). HIV and AIDS response seemed to be described as something not quite transmitted as everyone’s problem, especially across ministries and with the local government structures:

ORG_08_2: the question that the minister or the PS says, "no take this thing to health" AIDS is health, take it to ministry of health, take it to NAC. They don't understand their role…if World Bank came and said I will fund you to build the road, they will say come give money, we'll do it. They're going to build, come bring the money. Infrastructure they'll do it. The roads they will do it I promise you. But not HIV and AIDS.

Dealing with MCP as a core contributor is not at the interest of outside experts who specialize and profit from technical and clinical solutions. However, while outside funders largely dominate prevention programming prioritization and funding the lack of ground level individual and social change initiatives cannot be completely blamed on outsiders. The translation of MCP prevention knowledge into practice is also hindered by how deeply entrenched the practice of MCP is within the indigenous leaders and health professionals who would be expected to lead the movement dealing with MCP and its contributing factors fueling the epidemic.
Figure 15: Timeline of MCP research, policy, programming, funding dynamics and biomedical technological innovations in Lesotho
The following excerpt is from an interview with an expatriate working within the MoHSW who reviewed the current study proposal, which at the time focused only on the NAC MCP project, and was trying to anticipate some of the challenges and provide suggestions to improve the study:

\[\text{X\_ORG\_07\_2: … What I want to know for the country or as a professional is what is the current concept of the community on Multiple Concurrent Sexual Partners. …The professionals and the staff and community have a certain knowledge of this problem, MCP and that now, first of all, we would explore the questions how much they know, about MCP.}\]

\[\text{Interviewer: who?}\]
\[\text{X\_ORG\_07\_2: The health staff and the community and then when we know their level of knowledge and attitude and also practice we would like to explore from where do they get this information. …before you interview me I would like to ask you another question, if somebody or myself actually asked what is the current situation of MCP in Lesotho what would be your answer? How would you answer your question?...What about the accepted data, the prevalence, what is the accepted?...Based on what?...2009 DHS? We should think about that also, rates that are done scientifically in the community…From where do they get the information that MCP is a risk factor…or an important risk factor for HIV?}\]

Later in the interview, he looked at me quite seriously and said:

\[\text{X\_ORG\_07\_2: I would like to tell you something, this is my personal that I get from my friends. Even the health staff here, and some are elsewhere in the country. They say that for the Multiple Sexual Partners we can't avoid. It means that they participate in MCP even though they are the health staff…yes, yes…}\]

\[\text{Interviewer: so what do you do with that?}\]
\[\text{X\_ORG\_07\_2: Yes,… yes… so how can we manage? It’s very difficult.}\]

Initially this was a puzzling conversation, was the individual doubting the scientific basis of concurrency or sexual networks as a driver? In reading, over and over this transcript I realized that his questions, his suggestions, his guidance may have been to fulfill a gap in research that he on the ground in the middle of the Ministry of Health could see as pertinent and needed. What I believe he was trying to tell me was to study up, study the decision-makers, study different sectors of the population to find out what they think, know about, and practice in regards to MCP. At the root of why there has not been more done programmatically about MCP is not just the diffusion of research on the topic but also the ideology surrounding what people “believe” about the science of concurrency and the transmission of HIV as well.
as, perhaps, their own current practices. From his perspective, he already knew the “resistance”. Another expatriate working in HIV prevention in Lesotho highlights this type of resistance:

X_ORG_07_4: I mean come on that technology [male circumcision] has been around for a while...But you know the DG [Director General MoHSW] will say this will happen at the pace that we want it to happen. We can argue about it, we can bang our heads against a wall or we can try to work with it to grease the skids and try to make it go a little faster or at least to be behind enough so that...you know as decisions are made resources are available and some mechanisms are in place to carry the load. The argument can be made a different way that with every day that goes by someone else needlessly dies...The former head of the Directorate of Disease Control, got up at the DHS Dissemination Meeting and said there is no scientific proof that male circumcision reduces a Masotho's chances of contracting HIV, no scientific evidence to say that it has a negative impact (non circumcision). The room was like...what do you say to that?

Interviewer: so what happened?

X_ORG_07_4: No male circumcision happened, all tell you that...you know you can present the bodies of evidence in the operational plans but until the political will is there to make it move...you know all the data in the world has never moved Lesotho before and it’s not going to now. So working to enable, engender support that kind of leadership in a... positive deviant way when you find that leader to make sure that there's voice and platform to them...yeah the political will here is everything this is one of my first observations here. (referring to when he first arrived in Lesotho) you walk in and everything is new and your reading, your listening and trying to connect the dots, and one day it dawned on me that...listen risky sex is short-term thinking, you know what the possible consequences are even if it isn't an era of HIV whether it was STD's or anything... but that it’s not in your frame of decision making right, and the political system here is incredibly short term oriented. And so I started to see, ok well, if I don't want to piss off the traditional leaders or healers as a core constituency I'm not going to come out for male circumcision, I'm not gonna come out against MCP you know...why would I? It’s no skin off my back and so...all the science in the world will not equal an ounce of political will you need to have a critical mass of political will to make the science stick. Full stop. And there hasn't been that political will...that is an indictment. It's this big, we're only that big [said in a whisper] I know you, and I know your sister and I know your mom, and I know who your mom is with and who your dad was with and who your dad was with and it’s just where is the political will? I mean it’s too... everyone knows everybody.

Interviewer: so in order to call anything out...or to make any difference

X_ORG_07_4: you better have lived a pretty transparent life… in a fish bowl and I don't think...even beyond that... I don't know if anybody would call you out I don't think it’s a mutually assured destruction disincentive. I see it as just... it’s not in my frame. That's over there...I'd have to look beyond this chair to see that wall.

From this discussion, we see that resistance to getting MCP research into everyday practice and interventions is not limited to financial or outsider dictated priorities, but also includes an indigenous ideological resistance to dealing with a culturally embedded problem. A problem so entrenched within the social system that speaking out would mean facing your own explicit or implicit role in maintaining a common, but in the context of HIV, non-adaptive behavior. I end this chapter with a long dialogue.
between myself and an indigenous educated professional giving his perspective on the challenges of translating MCP knowledge beyond the research and professional realm and into the personal world of individual and social change. I leave the dialogue in its entirety in attempt to follow Restrepo and Escobar’s call for a new anthropology inclusive of indigenous theory and sub-altern voices.

ORG_04_3: … So I always, personally explain it as people having our own fears. Our own nightmares where you'll find that there are some certain you know practices that we partake in, or even if you don't, but we know that it’s sort of a known to the extent that even if you don't partake in such you know activities yourself but you know that ok, my wife (pounding his hand on the table) could be partaking in this kind of activity, my brother (pounding his hand on the table) could be doing so, my.... you know a whole network of people that you know may be engaging in some certain activities that are taken to be a known even if it is not you in particular.

Interviewer: and what certain activities are you referring to?

ORG_04_3: the fact for example in our culture its, its....well...it’s my observation...I think culturally multiple sexual partnerships it’s really not SEEN as…uhmm…how shall I put it...because Sharon if you talk about something to do with behavior, people will tend to say this is good and this is bad behavior

Here the indigenous participant is reinforcing what was said by the expatriate organizational representatives, that the behavior of MCP is so tightly embedded in the social fabric that people cannot socially afford to place a judgment of MCP because it will fall upon people they would never want to condemn:

ORG_04_3: eh yeah we put it that way that sort of judgment but at the same time I can have you know, an eating behavior, you’re not having any meat right now and I'm not judging, you see. So I think with sexual activities it’s…once it’s behavioral it’s in the positive form. In fact, I'm not even going to say positive because we can have different definitions of those two. But it’s bad or good it has a judgmental element on it so you find that I always believe that people maybe, you know averse of discussing things to do with HIV and AIDS for the reason that if I acknowledge this thing then I have to acknowledge that you know so many people around my own network are you know the walking dead if you like, you know. And I am going to have to also acknowledge that I'm a bad person because this is bad behavior. You know.

In order to make his point clearer, about the avoidance of acknowledging “the walking dead” or that “I’m a bad person” he provides an extreme example of MCP and his own cognitive dissonance:

I'll give you an example that I think can capture what I am trying to capture very easily. Now I was telling my friend that I read from this newspaper that in Mafeteng a soldier fellow was shot by another guy at the residence of a Catholic nun during…it’s quite recent, about maybe two weeks ago.

Interviewer: oh I saw it in the paper.
Figure 16: Newspaper clip from (StaffReporter 2012: 2) of a story referenced by a participant trying to explain the ways in which the reality of MCP is simultaneously acknowledged and denied. Copyright 2012 by Lesotho Times reprinted with permission.

ORG_04_3: yeah, I was saying to the guy who was telling me this I...it was so incredulous for me that this was a sexually related death because apparently the fellow who was with the nun on that night got a knock on his door and unfortunately it happened to be this soldier fellow, who also happens to be another sexual friend of the same nun and this guy got jealous. I think in fact the guy who was the first to be with the nun was probably I think we are told he's a policeman or something and this guy they had some kind of an argument and he shot dead the soldier. So when this guy who was relating all this story to me was doing so I was so incredulous, Sharon, it...I just didn't get it so this guy was saying "come on man don't act so naive you cannot mean to tell me that you don't expect a nun to be sexually active?" So I said to this guy "man you know you are right" but that is probably because I grew up amongst nuns you know, from standard one up to...for the rest of my primary years and education and so forth I was in these convent schools and so forth. High school same thing until I went to Varsity, so from such a young age it’s never something I decided upon it, for myself, but from such an earlier age, a very early age I saw when I see a nun I see someone absolutely incapable despite the fact that these stories we see them all the time but STILL there is that thing inside me that will just not take it at all. That will DENY the same reality that I can see it happens whether I like it or not.

The reference to the story in Figure 16 newspaper clip from (StaffReporter 2012: 2) epitomizes for the participant what he sees as the reality of MCP being simultaneously acknowledged and denied.
The participant explains, “I see a nun I see someone absolutely incapable despite the fact that these stories we see them all the time but STILL there is that thing inside me that will just not take it at all. That will DENY the same reality that I can see it happens whether I like it or not”. He goes on to link this type of denial with attempts to change individual and social behaviors:

I think people do not want to take it upon themselves that I REALLY must see and make sure that I do something about my behavior because NO NO I don't want to forego that behavior I want to keep on doing what I'm doing I like it, it’s a norm, there's nothing wrong with it but at the same time I cannot afford to ALWAYS be worrying about "my goodness I wish I'm still alive after I've done that" so you divorce them.

He goes on to describe further the cultural mechanism of divorcing the sexual behavior of MCP with the transmission of HIV. He draws on a television commercial that compares a man and a woman’s brain to make the comparison of what he believes people in Lesotho do to keep themselves from facing their own fears:

One year back I don't know if you have seen one advert, television advert where it says, "the gift" it’s about some insurance for women so they make a difference between the mind of man and the mind of a woman now this guy says, "a man's brain is made up of little boxes and there is a box for everything and the trick is that you know, these boxes don't touch" if we discuss money we take out that box that contains money and we discuss only what is in that box and then we put it away, make him very certain that it doesn't touch ANY other box you see. So I think we compartmentalize it just in the same manner. That you can think about behavior whether it’s good in this way and then you pack the box for behavior away and now you can come and look at HIV and AIDS or the fact that someone is sick and decide that must not be AIDS....it goes in this box and so forth. And when you compare the man's brain with a woman's brain in that same regard, this guy says that on the contrary a woman’s brain is made of a ball of wire and everything is connected to everything so I think we have had, culturally, I am not even saying women this side men this side I think culturally as a people, as a whole we have that thing of you know where we have our fears, where we have our fears where we can put those fears in a box pack them somewhere away and you know go on making out as if nothing is wrong. I think that is the tendency most of the time.

Thus the sick, the dying, MCP as good or bad are all compartmentalized, thereby blocking people from facing the reality of the interconnections between the social and individual experience of HIV. He goes on to explain how in the rare cases in which the box of HIV is brought out it is usually in a nonspontaneous, professional and academic context:
Most of the time even when we bring ourselves to even discuss some of these things, you will find that our discussions are not you know spontaneous conversations you find that oh these are really on an academic level rather than...THIS IS LIFE this is to do with... it’s like that ball so that everything links to another … I always have this feeling that ‘no, no, no we sort of are academic about it rather than down to earth, you know, intimate and that sort of thing

Interviewer: but here you are making a cultural comparison of the discussion

ORG_04_3: yes, exactly, whereas you would expect everything to be in a ball where everything is connected so that you know ok, its connected to food because I won't be able to put food on the table if I'm sick or if I'm not around

Interviewer: Or maybe I have these relationships to have food on the table but it’s not talked about

ORG_04_3: yeah you know it’s not talked about so whereas you think that the most beneficial approach would be culturally to take this thing like a ball that is connected to...rather than taking it as different compartments where you can file this thing away...even the consequences of eh some cultural practices themselves where you find that our culture really does sanction you know, multiple so you don't want to acknowledge, you don’t want to say why will our culture (not) acknowledge, discourage because if it’s about that than you realize that everything is linked to one another so you are going to have to have a rude awakening as they say to be sure that our culture is wrong because it, it perpetuates this scourge you don't want to go there…You know what, this is why I'm saying we keep it on a, on an academic level really. Where you'll find that there are people that I can discuss some of this with like it’s okay with me to discuss some of these things. But, look it’s, it’s this is not a spontaneous conversation that we are having you know it’s on another level all together. So you find that you know there are people that for example, I can talk to my brother, I can talk to my sister but remember these are people just like myself who have had good education, so to speak,

Interviewer: and do they talk about it?

ORG_04_3: they do talk about it, but, honestly I never really feel that we discuss it on that level you know. It’s just that there are some certain realities because of maybe our educational background not only myself and my family but all those who have had chances to have some formal education. Some things and some certain fora that you may find we may feel comfortable discussing quite a number of issues to do with HIV/AIDS but I still don't think we, we, we as individuals.....

Interviewer: go there.

ORG_04_3: No we don't.

Interviewer: so what does that make you feel like?

ORG_04_3: (pause) it’s frustrating it’s frightening but honestly I will say at least for myself that you just, you know like, we have had this discussion this afternoon it is still, it is fresh on my mind then I will be thinking about it but let me assure you its Friday for example. I get home I will be with my friends and we share a beer or two. And we will listen to some music and it will be totally packed away, like the box kind of, you know. To be unpacked another day.

Despite thirty years of HIV prevention messaging, HIV and MCP especially in Lesotho, are left for “professional” or academic discourse. The “rude awakening” that your culture is “wrong”, as the above participant describes, has not happened for most people. The next chapter outlines further how people in 2012 talk about HIV and MCP. Creating the context for Chapters 6-9 that demonstrate how the qualitative
research experience served as an awakening and changed research assistants discourse out of the professional and into the personal.
CHAPTER 6. THE CLIMATE: LESOTHO 2012 MIDDLE CLASS TALK ABOUT HIV AND MCP

![Figure 17: ISF framework applied to describing the context specific climate in which the diffusion of the MCP innovation is translated. Copyright 2008 by Springer adapted from (Wandersman et al. 2008) with permission.](image)

The goal of this chapter is to describe the overall climate in which the MCP research innovation was to make its way into “prevention delivery,” This is done by presenting a quick glimpse into how the middle class research population, all employed men and women between the ages of 26 and 45, discusses the way in which people in Lesotho talked about HIV and MCP in 2012. The chapter presents data across all participant categories of interviews I conducted in 2012 with former team members, the comparison group of researchers (the four individuals similar in age, education and HIV prevention work background but did not implement qualitative research) as well as from organizational representatives. I assigned pseudonyms to all participants. Here we draw on emerging themes from responses to standard questions on my interview guide and present responses to the question, “if someone that we knew had passed away and their funeral is coming on Saturday would we be able to talk about what they died of?” References
that were not directly asked or probed but where the participant mentioned how the topic of conversation came up because of a funeral or death are also illustrated. Finally, the chapter includes responses to the question I asked about, “The average person who didn't take part in this kind of experience, what do you think is their level of knowledge? What do they know about MCP and HIV?” The objective of this line of questions in the interview guide was to further our understanding of how people perceive of and talk about their local epidemic. This understanding sets the context for understanding the effect of their research experience. It also allows us to take the pulse on dynamic social and ideological aspects of the local epidemic that would not be captured on a standardized closed-ended survey.

6.1. Just How Close

The reality of living amidst a generalized epidemic is very evident in the study population highlighted in this research. While there were no direct questions about participants’ personal or family member’s HIV status, over half of respondents in conversation relayed just how close HIV is, by telling a personal story or giving an example of their own feelings about the high prevalence. Several participants told stories about cousins, aunts, and uncles who had died. During the demographic section of the interview one participant emphasized that she had “two live parents” as if it were a true rarity. One participant’s ninety-two year old grandmother had buried six out of nine of her children due to AIDS related deaths. Another participant describes how, “my mom calls me and tells me that people are passing away at home… I mean it’s one of those issues that you cannot, you can't ignore I mean it’s affecting everyone” (Lebona). Another participant highlights how in their partnership, discussions about HIV span from professional aspects of working to educate other people about HIV and AIDS as well as personal, “part of talking about the work that we are doing we do still talk about HIV and AIDS…because it keeps affecting people around you. People you know, people you live with in the village” (Khabane).

Thirty years into the epidemic in Lesotho, one of the highest prevalence countries in the world, where HIV is not contained to any one “high-risk” population such as injection drug users, sex workers, or truck drivers but cuts across all sectors of the population, one might expect that public discourse about
sex and HIV may have shifted towards more open dialogue between parents and children, within couples, in churches, and in traditional institutions. Instead, according to participants, discourse on sex and HIV is still predominantly couched in metaphors, euphemisms, indifference, and misunderstanding.

Across all participant groups—original research team members, comparison group, and organizational representatives—participants noted that talking about sex and HIV is awkward, uncomfortable, a discourse that is not “Basotho” or “African” to discuss. One participant explained with emphasis, “Look, look Sharon this one was one of the most sensitive topics that we are dealing with. In Lesotho, as with many African cultures, sex is not an issue that people are open to talking about” (Tsebo).

According to participants, the “not talking” cuts across education and socio-economic categories:

Like I said, here in Lesotho we don't talk about those things, we just don’t. Even if you come from, I think my family is much more, more modern but still you can't, you don't get to talk to your, your elders about sex, you don't get to talk about sex at all. It’s something that you see in the movies. You see, you experience on your own. I did a lot of interviews and group discussions with teenage girls and some of the things that they had to say about relationships and sex...I was just like are you serious?!.....this is outrageous, that this is what people think. I mean with access to like seemingly all this information that I just assumed everyone else had, this is CRAZY. (Lebohang)

Participant comments reflect their feelings of being saturated in certain types of messages. Discourse on HIV has the tendency towards stressing transmission through the innocence or the ignorance of people rather than through active blamable modes of transmission. There is knowledge but there is also a simultaneous process of blocking out what people do not want to hear, or sick of hearing, or aspects people don’t feel like acting upon, perhaps a form of cognitive dissonance. Participant comments about the general population convey a ‘flip the coin’ knowledge about HIV. Where the side with aspects of HIV knowledge that fits into their paradigm is heads up and flipped down is the coin side with aspects that do not fit into their paradigm or would make them feel guilty: or culpable.

Tebello: I remember when I was in a taxi going to Roma one time in 08. So there were these new bumps that have been built in the road. So I think the driver had not noticed there was hump there so he kind of garuehoeu (imitating the sound of a car scraping the bump) and this guy got cut on the head. Ok the one who was sitting two seats next to me. So the lady who was between me and this guy said "uhuh your blood is contaminated" You know what I mean? That's how bad HIV is. (the voice she uses to imitate the woman is an angry female voice with an attitude) Listen! She had her hand on his shoulder like "uhuh" "brother no, ok, your blood is sick" that’s what she said.
Interviewer: But why are people like that with the blood but not with ...semen?
Tebello: Exactly. Semen is sick! Because sex to us we do it but we don't talk about it. We have a culture of silence towards sex, this is why we'll die...people will not, will not touch, will not you know they will want to wear gloves when they touch your hands after an accident. But nobody is going to wear a condom to sleep with you. Well they would but after six months, “I mean I know you, you know me, I love you”

6.2. Ignorance and Poverty

The association of HIV with the ignorant, rural, or poor is another type of discourse that fits nicely into the middle class paradigm because it simultaneously justifies and distances the culpability for HIV in the population. The levels of poverty, vulnerability, and lack of resources in rural Lesotho are an undeniable fact. The link between poverty in rural areas and the promulgation of HIV is also often assumed as fact. The following examples from educated employed people from the middle and upper middle class reflect this assumption. As they discussed and tried to explain what the average person knew about HIV or how they would explain the high prevalence of HIV emphasis often turned towards the root cause of poverty. The intention here is not to relay “new information” but to convey how these individuals think and talk about HIV.

The first example highlights the connection between poverty and the lack of infrastructure in the highlands as retarding the level of knowledge and awareness of HIV issues:

You know what Sharon, it (between the rural and urban population) differs, I mean, you and I know that Lesotho has mountains, it has the highlands and lowlands and mostly in the highlands... they do not have access to educational facilities including radio stations, some of them are not going to school, they are looking after their parents’ cattle at home …who might have some information about HIV but they might not have the resource person or resource center where they can go and ask difficult questions about HIV with anticipation that they will get a response to their questions. (Lebona)

Another participant describes the content of one of his last conversations about HIV, he draws attention to orphaned children and poverty:

I was with this lady who had an orphanage home. [S]he told me that most of the kids there lost their parents through HIV and AIDS, so it was kind of sad. I mean guys dying at my age, you know, you’re living, I can't bear the thought of leaving my son. It would be too painful for me, and those kinds of things. We actually went down to the point, that, you know in Lesotho again HIV and AIDS goes hand and hand with poverty as well. Because some of the people who get infected with it is because of...well they get involved like, sexually with people because of
money. Mostly girls, you know the vulnerability because of poverty those were the kind of things that we were talking about. (Paseka)

The next participant mixes ideas about the inequality in society both economically and in knowledge with the onus of HIV falling on the rural population:

Lesotho is such an unequal society there are those people who have light and there are people who are completely in the DARK. Just like high, middle, and low income people. We have people who don't know anything, people who know something, but they are still wrong in their knowledge, and some who know. This discrepancy between those who know a little and those who know nothing is the thing that is killing us the most. People in rural areas do not use condoms, Sharon. Do you understand me? THEY DO NOT….They don't use condoms. How are we hoping to end HIV if the people who are having sex, half, almost half of the population… stays in rural areas.

These examples demonstrate the strong perception that some of the main contributing factors for high rates of HIV are ignorance, poverty, and/or “rural” thinking. Yet, statistics from the onset of tracking the epidemic in 1988 to the present consistently show rural populations with lower HIV prevalence than urban ones, as reported in the National Modes of Transmission study conducted in 2009 (See Figure 18). Thus, how people talk about and perceive the problem does not necessarily match with the science tracking and monitoring the epidemic in Lesotho.

6.3. Rich Kids and “Modern” People

The perception of the root cause of poverty also co-exists with the idea that HIV is a disease for rich kids and “modern” people. One respondent described the people from her village saying, “yet people are still, they still have that mind that HIV is from… is for rich, for modern people so they don’t take initiative they just don’t, they think it’s a lie something like that” (Neo). Another participant juxtaposes his connection of kids with money, alcohol use, modernity and the loss of traditional morals:

…you'll be surprised these are the kids with money and they will be drinking the whole night. Then from there you'll find them having sex with almost everybody they meet for the first time. I'll like to call it, I don't know, but uhm I think it’s also the influence of alcohol … It’s so coming to a point of people with high standards of living, people with money they still have the problem of HIV and AIDS. I would still get back to what I told you about that lady, [name of researcher omitted] talking to the traditional healers. What they said to us was, it seems like we have lost our moral[s]…we no longer respect certain things in our culture, for example, if I'm not married I'm
not allowed to have sex until...and it’s no longer the case. And that's what they were arguing. So … it’s so simple having sex these days. You don't even have to wait for the right moment, 'cause I know of girls who are sleeping around by the age of thirteen, fourteen with grown-ups. It’s sad, so, I think our morality, our principles affected as well. Like those traditional healers were actually saying. (Paseka)

As anthropologists (Green and Herling Ruark 2011) have argued, there are aspects of “traditional” practices that people working in HIV prevention should re-emphasize. According to participants, cultural norms, sexual education, and discipline taught in initiation schools and stressed by traditional healers lead to HIV protective behaviors.

6.4. Rape and Passive Victims of HIV

Discussions with research participants also included the theme of the perception of rape and HIV. This discussion evoked anger, sympathy, and a sense of injustice that seemed to motivate
participants to want to do more to build awareness and empower individuals. When participants recalled stories of rape, their tone of voice and emotions came to surface. The topic seemed to trigger a response to protect those who cannot protect themselves. The concept of rape may represent their own fears of impotence against contracting HIV and facing the reality of how many of their friends and family members were raped and could potentially be raped. The following excerpt from a female researcher, mother who has an employed nanny watching her child, describes a recent case she saw on the news in 2012:

The mother comes home from work one day and the baby is just crying and crying, and crying. When she tries to hold him he just cries more. It hurts mommy, it hurts, it hurts. Where does it hurt. He points to stomach. The woman looks at the stomach, the stomach is bloated and blue because it's full of urine. Like he has not been urinating two to three days now. She takes the baby to the hospital. He's about six seven years she takes the boy to the hospital, when he gets to the hospital they put a catheter in and this child just cries for hours. The peepee was so shot with the infection, like he couldn't pass the water. So as the nurses call the police, right, and the police come and they ask the mother what happened, this is a sexual transmitted disease, like what's going on? And then after investigations they find that the nanny is the one who has been raping this boy. And the boy is HIV positive now. Do you understand Sharon? Do you understand what's going on? This boy is HIV positive. You gave birth to a negative baby and some bitch comes to your house and infects your baby. And they give this girl twenty years, who's positive and the girl is dead now. Do you understand? The girl died in prison. Your son is alive he's positive (Tebello)

The same participant also pointed out the recent changes in society of people beginning to talk about rape and incest as a reality in their own country:

We've been hearing of these cases of pedophiles in America, you know, but what happened was because our society was so closed, cases of incest, of family rape, of things like that were not very common. But today, people talk about it and then realize exactly how common it is. Uncles raping their nieces that kind of a thing. Fathers who rape their own daughters. (Tebello)

Participants were asked to recall an experience that stuck out or seemed to haunt them the most from the original 2008 MCP research experience (192 In-depth Individual Interviews (IDI’s) and 30 Focus Group Discussions (FGD’s)), one researcher explained:

What I found really strange is that there were a lot of people who had been raped as sort of like their first sexual encounters but in their minds it never occurred...it's like it didn't register in their minds that they had been raped. Which I found really strange. Yeah and I kind of had to keep like, a blank expression on my face which was probably readable anyway, I was just like do you realize what's just happened and your telling me so casually. (Lebohang)
Rape is often described as a universal crime. Incest avoidance with certain categories of kin is a near universal (Brown 1991). What about the concealment of rape and molestation within families as another type of near universal? In many cases inter family rape and molestation provoke public admonition and shame on the victim and the family. In the context of Lesotho, rape in general and that by family members may have been/be grossly underestimated. There are currently new laws and legislation on the issue. However, historically, the concept of rape was not an explicit offense listed, instead reporting “seduction” or “kidnapping” was part of legislation and could result in seeking damages from the offender and his family (Duncan 2006 reprint of 1960). Unlike modern or western discourse on rape, sex was not always assumed to be part of or the focal point for the legal conception of kidnapping or seduction, but in cases of pregnancy a fine would have to be paid. There was a slight ambiguity in some cases of “seduction” and “kidnapping” as a way of a couple or man trying to demonstrate his desire and commitment to “marry” and be with that woman. For example, after two “abductions” by the same party, if a court is satisfied that a young couple wish to marry, it may order the parents to arrange a marriage, or in one case they ordered a wedding to protect a girl from a father who wished to receive compensation from repeated abduction (Duncan 2006 reprint of 1960: 109). Culturally, the historical context and consequence of rape are extremely different from Western conceptualizations. The social consequences of the act were often publicly, familiarly repaid, and in some cases were the initiation of a “love story” for some couples. However, if rape happened within the family, seeking justice is complicated by the potential to sever kinship ties, which include certain obligations and safety nets; in fact “fining” an individual’s own family members IS fining themselves. As one of the participants stated:

You know when it’s a family thing and nobody to come in between to say this one is wrong or this one is right. But it was very bad because the man was already married then, yeah. But as I said my aunt was left here alone by her parents and they were staying in South Africa and she was the only one left there. So I think the guy [her uncle] took advantage of something. You know my aunt was vulnerable, a twenty-one year old woman staying by herself and....no money, nothing. You know the vulnerability of women, you know how, how a few grown men with money can do (Paseka)
This example brings to the forefront the structural issues of lack of employment in Lesotho, immigration, and South African legislation that prohibited families from staying together. It is common to hear about HIV, multiple partnerships, and sexual networks in terms of the relationships a person chooses to be in to satisfy material, emotional, and physical needs. What is less common is considering the compounding factor of a high frequency of rape within a small network. The “normalcy” of rape in early sexual encounters may be more of a vector than suspected. The likelihood of negotiating condom use in these cases is obviously lower, and there is seemingly nothing the victim could have done to avoid contracting HIV. As the previous examples discussed, another dimension of unlawful sexual activity coming more recently to the public fore in Lesotho, are cases of incest and pedophilia. The overall coming to terms with the topic of rape and its various typologies within the unique Basotho cultural fabric may open the possibility for discussing interconnected social issues perpetuating rape and inadvertently HIV. As mentioned previously, participant discussions on the theme of rape and HIV evoked emotions that seemed to motivate participants to want to do more to build awareness and empower individuals.

6.5. What about Multiple Concurrent Partnerships?

Now we need to shift modes to the opposite end of the spectrum. Unlike all other modes of transmission, sexual transmission by having multiple concurrent partnerships is unavoidably, socially, uncomfortable. Sexual transmission of HIV from choosing more than one partner or being with someone suspected to have more than one partner themselves, or even choosing, negotiating, and wanting to use condoms puts the blame for transmission on the actor. It embodies an individual pleasure, as well as a social norm in Lesotho where the practice of having multiple concurrent partners is acknowledged to be a higher risk HIV transmission activity, but accepted as something that will continue. It brings transmission of the disease to the fault of an individual. Former research team members point out how the 2008 original MCP study made them realize just how pervasive MCP was as a social norm:

But then the study, the experience has taught us that in most of Lesotho that men like going here and there, and there, and there. And if you ask them things like in the discussion groups you find
that they (women participants in focus group discussions) have accepted that the men are cheating and are not doing anything about it. (Neo)

I think I saw the reality of how Basotho, not all of them, how Basotho perceive sex that they can engage into sexual relationships with many people and still feel ok and keep it as a secret. (Mosa)

I argue here that we do not need to further document MCP practice, but change our focus to understand what this knowledge means to people. There are undoubtedly certain types of knowledge about HIV that are important but difficult to measure. The UNAIDS general population survey, DHS AIDS module, FHI BSS, UNICEF MICS, USAID, and WHO all measure comprehensive correct knowledge about AIDS by the percent of participants who correctly identify the two major ways of preventing the sexual transmission of HIV (using condoms and limiting sex to one faithful, uninfected partner), those who reject the two most common local misconceptions about HIV transmission, and those who know that a healthy-looking person can have HIV (DHS 2015). Is this really the type of comprehensive knowledge that moves a person towards changing risk behaviors?

Several participants discussed their early knowledge formation about HIV. In the 1990s, a communication campaign in Lesotho translated the research of the cultural practice of “sharing blankets” at funerals, or the practice of having sex or sharing your blanket with an additional partner, into a child friendly subtle way of saying don’t have sex. Unfortunately, for many people the message “do not share blankets or you will get HIV” in its translation into regular understanding and use, left some people afraid to literally share blankets, as if HIV was transmitted like smallpox. The participants explained that, without a clear understanding, as a young person, one could do their own research and see that, hey I share blankets and nothing happens—those people must have lied. Thus, the message “Do not share blankets or you will get HIV” became discredited. However, the underlying concept of the risk in sexual practices of additional partners is still valid, even if the simplification of the message has rendered this knowledge useless. Without education or attempts for dialogue, this useless, tight, message, actually becomes another factor of desensitization. Thus, sharing blankets does not give me HIV.
Now that we see how the information that having more than one partner at the same time increases risk for contracting HIV becomes diffused, how this information actually gets translated into practice and in ordinary ideas about HIV is not as straightforward. A person may be able to say, “Yes, I know that MCP means you are more likely to get HIV, having more than one partner.” Yet, if a person knows this without exactly understanding the mechanism of the risk, then this message of risk, like the previous, has the potential to discredit the message and messenger, leading to further desensitization. Another example is if you take two people, person A and B, who “know” that having more than one partner at the same time increases their risk for HIV, person A interprets this ‘knowledge’ as a cumulative risk—the more partners I have creates HIV. Person B, on the other hand, knows that the risk lies not in a cumulative effect, but in regards to exposure to the virus in peak transmission periods within a web of sexual relationships. Putting together the normalcy of polygamy in Lesotho and the normalcy of having more than one long-term partner preceding the advent of HIV, when people were healthy, the argument for Person A, that simply having multiple partners causes HIV, is naturally discredited. If the argument does not make sense; if one sees no proof of this in their reality, then the information they have been given does not motivate critical thought about the risks. Polygamy is, after all, a type of multiple concurrent partnership, and if none of the partners has been exposed to HIV, it is technically a “risk free” partnership as well. The correct (DHS 2015) comprehensive knowledge answer of “limiting sexual relationships to one faithful partner” does not apply.

This following section presents examples of how the study population discusses and perceives what the “average person” knows or how they talk about multiple concurrent partnerships. The definition of “average person” was left to the interpretation of participants, but, where needed a clarification was provided in the form of, thinking about a person similar to them who had not had the opportunity, like they did, to learn what multiple concurrent partnership is and how local practices increase HIV risk. Participant responses reflected variation in how people received the messaging on MCP. One participant, working in a Ministry of the Government, that has nothing to do with HIV, directly said of his colleagues:
Moeletsi: I think they [average people] do not have information and as I said, I was surprised …that most people don't, didn't even know about the, the MCP risks

………………………………………

Neo: [People] know what [MCP] is … but they don't KNOW… the risks… they know about like we found that there are people who are having more than one partner who are having concurrent partnerships, who are having multiple partnerships and I think they know it at that level, they just know that if you have two partners or three partners it is a higher risk than having one partner… there are no such initiatives that bring a light right at your face that what you are doing is risky and that you should stop doing it. Like the network.

During the interview, I explicitly asked participants to compare themselves to someone just like themselves who did not take part in the 2008 MCP research and didn't have the same exposure to understanding HIV and understanding WHY concurrency increases the risk of transmission. I asked how their perceptions of risk may differ:

Tumelo: No. they don't (understand the risk). They just carry on just like MCP is said. They just carry on with their nyatsi, their advantages of having a sugar daddy you know.

Interviewer: it’s going on still? Even with all the campaigns and all the stuff, you think people are still...

Tumelo: People do it but then, what they do now, they will say oh no use protection but then the thing is why do you do it at all?

As a black researcher myself, who worked with food security and HIV in Lesotho, I often felt like outsiders working in prevention in the southern African region in the mid to late 2000’s were, in fact, exaggerating the role of multiple partners and sex to the minimization of other structural and economic issues promulgating the epidemic. My bias is certainly towards not presenting anything that would further stereotypes of black hyper-sexuality. In fact, the 2008 MCP study documented concurrency and multiple partners but also found people were not reporting having more sex in a given time period. Simply put, “multiple partners” does not mean a multiplication in the number of sex acts. However, there is a large body of evidence of overlapping sexual partnerships in Lesotho practiced by both men and women that cannot be ignored (Spiegel 1991; Romero-Daza and Himmelgreen 1998; Magrath 2005). There are also structural factors, related to work and livelihoods, requiring separation of couples, for example, those working in South Africa, or those attending University, or even urban work within Lesotho. In addition,
very modern trends in music and TV shows depict casual sex with multiple concurrent partners as “normal”. The following example could have been taken from a Sex and the City script, or an episode of Desperate Housewives;

Tebello: You see Limpho, she's really married isn't she. I know her and her husband very well isn't it. I'm not married, I may just decide for sport to go after her husband. No, no, no, no I may. And we might keep it on the down low, yes.

Interviewer: For sport?

Tebello: Yes for sport, why not? How can...Limpho is not the most attractive lady, how can she have a husband and I don't? I'm just...making an example...like no, I can get Luca (Interviewer’s husband), he looks like he's gettable. The word gettable. Like for sport, let's see if I can get him, sometimes it works, sometimes it doesn't work. There are people in Lesotho who would actually go out with somebody's partner just to see how big he is. Yes the length of the size of his dick. Luca looks like he's carrying something nice...let me see what he's got. And it’s a horrible, horrible, horrible thing that we're doing for sport. I feel like we can talk about it, there's possibility for change...to seek opportunities to work against the spread of HIV. I want to do that, I can do that, in my small way I am doing that. But at the same time I'm also very much aware, it’s not going anywhere. It is not. So I'm definitely discouraged I can look at AIDS in Lesotho in ten years and tell you, we'll be at forty-six, fifty percent. I can tell you that right now, comfortably, today people know that multiple and sexual partnerships are the reasons why we're having this thing. Anyway, “I'm safe and unprotected”, yet, people are having affairs, even right now as we speak, isn't it? So what does that say?

Interviewer: Maybe they're using condoms more?

Tebello: No, they're not. There are so many pregnant women in town. So many.

As much as we try to rationalize and justify sexual behaviors and make humans seem better than they are, sexual relationships involve all sorts of irrationality. Modern media portray the West to be much more sexually liberated than the average person. According to TV shows, music, and music videos casual sex and affairs are portrayed so frequently that there seems to be sexual “freedom” without limits in the U.S., making it seem like multiple and concurrent partnerships are a norm in the U.S.—from Dallas to Days of our Lives to MTV or HBO specials there is not a difference between “us” and “them” referring to high prevalence and low prevalence populations. But according to one of the few sexual surveys conducted in the U.S., the 2004 General Social Survey, found 3.9% of married American men reported having more than one partner in the last year and 3.1% of married women, and furthermore the rate in men from 1988-2004 never exceeded 5.8% and women 3.4% (Smith 2006: 54). But in the case of Lesotho, when you add in the knowledge of an already high prevalence and smaller concentrated networks of partners there is an exponential difference. Most people do not have that knowledge so there
is space for doubt, for ideas that our behaviors are the same why is the epidemic not as high in the U.S.
From these interviews it is unclear if promiscuity, concubines, sleeping around for sport, sugar daddies
vs. survival sex is something believed to be relatively new or if there are aspects that are “old” and
aspects that are new. One male participant describes the way multiple concurrent partnerships are
discussed in real life situations:

Paseka: We don't sit down and say "now we are talking about HIV" You still find somebody that
you can actually talk about HIV and AIDS and discuss issues of this promiscuity and having
concubines. ‘Cause a lot of people find it a norm, all the concubines. I don't know why…
because you know it’s unlike in the past when people would be like "why are you doing this" I
mean these days it’s just swept under the carpet and people pretend as nothing’s going on I mean,
‘cause you know even our Prime Minister has one...so why not? You remember the President
Zuma of South Africa has about, how many wives, I mean the King Maswati or even our King,
but don't tell everybody I told you…Our king has a lot, has a lot of concubines, he even uses, he's
got even illegitimate children outside. You know that? So I think it’s becoming a norm, like I'm
saying, like ok you’re married and you have a concubine, or you’re having an extra-marital affair.
And you shouldn't...make sure that your wife doesn't find out, that's what they say. Apparently,
even our own parents would say that. You should do it secretly so that your wife doesn't know. I
guess even the parents of the wife would say that!

The above quote highlights that this is a “norm” that is “unlike in the past” and then links the
behavior to three of the most powerful men in his reality. Three men that are rich, successful, have
multiple concurrent partnerships, apparently lots of unprotected sex (producing illegitimate children), and
yet, do not associate themselves as personally associated with the disease. The same argument applies
when we compare European and African political leaders’ reputation on sexual practices. For example,
there is the Italian PM Berlusconi, with his numerous sex scandals and orgies, or French presidents and
political figures like Hollande and the IMF’s Dominique Strauss-Khan do not seem much different from
their African counterparts. However, in France there is a big difference between the portrayal of French
politicians’ behaviors and those of the average citizen. A 2004 French national survey found 3.8% of
married men and 2% of married women reporting having more than one sex partner in the previous year
(Druckerman 2007). This is in comparison to various surveys in Lesotho finding 40% of sexually active
men, including married men, and between 11 and 30% of sexually active women reporting more than one
sexual partner in the previous year (Caraël 1995).
6.6. What about Condoms?

THE MAN IN THE ARENA

It is not the critic who counts; not the man who points out how the strong man stumbles, or where the doer of deeds could have done them better. The credit belongs to the man who is actually in the arena, whose face is marred by dust and sweat and blood; who strives valiantly; who errs, who comes short again and again, because there is no effort without error and shortcoming; but who does actually strive to do the deeds; who knows great enthusiasms, the great devotions; who spends himself in a worthy cause; who at the best knows in the end the triumph of high achievement, and who at the worst, if he fails, at least fails while daring greatly, so that his place shall never be with those cold and timid souls who neither know victory nor defeat.

Excerpt from the speech "Citizenship In A Republic" by Theodore Roosevelt
delivered at the Sorbonne, in Paris, France on 23 April, 1910

The prevalence rate of HIV in Lesotho is a steady 22.9%, the second highest after Swaziland (UNAIDS 2014 ‘The Gap Report’). If this is true, “the reality of how Basotho, not all of them, … perceive sex, that they can engage into sexual relationships with many people and still feel ok and keep it as a secret” (Mosa) among both men and women is accepted and it appears that no one is doing anything about it. But, what CAN actually be done to prevent the sexual transmission of HIV? According to an American expatriate working for PSI in Lesotho there is a solution:

You've got to...and this is PSI's research...I've gotta find that behavioral determinant in you that is going to trigger that and it isn't punitive cause “AIDS kills” doesn't work, right? But what does work? Well, I'll tell you what works because we've researched it. Now it’s that guy, that misbehaver going back to PSI's world, that 25-39 year old guy whether he is in that village or whether he's in his crowd he aspires to be one of those guys who people look up to who they respect. And one of the ways that he can do that is that he protects his family, how does he protect them? Well he, whether it’s through money,...protection part of it is a big deal that was one of the words that jumped out and respect came out. So if you've been driving around Lesotho you see this guy on the billboards with the red, with the yellow hard hat and it says with Trust Comes Respect. Be the guy who’s, that guy, looking smug wearing the hat being the protector right? That's you, that can be you. Now put this on. I don't care how many partners you have, I mean we haven't gone out with concurrency messages we've gone out with safer sexual practices messages. And honing in on that determinant, and total market, these are for purchase, these are free and so are these, and this is purchase...ok you're Malifi your from Thaba Tseka you're never going to buy a condom. It's okay. If you find one in the work place would you use one, if you found one at your, at the chiefs place would you put one in your pocket? You'll never value it but will you use it and if you will what will make you use it, and how do you get, where do you get it? Is it available; is it accessible do you know how to use it?

“We haven't gone out with concurrency messages we've gone out with safer sexual practices messages,” in other words, if people do not want to change their sexual behaviors of having more than
one partner at the same time, just make sure they are using condoms. PSI is recognized for its 20 years of effective work in Lesotho. One of its most significant accomplishments in Lesotho is the trend of increased condom usage. According to this representative, sales and distribution numbers “are going through the roof”. In regards to measurement, the correlation between the stabilization of the epidemic in the categories PSI is targeting is inferred as condoms distributed and condoms being used.

So we've got people all around the country seeing today [flipping through sheets of paper] 2,375 people last week with one-on-one condom demonstrations, female condom demonstrations, talking to people about sex and...they think it’s funny and it’s kind of cute but its reaching them where they are. What I was going to show you was a picture, I mean we're working with, they call them "herd boys" but they're not boys. I mean some of these guys are in their mid to late forties, I mean they're herd men. I mean we've got these young girls out there sitting down with them all around putting condoms on wooden penises you know showing them how a female condom works and these guys are fascinated. I mean it's better than like sex ed in school. You know. And they're just clamoring for the condoms. You know and it...you know there's an edge there but play to it don't run away from it, if it gets people you know, by the time they start and end, I mean it’s amazing how different it is. So...I mean...and the messages are not, I mean they're all adult learning research based how do I reach you Malifi herd boy, or how do I reach you Thabiso sharp guy with lots of girlfriends you know, you know Trust, you know this is for the worker, this one is all about the lady, you want to impress your lady, you use this one and ...you gotta play to it, you play to what triggers the positive affirmative decision. And you know, inside of our testing, I mean you go in and it's forty minutes long! It isn't that prick your finger your positive, I mean there is a discussion about risk reduction, levels of risk, condom demonstrations are you ready for this decision, do you want it, do you want to test are you ready for this? What are your choices if you’re positive, if you’re negative and it goes into when that person walks out they may have the information to change their life...in the arena...if you know the Roosevelt quote... (Lesotho PSI Representative)

The education encounters that PSI conducts are innovation specific: this is a condom, this why you use it, this is how you use it. As a health initiative that is relatively low cost and measurable---count how many condoms distributed/sold, count how many people encountered. They do indeed trigger and play to the affirmative decision. But, is this enough or is this type of approach the type of knowledge producing encounter that can not only trigger a temporary affirmative decision but sustain a “consciousness” that can affirm longer term behavioral changes? Describing 40 minute counseling sessions and one-on-one condom demonstrations as “adult education” may fall short of the intended description by Paulo Freire. What is the long-term message of having a “young girl” give condom demonstrations to older men, especially in consideration of the identified problem of inter-generational
relationships between older men and younger women? Are we triggering behavior change or arousal? A recent study found that “conservative” men are actually swayed more by sexual cues; the experiment found that men with low behavioral intentions for casual sex at baseline increased behavior willingness for casual sex when exposed to sexual primes (Roberts, Gibbons et al. 2014). In considering that Lesotho is in the midst of rapid changes between traditional and “conservative” attitudes towards sex, the influence of these types of outreach activities and marketing may be much greater and diverse than we assume. “Playing to the edge” having men “clamoring for condoms” and plastering an entire country with images of condoms and sexual innuendos suggesting the use of condoms may inadvertently put sex on the mind even more. During an interview with one participant he indirectly applauded the work of PSI:

These young age at least here at home, they actually take it as cool to use a condom. That cannot have happened you know by accident…. it must have been influenced by something… What it is...maybe that is what we need to find out, you know. (Tsebo)

This reflects success in the total marketing approach, however he goes on to say:

…the way people have looked at HIV and AIDS here at home you might also categorize it according to age. You know, a lot of young people who are already sexually active they have this idea that it is "cool" as they say to use a condom. But when you really try to get deeper into this you find that no, no, no this person yes he makes sure that he uses a condom all of the time you want to but he is really using it because it’s "cool" and that is his answer he, "no, no this one is cool" when you have sex without a condom it's so old fashioned, so belongs to the old people. For example, even if maybe she was thinking maybe you are young but probably just decide soon after discovering that you ehhh do sex without a condom she might even decide how old you might be or even suggest it. You know? So it’s just frustrating because you wish that this guy would really understand the favor he is doing himself by using a condom but if he is doing it simply because it’s cool, it’s good yes BUT something that is cool today may not be cool tomorrow because it’s a fashion kind of thing to the extent that it makes you so frustrated, that ok, which means that this guy the day it becomes not cool to use a condom he will continue to do sex without a condom because it’s cool to do sex without a condom. You see? So you know it’s really frustrating I don't know because you don't know what you can do about it so that you think that if we were to control this mob thinking so that we all behave the same way. Maybe it would help us whatever influences for example, fashion you know, so that we can sort of devise strategies to use that kind of crowd thinking because it seems to be the only way to actually make things change. (Tsebo)

It does appear that condom marketing and crowd thinking seems to be working. The LDHS 2014 Key Indicator showed that 92% of women and 88% of men know that consistent use of condom is a means of preventing HIV infection (LSO 2015: 10). About of 99% of women and 87% of men know that
limiting sexual intercourse to one faithful and uninfected partner can reduce chances of contracting HIV. Eighty six per cent of women knew that both using condoms and limiting sexual intercourse to one faithful and uninfected partner can reduce chances of contracting HIV, this was an improvement over a period of about 10 years where in 2004 and 2009 the figures were at 71% and 81% respectively. Among men in 2014 about 81% showed knowledge in this parameter, an improvement from 60% in 2004 and 72% in 2009. Condom use has been improving steadily more so among men than women. Among women it was 42%, 38% and 54% in 2004, 2009 and 2014 respectively; while among men it showed consistent improvement of 46%, 52% and 65% in 2004, 2009 and 2014 respectively. However, urban educated populations who reported higher knowledge and use of condoms also had higher incidence rates than rural less educated populations, consistent in both younger and older populations. Regardless of the increase in condom knowledge and usage the incidence rate of 2.1 to 2 in Lesotho has remained relatively unchanged (LSO 2015: 1). UNAIDS 2013 estimates the number of new infections to have changed from 32,000 in 2001 to 26,000 in 2014 (UNAIDS_Profile 2014:4).

There is a significant amount of money that has gone into condom research, marketing, and campaigns. In terms of behavioral change prevention in 2011 PSI was the main player; condom knowledge and usage may be one of the few indicators seeing positive changes at the moment because it is the highest and most sustained funded approach. Between 2011 and 2015, $112.9 million US dollars were spent for the provision of condoms, by far the highest prevention line item and nearly half of the entire $241 million prevention strategy (see Table 4 pg 203) (NAC 2011: 98). As of 2012 funding for community education and outreach was at a low, the trend is in social marketing, relying on fashion, trendiness, an image to mold crowd thinking rather than investing money and time into the hard stuff of hosting dialogues and longer term community based holistic sex and HIV education. The Essential Service Package Program was no longer in action and PHELA dialogues suffered reductions in funding thereby limiting reach and program duration. The type of communications with condom distributions, testing tents, and monetary incentives relies on a superficial awareness by people of their own body, the way the virus works, and the latest scientific view. The short-term result is that USAID/PEPFAR and
other NGOs will get their “target numbers” for testing and condom distribution, but the level of long-term investment in people understanding why they should use condoms remains elusive. Quantitative analysis of reported condom use continues to give a partial view of attitudes and practices in Lesotho. As one of the respondents stated:

The peer educators, they talk about AIDS like it has been talked about for two decades, like AIDS kills, take your treatment, a person with HIV is still the same person, they say the same things. I think right now we should change like the attitudes at once about HIV. Because it hasn't been working. We've been giving away condoms free, condoms and everything else but then people don't use them (laugh) they've been flavored but people just don't use them because they don't see why should I use this? But if people can get to really feel like they can make a difference, like it can, I can contribute towards an HIV free generation I think it’s something positive. You would want to do something, not because they said AIDS kills but because you want to see a difference. (Neo)

A 2008 review of the PSI Trusted Partner regional behavior change communication campaign in Lesotho, Mozambique, Uganda, and Zambia evaluating the impact on elements related to trust and condom use with regular partners by youth aged 15-24 was shown to have no impact on the level of caution people use before having sex with a regular partner (PSI 2008). A 2005 prospective study of approximately 400 Ugandan men also revealed unexpected outcomes. The intervention group attended education session foundationally focusing on condoms with HIV and STD prevention as a secondary focus (taught condom technical use skills, encouraged condom use and provided coupons for free condoms). The control group instead, provided informational presentations about AIDS and STD prevention and secondarily provided information on condoms and coupons for free condoms. The end of study results revealed an increase in the number of sexual partners by 31% in the intervention group while the control group decreased their number of partners by 17% (Kajubi, Kamya et al. 2005).

Throughout the interviews, participants noted the norm in others and in their own relationships of not always using condoms “You will find that people that are in a relationship after six months they don't use condoms anymore. It’s like, its engraved somewhere in like we don't use condoms after, you know this person would never cheat on you”(Neo). The concept of trust is not something seen as an individual
concept “I trust you,” but a cultural identity of trust, of being a trusting people, wanting to believe in the basic goodness and honesty of people.

Because us as a nation we have this, I see you, you look good, you must be healthy, let's have unprotected sex. Even though we may use condoms one, two, three, four, five times, the trust element Sharon, Basotho we are a very trusting nation. We are taught by our parent's to trust strangers. This is why we greet everybody. We don't have the individualistic thing. You know so as long as we still think, believe in the basic goodness and honesty of people we are going to die. Do you understand what I mean? As long as I still think that because you like me and I like you I don't want to know what you were doing last year, five years ago, that is what is going to kill us. I take you at face value, as long as we still take people at face value we're going to die. MYSELF included, by the way. Myself included. (Tebello)

Believing in the basic goodness and honesty of a people can be a good thing in society, but the way the packaging of the element of “trust” is used with Trust brand condoms is asking people to NOT believe in the basic goodness and honesty of the person you believe loves you rather in a rubber condom of Trust. What does this do to a person? What are we asking of people?

While PSI is trying to exploit cultural norms it is also reifying norms that others are trying to challenge, as explained by one of the participants:

There’s a big poster at the circle (the central roundabout in the capital city of Maseru). A man who uses...you can trust a man who uses...or a man you can trust is a man who uses trust condoms, ok? YES, now if you look at this ad it’s always about a MAN isn't it? You see what I mean, it’s always about a man. What about a woman, Sharon? What about a woman? “A man you can trust uses Trust Condoms,” this is the slogan and it’s a picture of a couple. You see the power of being in control of sex is being taken away from women. How can we end HIV if women are not responsible for decisions concerning sex in Lesotho? We are not. Women are not expected to have condoms this is why it’s always about...look at the picture it’s a man. Look at the picture. This says a lot... I'm all about gender. Do not target men, do not target women, do not leave another sex out. These ads leave women out. Women are not supposed to be responsible for sex. (Tebello)

There is a delicate balance in targeting the “misbehaver,” the 25-39 year old guy, to “protect” and be a man you can “respect” and that of reinforcing the idea that condoms are something men use to “protect” and be “respected” while women remain passive receptors. The negative connotations of a woman who carries condoms in her purse are already thickly imbedded. Instead of thawing these misperceptions and moving towards new ideas to a type of woman who carries condoms, who can negotiate their use, these campaigns may be adding and abating misconceptions. The same participant goes on to elaborate on how
she sees the relationship between these images and popular ideas about the type of woman who carries
and negotiates condom use:

Because it takes out the power for you to be responsible for your own sexual activities. You know
in my village there was a woman who was about to be raped. And as the assailant pinned her
down with a knife on her neck she said, "Before you rape me, just let me give you this condom,
use this" and this guy ended up not raping her. I mean it. I'm being serious like a heart attack.
And now this woman is being labeled in my village that you know she's on heat, like she's always
ready for sex and its A BAD thing the fact that she said to the guy who was about to rape her,
"Please I beg you I'm not saying no do it, but just use this condom." And then this guy was
disgusted like, "seese (Sesotho sound) what kind of woman is this? Even when you're in trouble
all you can think about is, you know, use a condom." Because we're supposed to fight and scream
and kick and cry and be victims isn't it? At least if you try and take control of your victim status
and you tell this guy listen use a condom at least. He didn't rape her.
Interviewer: But now she's being stigmatized in the community?
Tebello: YES, that she's on heat. This one is on heat.

The negative connotation about a woman with condoms in her purse is a relatively diffused idea.
But when this idea is placed into a context where PSI has been working for 20 years, such messaging
focused predominantly at males may be reinforcing the idea that condoms are owned by good men and
bad women. This example demonstrates that the global health community continues to place “faith” in the
rational use of condoms. Yet, from DHS statistics and the words of participants, we see how condoms are
not being used consistently. The assumption that we can let go of education on social, cultural, and
behavioral dynamics and focus only on “safer sexual practices” and condom usage, is flawed. Participants
repeatedly highlight the lack of condom use and the need to talk and explain to people why certain
attitudes and behaviors put them and others at higher risk for sexually transmitting the disease. The work
of explaining and raising consciousness is not as easy or low cost as distributing condoms. But, according
to participants that is the type of work needed. Thus the work of PSI in the “arena” in Lesotho has done
some good but it is also important not to lose a critical perspective on the unintentional consequences of
their work in Lesotho. Thus balancing the words of Theodore with that of Eleanor Roosevelt when she
stated:

Criticism ... makes very little dent upon me, unless I think there is some real justification and
something should be done.
- Eleanor Roosevelt
6.7. It’s for the People?

In this section, I present a few examples of the various ways that people talk about HIV in a reality where exceptional resources have been dedicated to AIDS but where AIDS prevalence continues to be exceptionally high. My goal is to present an anthropological observation on some of the ways people were talking about the disease at a particular moment in time, three generations into the epidemic. In 2012 when I conducted fieldwork several participants discussed the reality of HIV within the population with undertones of inevitability:

Tebello: eishh Sharon, I don't know what to tell you but everybody in life we have this self-preservation thing that, that person and not me. It's like having a child who’s sick or mentally disabled. There is nothing that you did to make your child like that, like a blind child. You could have a child that is born blind, but you were pregnant the same, just like everybody else. So...it’s a realization that actually this, this could actually happen to me and I wouldn't even know. It doesn't hurt. So one day you'd be going around living your life and then you’re e positive. Do you know what I always tell my students, it's just a matter of time. I've stopped being you know, optimistic that it will end. I don't have that, I just feel like you should be careful and not let it happen to you. But at the same time it’s just a matter of time, Sharon. I think eventually we'll all have it in Lesotho. It’s a very strong statement to make isn't it?

The participant goes on to link her lack of optimism with the need for behavior change at the societal level:

…It’s taken me twenty-nine years to trust people so it’s going to be very difficult for me to change. Behavior change...do you know how behavior change works? If I change my daughter’s behavior at one and half years, teach her, do not trust, DO NOT, you see, THEN probably it will work. But for us..., you know I was telling my students the other time that at twenty-one years old you are told you must have only one sexual partner. Yet, you grew up in a society that thought, that believes it is ok for a man to have two or three girlfriends from twelve years old. You see boys in high school have three, four girlfriends. What are you going to tell them at twenty-one years old that they must have one partner. It is impossible. It is impossible…You as a girl you know this boyfriend of yours has another girlfriend and you tell yourself we'll fight for him. How is it then going, you always take that kind of thing even when you are married, even when you're a woman. You always accept that...you know, even our culture sanctions it. If your husband cheats on you, the family will sit down and discuss it. Don't do this anymore. Don't do it anymore. That's how our culture works. But the problem is not being dealt with, its BEHAVIOR, our BEHAVIOR. Our Behavior is the problem. It’s just a matter of time. I tell you it’s just a matter of time, Sharon. Twenty years we'll be gone. It will not stop. Every single day 18 new infections, you know that? You know this right? Even today! Pictures everywhere, posters please stop, stop having sex with strangers, stop, stop, stop...nobody's listening. There is a reason for that. Because everybody thinks it won't happen to me or my partner is not HIV positive.
In 2007 Lesotho spent 64% of its health expenditure on HIV/AIDS (Amico 2010). That is only counting the public government spending and not the private sector of NGOs, international, or religious organizations. Where other development initiatives have failed, HIV has been an economic advantage in Lesotho. It has provided access to resources and jobs that otherwise would not have been there. In fact, there are over 250 entities funded and implementing work dealing with HIV in the country. Despite all of the organizations, behaviors and incidence rates are not changing; in 2013 there were 360,000 people living with HIV and 26,000 new infections (UNAIDS 2014). The next example brings together the themes of inevitability and solidarity within the context of AIDS exceptionalism:

Moeletsi: and some are saying that HIV/AIDS is FOR THE PEOPLE.

Interviewer: is for what?

Moeletsi: people.

Interviewer: it’s for the people?

Moeletsi: yes

Interviewer: and what do you mean by that?

Moeletsi: that is...that they are not afraid of HIV/AIDS.

Interviewer: they are...it’s for the people? Is this a good thing?

Moeletsi: I [pause] yes in a way you would say yes, they are saying that is a good thing because of when you try to talk about HIV/AIDS you say "ahh" you really know a lot about it, but then looking at their behavior you will see that they do not know about HIV/AIDS.

Interviewer: hmmm so what does this statement mean "for the people"?

Moeletsi: I think it means they do not have a problem. It’s like they are just saying that we are all going to die so...[pause]

Interviewer: so it’s no problem?

Moeletsi: so it’s no problem.

This, “it’s for the people,” echoed in my head like some sort of power chant. He said it in the same tone of the “I’m black and I’m proud.” The repetition of a phrase is rendered all the more powerful because of the shared social knowledge of its meaning. But what does it mean? That we are all going to get it at some point, so we are not afraid and so it is “for the people?” “It is for the people.” How is it possible that this, HIV, is a “good thing?” I probed further asking that if AIDS is “for the people” are people more willing to disclose their HIV positive status he responded by saying:

Moeletsi: what I am saying is they might or they can't even tell you about their status...But then when you are trying to talk to them about their behavior like come on man don't do this and don't do that they will be saying no come on...Have you ever heard of an animal suffering from HIV/AIDS? They ask you. And then they say THIS is for us. HIV/AIDS is for, for the people. It’s for the people.
Interviewer: It’s for the people? so kind of like a way to say you do not need to talk to me about that?
Moeletsi: yes…hmm even if I die I will get something for HIV/AIDS……for some of the things we are not sure in some areas peoples started even infecting themselves because they were looking for support they were saying that people with HIV/AIDS are receiving some food packages and some things so there was a saying that some people are trying to infect themselves...

During the interview and still today, I do not have all the elements to understand all that he was trying to express. The layers of meaning and how “it’s for the people” is used within the population deserves further attention. What is clear is that having HIV within a resource deprived and extreme wealth inequality context is associated with being “eligible” for goods and services that otherwise would not be possible. In 2008, I wrote about the potential harms we, the NGO IGO community, could introduce by using selection criteria that introduces short-term “benefits” in small communities without considering the need for wider, more inclusive, sustainable solutions (Watson Lai, Mpemi et al. 2008). Here, four years later, I was hearing how this “idea” manifests itself in discourses about not just avoiding risk and agency for changing the HIV/AIDS situation but actually potentially promoting the spread of HIV. I probed the participant if these cases were actually proven to be true. He noted that the problem was actually discussed in 2010 at the National HIV/AIDS Forum and intentions were stated to try to investigate if these claims were true. The participant remembered that there were suggestions at higher levels to take it to the cabinet and have a Ministry assigned to conduct an independent investigation. Neither he, nor myself, could find evidence on the occurrence of any investigation.

This theme of a mixture of ideas between a sense of injustice in the distribution of benefits brought in by HIV with a resignation towards the inevitability of it continuing is present in other interviews as well. The notion of “benefiting” off of HIV is not only present in the rural poor, but also in more financially stable sectors of the population. This points to the reality that there may be an association at some level between disease that kills and disease that gives advantages, disease that is inevitable, that brings inequalities, but a disease that I may benefit from through jobs, food packages, and support.
…to discriminate is bad, it does not really matter whether you are doing it against people who are positive or who are negative the idea is not to discriminate at all. So why should I be discriminated against myself simply because I don't have. I'm not HIV positive. Now it becomes a vicious cycle again, I'm convinced that if I'm positive, me the potential employee, I'm convinced that if I'm positive I can easily land a job. So let me see what I can do...I become positive as soon as I can…it’s even better, it’s OK. Make the best of it. So it’s whatever. There is this song by I think it’s this lady, I don't know whether it’s Spanish to say "que sarà". [Starts Singing] “Que sarà sarà sarà, sarà whatever will be, will be”. [Stops singing] You know don't make any effort. No, no AIDS I know it has been killing people, I know it will continue killing people if I die, it doesn't make me any different from all these other people. I have it, I don't have it, I take an effort to try and avoid having it and what not...que sarà. (Tsebo)

6.8. Funeral Coming Up

In the previous section, I demonstrated how the dynamic of positive discrimination, as in for those who can demonstrate their positive status, having greater access to resources and opportunities that the total population desires, has created a situation of perceived “reverse discrimination.” However, the existence of perceived “reverse discrimination” this does not mean that negative stigma and discrimination towards the disease is a phenomenon of the past. The persistence of stigma in Lesotho is evident in the way people avoid talking or associating their loved ones with the disease. The following example demonstrates the normal way of avoiding explicitly associating HIV and AIDS with sickness and death:

There is something that is really common with us, you know, where you will find that we have somebody close maybe a friend, maybe even an acquaintance it doesn't really matter, who maybe is sick, who actually maybe late and you find that it is really common towards this thing. This is something that we share even if we meet up with a friend, "my goodness man have you heard that so and so what is the problem?” You know you find that most of the time I think that thing is quite common where people will sort of… something that happens unconsciously most of the time, shut off from the fact, that it may have been HIV and AIDS and to be looking for ANY other reasons but that one. You find that even when people might be suspect that that may have been the problem they will, even when you do ask, "what was the problem with this fellow?" They will rather not even offer any suggestions. "I don't know maybe he was sick, I don't know" even when people are talking health. (Tsebo)

This is not an isolated example. When participants were probed specifically ‘If someone that you knew had passed away and their funeral is coming on Saturday, would you be able to talk about what they died of?’ A majority of participants said that the cause of death would not be stated and it is actually rare to specify a death as being related to HIV.
One of my friends, her mother died, and she was HIV positive like she told me, her mother was 
HIV positive a few months before but when they were talking about it at the funeral, they said 
that she had kidney failure and we were just a bit like...yeah but you know….(Lebohang)

Despite the large number of people infected and affected by HIV and AIDS related deaths, 
discussing the real cause is still not part of the socially acceptable discourse about illness and death:

Lebohang: ….my cousin died and she was HIV positive but that was here, and they didn't want to 
go there, well, I mean it was just out of respect for her family they didn't believe that she was 
HIV positive and they were a bit like...evidence is all there but you know, don't really want to 
have an argument when you're mourning… [we]Didn't talk about it, which is in contrast again 
cause one of my other cousins passed away and they were HIV positive and the family was a bit 
like, we'd rather tell people so that people know that this is a reality and so that people can deal 
with it and know that it is actually a problem... it’s really strange cause like I live, where we live 
[Maseru, Lesotho] every other person has got someone who has either died of HIV or who is 
affected that we know of….

Interviewer: so what do you think this not talking about it is about?
Lebohang: I have no idea, I guess it’s the stigma which is what people say that people might kind 
of look down on you…I think its stigma, yeah…I think people will look down upon you, if you 
openly come out and say you're HIV positive the usual kinds of things that people assume that 
your promiscuous or whatever.

Regardless of the “commonness” and the shared experiences of losing loved ones, caring for 
orphans, living with the disease, or supporting family members and friends, stigma and discrimination are 
ongoing dominant forces. People choosing to tell others following a death, “so that people know that this 
is a reality,” is rare. Similarly, the space for people to live positively and publicly without fear is not yet a 
reality, as reflected in the following conversation

Lebona: I mean people…diagnose you, they see Lebona and they look at some of the symptoms 
and signs of what could be HIV or related illnesses and they diagnose and say "ehh he does have 
HIV" (imitating a gossiping female voice)….and they just make a decision there and 
there….others are just saying no I'm not HIV positive, it’s a whole lot of issue of stigma. 
Interviewer: So they wouldn't ask you?... would a person feel comfortable to come open? 
Lebona: Uhhm I think it differs from one community to another, and differs from person to 
person and how comfortable they feel but I mean there are people I know in my community that 
have disclosed their status, they make it sound more acceptable rather than being something 
people would need to be fearfull of. And I think it’s people like those that we can look up to, 
especially, I mean other people die and they are just in denial but once you know your status 
whether you disclose it or not but the most important thing is to take necessary measures to 
protect your life. Like I indicated there are a few people who came out and said, “You know what 
I went for a test and I tested positive and I'm on my ARV drugs now and I'm responding very 
well and you can see so my AIDS is under control, my HIV. I can do things that you do, and I'm 
gonna live long.” (imitating a strong female voice) But it's few people that have come out, others 
are still, I think they feel like they will be discriminated and the whole stigma around that.
With access to treatment and higher levels of knowledge of the disease, there is hope that HIV will transition to be more of “just another chronic” disease like diabetes, high blood pressure, etc. While this may someday be the case, the current ways of talking and not talking about HIV in Lesotho, suggest that HIV is still a source of negative discrimination. Recent research from a large randomized trial of communities in rural Malawi demonstrate the positive effect of a single community meeting providing information on how antiretroviral therapy makes people less infectious having a significant impact on reducing HIV stigma and increasing HIV testing (Derksen 2016). Considering all of the clinical work and treatment initiatives in Lesotho this type of positive effect does not seem to be present. This may be reflective of an approach in Lesotho focusing on the clinic and the patient rather than attempting to engage and educate at the community level as done in the Malawi trial.


Whether it be HIV denialism, desensitization, lack of credulity in the message and the messenger, over-saturation of the message, lack of holistic sexual education, or any number of contributing factors, it is evident in this research that HIV and AIDS are often pushed out of the personal sphere and relegated to the professional. Rationally, looking at the statistics in Southern Africa one would assume that people are mobilizing and acting in their own spheres of influence to create awareness and change. That HIV and AIDS are acknowledged as a problem; that young people should be involved in the awareness and change campaigns, even if only because they “have” to for their own and loved-ones future. Yet, this is not the case as one participant explains:

A lot of young people are not interested in taking part in anything where they're not getting any benefits, an ipad, or a blackberry, or money, or anything they're not interested in doing it. To some extremes where people were like, it’s not my problem. And I was a bit like, you live in Southern Africa, what do you mean it’s not your problem? It’s very strange, anyway and some people were like, I have no interest, sorry. (Lebohang)
HIV/AIDS is not only a disease but also a vector of opportunity. It is possible that the generation of young people who attained degrees and set forth on the job market during the peak of funding ended up receiving the default message of HIV employment more so than an understanding and active will to prevent the spread of HIV. In this research sample, nine out of 11 individuals who applied for the MCP Research Assistant position mentioned money or a job as one of their main motivations for applying. In recalling his level of knowledge before he became a member of the research team, one of the participants stated:

Moeletsi: I only read about the world AIDS day 1st of December, I only knew about that when I was going to interview because I knew that they might ask some things about HIV/AIDS.
Interviewer: but before
Moeletsi: I didn't even know that (HIV/AIDS)...
Interviewer: [interrupted] but given all the education campaigns, all the posters...
Moeletsi: I didn't know about that
Interviewer: until 2007 when you went for this orientation you didn't know, no I am not quizzing you I am just trying to understand the situation because you see all of these campaigns and billboards and things
Moeletsi: yes, I think I only knew about HIV/AIDS but I did not have the FULL details...then after working for the UN mostly, UNAIDS and then after the orientation, I started seeing things differently...

In regards to education, or reading materials about HIV/AIDS, several participants noted the reality that in many cases people are not using them. One participant jokingly said, “You know Sharon, the best way to hide something from a Masotho is to put it in writing! We do not like to read.” (Khabane)

The participant from the above UNAIDS example talks about the pamphlets and booklets produced for educating about HIV and his opinion of who ends up being the reader audience:

Moeletsi: ….these people are not using these things we ended up distributing those materials to schools because nobody uses them....if you find somebody reading about HIV/AIDS related book you should know that she, he or she is doing some research on HIV/AIDS… [laugh] not because he is just reading ahh

This comment highlights the disjuncture between the “target audience” for readership and those who actually seek out information, not for personal purposes but for academic or work related research. Some young people seem to see HIV as “my problem” when it relates to something that can benefit them or provide a job opportunity. Thus, despite growing up in an environment lush with HIV campaigns Kick
for Life, Know Your Status, OneLove, and other institutional messaging (as opposed to educational dialogues), young people were not seeming to take grass roots ownership of the problem or the solution for HIV and AIDS. Instead, engagement took the lead from outside donors, the providers of resources and opportunities. As noted earlier, the participants’ engagement as researchers investigating sexual transmission and multiple concurrent partnerships was predominantly for employment, not because they were driven to work on this specific issue and aspect of HIV. In fact, many of them, like myself, were not concurrency “proponents” at project initiation. But the process of being trained on HIV, MCP and conducting qualitative research on the subject shifted paradigms:

*Interviewer: uhm so what exactly motivated you to apply to the job?*
*Mosa: To apply for MCP? In the beginning it was just trying luck it was all about maybe getting employed not just volunteering taking what you are doing, maybe further. But after that I liked MCP. In the beginning it was about [just getting a job], but as time went on it was more than that. Because, after I got into MCP I knew it was ok to just open up and talk about sex. Like it was not a taboo at all and I could talk openly with ANYONE about sex. Not just the research team at MCP but about to everyone, even at home.*

Even the opportunity on the research team of simply unpacking the terminology and understanding what is meant by the technical terms of “concurrency” impacted individuals:

*There was a time I'm sure where I would have actually used concurrent sexual partnerships and multiple sexual partnerships interchangeably as the same thing because really I...it was really my first time to realize that it is EVEN more dangerous for anybody to be maintaining multiple sexual partnerships BUT doing so concurrently...so that in itself, you know that sort of realization it is exactly what I am saying it, it enriches you to the extent that even if you don't necessarily want to say ok ehh I would like to see how people will respond if they also get to know that multiple and sexual I mean concurrent partnerships are not one in the same as much as you are not doing that but it surely, comes out even unconsciously for the fact that now you understand. (Tsebo)*

The term “eye-opener” was used by six of the nine original research team members to describe the difference in what they learned about sex and HIV during the MCP study experience. However, it is not a matter of HIV and AIDS information ignorance. The part of the population referred to is the middle class, young, and university educated. They have a certain type of information and knowledge on the topic but either the information or the way it is taught does not translate into a personal working knowledge that translates into prevention. Participants highlighted how their experience as part of the
MCP study changed their personal outlook on HIV and also their perspectives on the need for the broader population to change their attitudes towards sex:

But that study, the MCP study, I think it was one of the more positive, on my outlook on HIV/AIDS matters. Because you will find that what we are being taught. It still doesn't change your behavior. I don't know. HIV is a basic knowledge its being taught from sex education, from primary level, but it still doesn't change the behavior of people because you will get to know that when, when people reach a certain stage and then they have a boyfriend for over six months, they forget about HIV...TOTALLY. They totally forget about HIV and then they no longer use condoms, it’s in them, I don't know what's happening because you will find that if you can go to Roma The National University of Lesotho you will find so many pregnant ladies that they are...people will say that they are all for higher education and you know that they know these things but then why are there so many people pregnant? Because they don't practice safe sex. And then you'll find that this girl is with this guy and the next year there is a nice other one, you see? So I think what we need to change what we need to be teaching is like the B like behavior change. How we can change, how we can get people to change their attitudes towards sex. I think that is the thing that has got me really thinking hard…. I think there has been too much on abstaining, being faithful, and condomize. I think it should be more on behavioral change, the focus should be more on forcing people to change their behaviors towards sex, because sometimes, I don't know how, I really don't know how I could say we can go about it but then I think talking, like talking to people, I think it, its, other than informing them just abstain, be faithful, condomize. It’s like a song they know it by heart but it doesn't mean anything to them. I like this one "make it happen it begins with you an HIV free generation"; you see that slogan, yeah an HIV free generation it begins with you, I think that thing it says something to how can I change, it begins with me even if I am positive my child will not be positive how can I, unlike HIV kills, it’s cruel, we should focus on more changing people's behaviors towards sex.  (Neo)

This participant is emphasizing the need to change the message to one of possibility for change rather than continuing to overemphasize abstinence, condoms and generic faithfulness messages. For these participants, coming face to face with real life examples helped research team members to break down barriers of communication about sex and HIV within their personal networks:

….we don't talk about sex with elders. YOU DONT. But then after the study. I think I was always talking...when you get to talk to like your parents about things, talk to your neighbors, your colleagues, it gets easier and then you see that no… people can actually open up. People have been longing to do this but it was something like a taboo… (Neo)

Similar to the above participant, another participant highlighted the way the research experience made him realize how the educated are similar to the un-educated when it came to attitudes towards having multiple partners. He explains how he had enough information, before the MCP research
experience, to be scared of HIV and try to take “preventive measures” but not the type of consciousness to change his attitude toward having multiple partners:

I think all I needed was to interact with people who have done it all and seen it all. I had information. I had read lots of stuff you know, basically it was all about being scared trying to even...if there were still multiple partners you were trying as much as you can to work on preventive measures. Basically using protection but it was not about the attitudes. The attitudes had not changed. The attitude was still the same. I guess the attitude our attitude as educated people they were not that different from the attitudes of people who were uneducated. The only difference was there was that we had knowledge but the attitudes were still the same. So basically, the attitude towards having multiple partners was still the same. I mean its Africa. Where we feel like everyone is entitled to have two or three...whereas for ladies it would be, when you are a guy you know when you have one or two girlfriends you are the man. But for a woman when she has two or more she is given negative connotations. If you get what I'm saying. So whether you are educated or not it was still the same. But after that experience you had to, we learned that actually you know what, there is no difference between us and these people who are uneducated in terms of the practices and something had to be done. We had to do something by ourselves. First we have to have self-introspection, you'll change whatever attitudes you have you know, you change the other ways you've been doing things to proper ways of doing things. After learning and coming across all these other people who are telling you of the way they are living their lives. (Khabane)

Most of the MCP research team members shared the “it’s not my problem” mentality before the study. They sought employment on the project for employment not necessarily as point to make a change in HIV. They also described their own attitudes towards MCP, to treat MCP as a norm (be it new or old) but to just minimize transmission possibilities through condoms while still keeping multiple partners. But the study experience changed this. Participants noted how the act of conducting and transcribing other people’s interviews—the act of listening to people’s stories—made the reality of their own risk come to surface in such a way as to provoke change in attitudes and behaviors. All nine of the original research team members changed their own attitudes and behaviors in regards to MCP. They placed a value on the behavior and decided to change the practice of having multiple partners (risk elimination) rather than continue having multiple partners but using more condoms (risk reduction). Based on the changes they made in their own sexual relationships and the conversations they went on to have with others about ending multiple and concurrent partner behaviors (described in more detail in chapters 7, 8 and 9)—the MCP research experience completely changed their attitudes and behaviors a type of “self-introspection” as the participant above describes. That after “listening to all the ways people are living their lives” and
putting themselves at risk through multiple and concurrent partners, researchers decided to “change the ways you've been doing things to proper ways of doing things”. “Proper” in this case referring to no longer having multiple partners.

6.10. Seeds of Change

In seeking out what participants knew about prevention work they brought up some key examples of opportunities for the receipt of messages accompanied by dialogue included in the essential service packages program, CARE/PHELA, outreach campaigns, and work related training/orientation programs. The seeds of change are present but without funding they will dry up, as one of the respondents from PHELA Health and Development Communications (PHELA) stated:

I think as part of what is happening in the Southern African Development Community (SADC) region, we got interested in the findings by the SADC think tank that MCP was one of the major causes for HIV, so we took that up and said we need to find out if that is applicable in Lesotho, if that is so in Lesotho. And we agreed in the region that all of us were going to investigate that in the different countries. So when we did that, it really opened up a lot of information that pointed to the fact that it is really a factor that it is true. So we started going with that and we had radio talk shows where people gave us information and a lot of times when I was on air people would phone in and say for the first time HIV is being addressed in a way that we understand, cause prior to this we do not, people were talking in terms that we didn’t understand but now we are talking our lives and now we are talking what we think. (ORG_07_3)

The means of communicating and accessing information for many parts of the population has increased greatly due to internet and television. For people wealthy enough to have access to TV and South African stations, the edu-soap-opera show “Intersexions” was described as provoking prevention dialogue:

…as the story unfolds you find that… It’s very good. It was very well made…IT was good. VERY. Everyone after it ended they were saying “hayh if I would ever cheat after watching intersections then I would know that you have no ears”….that show that I was telling you about it got people to talk, it got people to talk…

Media campaigns such as these that are tailored to the specific, identified quandaries faced by the population evoke responses that need to be exploited and reinforced through dialogue. Participants noted
that most people in Lesotho, hear radio programs or see television campaigns about HIV that may touch them but often do not have the opportunity to talk, ask questions and internalize the information.

As already discussed in Chapter 4, and again in this chapter, by 2012 talk about the sexual transmission of HIV and AIDS had often been pushed out of the personal sphere and relegated to the structural—hospital/clinic, work, or school. However, the act of listening and watching real stories, being given edu-tainment information in a dynamic way, and having the opportunity to ask questions and critically interrogate what people think they know, had the potential to break through HIV denialism, desensitization—“it’s not my problem”— and to awaken the personal behavioral and social aspects of change.

One of the dominant findings in this dissertation is how the act of qualitative research, the practice of conducting interviews, transcribing, the first hand relationship with evidence that qualitative researchers have is a valuable resource in the diffusion of prevention information and more importantly as an awakening, or raising of consciousness, that can lead to personal and social change. The concluding example synthesizes what I have tried to demonstrate in this section by the juxtaposition of the attitude, “it’s not my problem,” with that of the veins of hope and change discussed by the participants. The excerpt demonstrates points made in Chapter 4 about true praxis and the role of professors, research trainers and the academic anthropological context on changing the world views of young people.

First of all, let me tell you this. Before working on the project, ok I was this generation where it was decided that like when we got to school all of a sudden HIV, like government started to decide to be involved. And that we had to learn about (it). When I was a freshman every single, from our orientation to the first lesson of every single course that I took, and I was a [subject] student right, so all my subjects were [subject] except for two. Because I had to have two fillers. Every single lecturer, every, the beginning of every, my first lesson in every single course, they all said the same thing. HIV, HIV, HIV, HIV and it was all during the shock campaigns. AIDS kills the scare tactics. And they would say stuff like, "count from your right the fourth person on your right has AIDS is positive, whatever, whatever" and then you would count and some people would be like "whoo" and laugh and I would count and be like no matter where you start from the count there is always going to be the fourth person. I might be the fourth person in somebody else's count, just because you know somebody else I'm not the fourth person in my count it doesn't mean that I'm not in somebody else's count, and I know for a fact that I'm not HIV positive because I have never had any contact with anything that could give me AIDS. At this point I have never even had sex in my life so I'm like I haven't had sex, I haven't done this, I haven't done this....I'm not HIV positive so immediately what happens SHUT DOWN. So from
then on I didn't even see the posters, I didn't hear anything I wasn't, it was like numbers, statistics they could talk all they wanted it was white noise.

I did not hear anything then I accidentally ended up doing anthropology. And my lecturer, especially my final year, like our dean of department of Anthropology happened to be the lady [Name of Professor] and she was [Leadership Position in HIV Research/Practice] So it just happened to be her and so I think our first semester was like covering a lot of health and public health and you know AIDS in Africa and Southern Africa. And so, that was like the first time when it started having meaning when I started to hear and I started to understand the stories and people.

And then I had a friend of mine who contracted HIV and honestly she could have avoided, she did not have to have had it she was careless. It was as simple as that. She knowingly had unprotected sex with somebody who, who everybody knew was HIV positive. And only for the benefits. He was a rich guy, he drives a fancy car, he gave her money and stuff like that and he told her I...and we ran away from like...we met this guy as a group at a club and he was wearing, it was at a club it was a night, it was summer and he was wearing morning shoes because his feet were so swelled up he couldn't wear shoes. He could barely walk, he was walking with a walking stick. And he had his driver helping him to sit, he wasn't even drinking alcohol like he was at AIDS stage. And he was starting his ARV treatments then. But it was known, it was known because he spoke. He was one of those people who was like, a woman gave it me and I'm not dying alone. Like he was like that. So when he tried to make advances towards us as a group we were like "hell no, we're not going there". But she wanted those things. She was from a...you know when we were talking about with Limpho about in South Africa that you have the private school and then you have the suburban kids and you have the location kids. She was like from the locations. And so she was suddenly in a different class from us because we were more suburbs and private schools educated and stuff like that so she was more, she had that other lesser education. So she wanted those things, you know those things that she didn't have in her family. Like for us we were so safe because we got allowances from home, we lived in a flat that was paid for, money everything. money to get to school, we actually had jobs we had part-time jobs when we were in varsity. But the money we made from our part-time jobs was like our spending money. Like that was money to go to clubs every week, that was money to go buy new clothes at like nice high end boutiques like it was play money for us so it wasn't money we needed to live off. And so because she was friends with us, and you know how kids, you don't think about things like, what impression are you giving like the fact that, that the thing is that we included her you know, we would pay for her food, we would buy her, when we went shopping and we bought ourselves stuff we would also buy for her. So I don't know why so she ended up dating that guy KNOWING, knowing and he said and he told her and when she started dating him, we were like ok we sat down we talked to her "do not have unprotected sex with this guy, no matter what, we would rather walk out of his house in the middle of the night you can call us we will get you a cab, and come and get you" and she went and she had unprotected sex with the guy.

And then her family like they were in denial about it. She was an orphan first of all because both her mother and father had died from HIV related illness. And they didn't take her, she did not go and get medical aid/help. She was twenty and she was dying at her house. She had kidney failure, she was wearing a diaper, she was skin and bones she had some sort of blood disease I mean, she was living in a house and what they used to do is that they went to this church. Those pseudo-churches that I talked about the "Christian Faithful" and they would pray for her, and they would say she was being bewitched and so I saw this first hand. And I was like, "what the hell?" They would not take her to the hospital until an aunt of hers who wasn't on good relations with that
family because she wasn't going to that church. Went into there, picked her up, carried her on her back, like you know how Basotho carry their baby, and took her to the hospital.

She started getting blood transfusions she started getting treatment and going on ARVs she lived. But that's how extreme. She came this close, she was on death's door step so this was during my final year, this is when [Professor’s Name] was my lecturer this was when I was seeing it, I was for the first time it was...but it wasn't the first time that I had came into contact with AIDS but it was the first time it meant something to me. Because when I was in high school I actually have a math teacher who died from HIV/AIDS related whatever. We knew and we used to laugh about it. We used to laugh at him like "hahahaha" you know he was from Uganda. So we were like "hahahaha" it wasn't like, it wasn't like it wasn't there but it didn't mean anything to me. So then I left varsity and then ching, ching fast forward now I'm working in this project (2008 MCP research project) and I'm interacting with these people and you know so it was like, it was just drilled it wasn't numbers anymore, I wasn't listening to numbers and the statistics I was meeting people. (Keromang)
CHAPTER 7. CAPACITY BUILDING CONSEQUENCES IN EMPLOYING LOCAL RESEARCHERS

Figure 19: ISF framework applied to describing the prevention support system through increasing the capacity of local researchers. Copyright 2008 by Springer adapted from (Wandersman et al. 2008) with permission.

7.1. Introduction: Increasing Local Capacity Through the Inclusion of Local Researchers

This chapter presents data bringing to light the general and specific capacity building consequences in implementing a qualitative health research project. In the first section I present findings on the former research team members’ motivations for applying for the MCP opportunity, their perceived level of capacity in understanding, implementing, and conducting ethical research, and some of the anticipated consequences such as networking, future work opportunities, and HIV activism. I also present team members’ perspectives on the overall experience, whether that has motivated them to seek opportunities to work against the spread of HIV in Lesotho, or if it has left them disillusioned in seeing the possibility for a change for the better against the spread of HIV in their country. I also present their judgements about the overall value of the research personally and in terms of HIV prevention.
7.2. Research Assistantship: Original MCP Project Recruitment and Retention

All respondents claimed they learned about the opportunity to be a research assistant for the original MCP study through an advertisement in the local newspaper *Public Eye*. Nine participants saw the ad themselves and three participants had a family member or close friend/partner refer them to the ad. From a human resource recruiting perspective, this confirms that people are still reading and responding to this source of advertising for employment in Lesotho. Several participants commented on the openness and transparency within the recruiting and interview process. They compared it to the perceived norm in Lesotho where people believe that most jobs are given not based on merit but on nepotism and political favoritism. When asked, ‘What motivated you to apply for the position?’ responses revolved around five motivating factors (see Figure 20). The most frequent (nine out of 11) of which was the reference to needing a job or seeking a higher paying job. The second most frequent response (four out of 11) was related to the desire to increase knowledge such as wanting to know what is behind MCP, to know more about the spread of HIV in Lesotho, or to create knowledge to help the epidemic. Other factors included

![Motivation to Apply for Researcher Position](image)

*Figure 20. Motivation to apply for research assistant position*
enjoying research in itself or implementing research regardless of the topic, interest in the experience of traveling and seeing other parts of Lesotho, and the idea of being connected to the institution of UNAIDS.

**Job_Money.** While subtle and not exactly a socially desirable response most respondents admitted that they were motivated by economic reasons; several respondents highlight the fact that it seemed like a strategic opportunity in terms of opening up future opportunities or getting higher pay be that to help parents, family or themselves:

What made me apply for the job, first of all I mean I was a new graduate from the University of Lesotho so I was more eager to enter into the labor market then, and secondly I needed some income Sharon two, to, have some income in order for me to help my parents and help my family and myself as well. And thirdly was to try and see what contribution I could make in terms of trying to find solutions to the problem of HIV/AIDS that we have in Lesotho. (Lebona)

Participants noted that they needed a job and this opportunity seemed like something good to get paid and to prepare for the “next big thing”:

The truth be told it was in two folds. Well, first of all, I was unemployed, so I just wanted something to do as I was waiting for something bigger to come along. But, secondly, it actually caught my attention because I was really curious to know how this thing works. The AIDS thing, I wasn't really so much exposed to it, so I decided that you know what let me just join the survey and then see what comes out of it. (Paseka)

One participant blatantly explained that her interest in applying had nothing to do with the topic but all about employment:

Tebello: Honey, I was unemployed. It was one of many (applications), but I also felt like I had some prior experience being a research assistant. So I felt like I had the job experience…It was one of the applications that I put in and it was the one that was successful. Essentially that's how I got in. I GOT THE JOB. It wasn't because "oh my God I won't sleep unless I get this job" Yes if I'd gotten it somewhere I'd be working somewhere else right now, or I would have been working somewhere else at that time.

This is an important difference between degree holding researchers in resource rich and resource scarce settings. In resource rich settings, researchers have the flexibility to often follow a direct line of research interest and specialization. But in resource scarce setting the priority is getting a job and the “topic” or area is a secondary concern.
In the context of international health, and specifically clinical work, it is common to hear of ‘brain drain’, where the most qualified of the population heads outside of the country for better work and pay. I would like to propose another aspect of ‘brain drain,’ which is ‘inverted brain drain.’ This is where we see intellectual and capacity colonization through development research, in this specific case, HIV/AIDS research. I first wrote about this in 2007 after working with faculty members from the National University of Lesotho NUL, who earn relatively meager salaries compared to their educated counterparts working for development agencies. University faculty were easily seduced by temporary, but lucrative research positions, which consequentially undermined locally led, long-term, and even “unprofitable” studies critiquing the dominant paradigm of large funding agencies. One participant describes the phenomenon during his explanation of why he, despite being a civil employee, applied for the MCP research job:

Tsebo:... that the government has put into place what they call the subcommittee. It is a kind of contract where a civil employee will go to another organization that is not even falling under government and work with those people not getting paid by government but getting paid by the other organization. This is done only if it is believed that whatever this stint is, that this person will take back and the organization (civil department) will improve on its return because the idea is for such a person to go there and return, but the return having you know accumulated...So opportunities like these, they are really always good and obviously there are also financial implications because you know...the salaries for government employees here at home are...are really quite meager. And well I guess that is the state of our economy, it doesn't matter... but, one is always on the lookout for you know...some extra buck here and there. So you will find that even if you get seconded to say an organization that is willing to actually compensate you better than your workplace proper, than that in itself is also quite an attraction.

To Know. For some participants the motivation to apply was related to a desire to know more specifically about the topic of HIV and MCP. As one participant explains:

I had in my first degree did some small study on why people could engage in extra-marital affairs, you know, this also had something interesting. I was interested in some way this study seemed to be so interesting, I would really be, you know contented to know really what would be the cause behind this influencing people what is the issue? What are the issues around the MCP and so forth. (Secheba)

See_Country/Enjoy Research. For other participants the idea of getting to travel, see the country and conduct research, regardless of the topic, were motivating factors for applying:
I think because I was already involved in one research you know, and it was kind of nice to meet people of different backgrounds and all that so I thought why can't I just go ahead and be another research assistant in another project and see where it gets me. And also it's always nice to know about you know other about how other people are living or to learn about many other places outside of Maseru cause you know when you live in a big city that's bigger than other cities you don't have any motivation to go out of your comfort zone and to go learn about other people. Except for when you have to…(Khabane)

**UNAIDS.** Two participants highlighted the association of having the opportunity to work specifically for UNAIDS that motivated their application for the position:

I was interested in finding out more and also because it said UNAIDS. And I'd been reading articles and stuff about what UNAIDS was doing at the time in the world. They were having a lot of conferences. I think that was during the time when there was a move to go from treatment to actual prevention. Like that was a transitional phase. So there was a lot of things happening in the world….I didn't even know that it was a National AIDS Commission thing because it said the study was with UNAIDS and that was for me the thing. I was like ok I'm interested in knowing and finding out more. (Lebohang)

This section has established the types of motivating factors at play providing an idea about why research participants applied for the research position. The next section delves into the type of capacity built through the nine-month experience of working on the research team, regardless of their initial motivations for the job.

### 7.3. Building Local Capacity

#### 7.3.1. Understanding and Implementing Qualitative Research

One of the outcomes of the MCP project was to increase local capacity in qualitative research methods and the ethical conduct of research. The question was asked, ‘By the end of the research how would you rate your level of capacity in the following using a scale of 1 to 5 (where 5 is the highest level)’ (Figures 21 and 22).

As noted previously, most research assistants had more previous experience with quantitative than with qualitative research. However, through their participation in the MCP project, several realized
the depth of information gained through the use of qualitative methods. As one of the participants states:

I understand the importance of qualitative research, the depth of, the importance of talking to people and listening to their stories unlike the quantitative research where you maybe get the yes and no answers but in qualitative research you get the REAL stories the REAL content of what people have experienced and people are just free. It gives you the quality of what you want to know. (Mosa)

One participant consistently gave the lowest ranking and more negative responses than all other team members throughout all of the ranking exercises. For the most part this outlier felt that her experience did not go beyond what was learned at University, “It was just kind of putting the stuff that I'd
learned from University into practice, that's all it was”. This was in direct contrast to other team members who underlined that the experience furthered their theoretical and practical knowledge from university.

Five for me. First of all the only time I'd done qualitative research was actually at school as part of my coursework. Secondly, I had done some research I had worked regionally with government departments, different ministries, like the ministry of statistics or ministry of forestry and it had usually been quantitative. I hadn't actually had a chance to try out the finding out the why. It was always about the statistics, the numbers. What I learned was way more than what I knew, like you did the course (university) you got the skills, you got the philosophies behind…we learn about the theory and we get a little bit of practice, just a little bit, but you don't really get to see and know. So for me, it was a five because I learned so much more. I knew firsthand what it is to do a proper qualitative study, the pros and cons, the effort that goes into everything that happens…the bad stuff the field work like you cannot lie to me about field work. Like I KNOW, I've been there I've got the scars, I've survived, so I know what to expect and going into any kind of field work I already know what comes with it. And some of those skills are things that I learned there… I've even been able to apply in a different way. So for me it was a five. (Keromang)

Like the previous example, the next participant discusses the way the experience of being pushed out of his comfort zone during field work provided lessons he applies in his current leadership position:

The funny thing about all that experience was I'd guess we'd never been, I'd never been out of my comfort zone.. I'd always been used to getting whatever I wanted I'd always been used to getting everything that I needed just right there. And there I was stuck with this situation, after walking for something like forty-five minutes to some village that was on top of a mountain and when I got down there wasn't anything to eat…we had to eat anything that was there and that's when I learned that there are times that you eat stuff that you had never eaten before. That you'd probably even never eat! [canned fish] I remember I was using my front teeth to chew the fish. It just wasn't edible food but I just had to put something in my stomach. That was a nice experience even up until today when there is lots of stuff when there are hardships at work I still try to draw from some of the stuff that we came across. (Khabane)

In Chapter 4 section 4.3.2.3 I provided examples from (Pisano 2008) who argues about the key role of recruiting middle class degree holding civil servants to perform field work. We see in the above example how field work forced the research assistant to experience the rural realities of his own country. Not that urban individuals do not travel to rural areas but for some individuals it is often in the context of weddings, funerals, holidays so they do not experience the raw reality of rural living. The field experience helped this participant to get out of his comfort zone and learn lessons about hard work in difficult conditions. Keeping in mind that these individuals went on to work at Universities and in leadership
positions in government and nongovernmental agencies, results indicate that the investment in training and experience from the project went on to other entities in Lesotho:

Because I’ got a lot of experience from that, so much that when I had to go and teach it to my students ‘cause I teach research as well, I found it to be very easy because I told them this is how you conduct interviews, these are the kind of questions, probing, you know. (Tebello)

The participant who gave the rating of four reflected a sentiment that I have heard several times in different research projects, the desire by research assistants, hired to “collect data,” to have more of an active role in the analysis process:

Lebona: I think I mean that is a very valuable experience on qualitative research. On the practical side just to see how it unfolds. I mean looking at, first of all, the training that we were provided for before we went to the field and the practical side of training looking at the whole ethical clearance that needs to be done, looking at the transcribing, translating, and understanding how qualitative research is conducted. Going out into the field making interactions, building rapport, with your potential respondents, recruiting I mean making sure, just trying to see how best they can be involved in the research going back to office listening to the audios translating, transcribing them making quality assurance.... [But] you see Sharon I mean some of the data analysis was not done by us research assistants we processed data and…we had boundaries, the data was not analyzed by us. If we had an opportunity to analyze then I think I would have been a fully baked qualitative researcher!! (laugh)

Of special note, research assistants were actually part of a collaborative analysis process where they assisted in defining themes and developing the codebook. This involvement is often a higher level of involvement than many other research projects offer. Oftentimes, research assistants want training and practice in analysis software and in the process of analysis and synthesis, but many times in “north-south” collaborations the north does not budget for this type of capacity building. Nonetheless, most participants rated their capacity for implementing qualitative research at 4 and 5. They noted an increase in their ability to perform various steps in the research chain, from adapting the research tools to the local context and language, recruiting, building rapport, conducting interviews and focus groups, transcribing, translating, and for those who remained on the dissemination team—synthesizing and disseminating the research:

The MCP study was done at the National level. And for quite some time while it wasn't easy to put in place some components that we had been trained on, but with time I found myself being perfected, you know with all of the reviews, meetings practicing as a team in support by our
supervisors we were sharpening the skill which ultimately I thought well, I can do it anywhere and everywhere and VERY WELL. (Sechaba)

7.3.2. Ethical Conduct of Research

![Figure 23. Perceived level of capacity in conducting ethical qualitative research after the MCP project.](image)

The most notable sense of capacity built is reflected by the majority of participants giving a five in response to the question, ‘How would you rate your level of capacity in conducting ethical research?’ (Figure 23). Even the former outlier who gave threes to the other responses increased to a four in response to this question. Participants noted the comparative difference in the amount of attention given to training and maintaining ethical standards from their previous projects and university experience.

*Interviewer: So how did that training differ from previous ethics training that you'd had?*
Sechaba: yeah you know previous trainings were I could say general. But this was specific not only specific but also practical. This is what makes it much more valuable and rich.

*Interviewer: Do you still incorporate elements of it in other things that you have done?*
Sechaba: yeah you know following those studies. I haven't only been incorporating I've been assisting people including my wife who is studying for the Masters now. You know she is doing this research and I'm assisting a lot around the ethical considerations and developing some other components. So I think yeah it has helped me a lot. At work also, you know for each and every project that we do, we have adopted the culture of conducting a baseline that would help us to mark progress, the change, the social change that would come with our project, so I am applying the skills that I had from all those trainings.

Institutional Review Board (IRB) requirements and training over the last fifteen years have become an integral part of the U.S. research training experience. U.S. trained researchers can sometimes take for
granted the expectation of practicing transparency, respect and avoiding coercion with participants.

However, in settings where institutional training in IRB and ethics have been introduced more recently the importance of research participants “understanding” and that you do not “make choices for them” may not be so obvious:

Khabane: let's see its basically the ethics stuff that you learn in talking to people, in interviewing people. Stuff like confidentiality, like having to make sure that people agree to whatever you're going to implement in their community, they have a proper understanding of it, they're also involved in the choices that you make for them, you don't just make choices for them but most of the time you involve them so yeah, yeah.

These aspects of informed consent, maintaining confidentiality, and respecting the autonomy of an individual and a community are not necessarily natural in many research settings. Based on conversations we had at different points during the training in 2008 and again in 2012, it is evident that the norm in country for engagement may have been more of pressing, coercing, or bribing people into participation. These participant responses are noteworthy because they reflect a new way of thinking and practicing that despite having been trained at the University and having research work experience they did not have prior to the MCP project:

some things when you mentioned them you see that, oh this makes sense but then it wouldn't just come to you naturally. To think, you also think if you want something out of a person you can just twist their arm a little (laughing), so after learning about research ethics I saw that (ahhh) (tone of trouble-maker) eh the way things I have been doing, the way things have been happening around here (laugh) is not quite right. So and then it was surprising that people did not even want anything. (Neo)

Other participants noted a sense of surprise that people were willing to volunteer when given an opportunity to understand what is going on and how it will be used and that it is for the benefit of others:

I realize that it’s always good to get consent...when people want to be in a research. When they participate voluntarily, they tend to give honest answers rather than when they feel like they're forced. When they understand what the study is about, how it’s going to affect them, we don't need their names, they're not going to get benefits it’s just that they’re doing this for the benefit of everybody. People, you know are basically, good. There are some people who would want to participate, you know, just to do the right thing, you know, to give their voice...and you know I found when we were talking about ethics. People would ask why did you choose me? and I'd look at them "no, no I didn't choose you. I just, you were randomly selected, you could have been somebody else, so I don't know you. Do I know you?” So it’s always good to ask them "do I
know you? Do you think I know you? Do you know me?” So you see what I mean? So that it eliminates the, are you targeting me thing. You see? So, ethical research is very challenging. (Tebello)

This excerpt also highlights the role of explaining selection criteria where the research topic has an association with a stigmatized disease or behavior. By explaining the randomness and clarifying the “stranger” status of the researcher to the potential participant, the research assistant learned both to reduce the perceived notion of having been “chosen” based on behavior or disease status often felt by people recruited into research. The explanation of the randomness also reinforced the importance of absolute confidentiality by the research team members in relation to their participants—not being related or knowing each other—a dynamic that for many researchers is hard to comprehend when working in smaller communities, where everyone “knows” everyone else. This is a key concept that may be underestimated in clinical trials and other translational research settings. When people feel they have been chosen for a “reason” or that they are participating for financial or for some incentive they are more likely to give false information, in order to reciprocate, earn or keep the reward, or to minimize or maximize the behavior or aspect that they perceived you targeted them for. Informed consent is more than just a requirement or a process it is also a philosophy of practice that influences the quality of research:

…it was the fact the way we interacted with people. So it wasn't just that we collected this information from them in pristine and correct settings it was like methodical and surgical but it was also the interaction with the people. I think that's where the success from the study actually came from was for once we didn't treat people like guinea pigs. You know. They were not our lab rats. We had the respect, we had...yeah...we respected and the way we talked to them, we didn't talk down at them we didn't use them, we asked and we were given permission that's why they let us into their lives, I think. And that's why they opened up because of the WAY we interacted with them. It was refreshing for them but even for us because we treated them with dignity that means we also had to show dignity to ourselves. Even the harmony within like in our group and the way...it was from that I think. (Keromang)

7.4. General Capacity

This section contributes to research demonstrating how training and providing experience to locals helps to develop expertise and local capacity to investigate present and future issues. I describe some of the anticipated and unanticipated consequences of local involvement.
7.4.1. Anticipated Consequences

The term “anticipated consequences” refers to the type of consequences in building local capacity that are typically desired by both the development agency and the employees. In this case, the consequences of the original nine MCP team members, who experienced the entire nine month training and study implementation, working on a high visibility project that included large, well reputed, and well-funded stakeholders. I discuss the consequences of their career path, networking and HIV activism in Table 5.

Table 5. Career path of research team members following their MCP research experience.

<table>
<thead>
<tr>
<th>Researcher</th>
<th>Noted Connection</th>
<th>1st Year HIV Work/Volunteer</th>
<th>Type of Work 1st Year</th>
<th>4th Year HIV Work/Volunteer</th>
<th>Type of Work 4th Year</th>
</tr>
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<tbody>
<tr>
<td>K</td>
<td>+</td>
<td>+</td>
<td>G/NGO Research</td>
<td>0</td>
<td>Department Social Development</td>
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<td>University</td>
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<td>M</td>
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<td>+</td>
<td>NGO SBCC</td>
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<tr>
<td>N</td>
<td>+</td>
<td>+</td>
<td>G/NGO Research</td>
<td>0</td>
<td>Department of Urban Planning</td>
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<tr>
<td>T</td>
<td>+</td>
<td>+</td>
<td>NGO SBCC</td>
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In the four-year period between 2008 and 2012, several individuals crossed between work at the university, NGOs/international organizations, and the government level. None of these individuals noted working in the private for profit sector.

Within the first year after the project two out of nine participants went back to pursue a higher degree, while the other seven went on to work for other HIV projects. All of the participants noted a connection between the experience on the research team and their post MCP opportunities. One participant (the same with consistently lower ratings above) noted a negative connection describing a disillusionment with the system and how funds were managed that led her away from working with HIV related projects. The other participants described positive connections. These positive connections fell largely into three categories, having been recruited because of the association with the MCP research.
team, applying for a job and believing that the MCP project associated with the UN led to the job, or reporting an increase in workplace communication skills that furthered their upward mobility for future positions. As one participant explains his perceived connection with the MCP project experience and his future employment opportunities:

After working at UNAIDS man, I've basically never failed at any interview. I guess everyone who interviews you when you tell them that you come from any UN related work. Everyone just wants to snap you up because they understand that you have probably had better on job training…it's hard to get work there you know Sharon. For everyone else it’s very hard to get work there. Mostly you find that its brilliant people who get to work there at the UN offices. Its either you're brilliant, or you have lots and lots, and lots of experience or you’re highly educated. (Khabane)

As discussed previously, about the importance of the exposure of middle class educated individuals to rural setting, the experience of working at the UN building and for the National AIDS Commission provided the research assistants exposure to upper class, local leaders as well as foreign expatriates from all over the world. They were forced to learn how to communicate with people of different ages and from a range of socio-economic and educational backgrounds. The next participant describes this type of learning:

Being part of the research team did hone my communication skills. You know I feel like because you have to learn to communicate with people from different families, you know. Indeed it’s the same culture but its different understanding and interpretations of the culture. So you have to be culturally unisex, in a way. So that taught me to be able to communicate with people without letting the other one feel like you don't care about me. And that's a skill that has served me very well. (Tebello)

Four years after the project, two out of nine former research assistants still worked formally and directly with HIV projects. One participant was conducting higher degree research related to HIV and volunteering in the field. The other six were employed in non-directly HIV related work. Three participants reported a type of “disillusionment” with HIV related organizations and projects (more fully discussed in Chapter 10). Two of these individuals stopped working all together in HIV related activities and one participant actually refused work that was offered and instead worked for free full-time on HIV
related activities that directly related to the MCP project. By 2012 only one research team member was involved in unpaid voluntary HIV related activities or activism.

7.4.2. Unanticipated Negative Consequences

When asked, “Did you experience any consequences that you were not expecting due to your involvement in this study?” most participants responded by talking about how they did not expect the way the study would change their ability to talk about sex and their own attitudes and behaviors regarding their own sexual relationships. When probed about unanticipated negative consequences from family, friends, or in job opportunities they all indicated that there were none, and three respondents highlighted instead positive consequences in their life. As one participant explained:

I think it was more positive. Because, if we can get to talk about sex like openly, and I think that there is nothing much that can be ashamed to talk about so it made like our relationships much easier, both with partners, my parents, everyone. Easier. Like I never thought before. (Neo)

Several participant linked this lack of unanticipated consequence, with the unexpected outcome of learning to talk about sex and relationships openly. Furthermore that learning to talk about such sensitive topics, the art of getting people to talk and to listen well, improved their relationships and ability to communicate.

I didn't get any consequences rather I got encouragements, I got, I even considered studying for something to do with HIV and something. I think I got a lot of encouragement from my family, from my partner, from my friends...the communication, at home became easier. You know I could talk to my younger brother, I could talk to my younger sister, freely about everything and then they could talk to me, you know about ANYTHING. So I think that is how it helped us. (Tumelo)

7.5. Motivational or Discouraging-Overall experience as a Research Team Member

As discussed in the previous sections, the research experience had diverse consequences on the research team members. Participants agreed that the experience built their capacity in terms of expertise in conducting, transcribing, and translating qualitative research. They also agreed upon their increased capacity in work-place communications and their ability to apply relatively high standards of ethical conduct that spilled over into their
future careers. They also gave specific examples of the way the experience opened up future opportunities. However, they also described the difficulties in coming face to face with an eye-opening experience like HIV/AIDS. They articulated the conflict between “being human” and being a researcher. This section presents the series of questions that followed the previous questions about capacity and their role as researchers. It explores how they perceived the overall experience of being a member of the research team. Two statements were given with the intent not to serve as a true summative reflection of their experience but rather as a value statement that would provoke explanation (Figure 24):

![Overall Experience: Motivate or Disillusion](image)

Tell me which one, and why, best describes how the overall experience of being part of this research affected you: my experience motivated me to seek opportunities to work against the spread of HIV in Lesotho. OR my experience left me disillusioned for the possibility for change for the better against the spread of HIV in Lesotho.

Figure 24: MCP research experience as motivating to work against the spread of HIV in Lesotho or disillusioning.

Participant explanations for their choices included the realization of just how bad the situation was and that not enough was being done, to seeing that sexual behaviors are indeed a problem but believing if people could talk and understand then there was hope for change.

I think there is still possibility of behavioral change but it depends on whether people are really willing to change their behavior, but I think they’ve…if the mindset can be changed when it comes to certain things I think it can still be better. I am not yet discouraged…I think it’s possible AIDS, we can start talking to the young kids, talk to them… (Mosa)
Several participants linked their hope for the future in the younger generation, stressing the importance of teaching children as well as getting people to talk, acknowledge and deal with HIV. Another participant explains:

I think we can defeat HIV in Lesotho, I think we can. All we have to do is just talk about it, just acknowledge it, know that it’s there. I mean, just encourage people to come forward, encourage people to get tested, just show people that it’s not a death sentence. I mean I think we can defeat it. (Tumello)

One participant’s explanation for his motivation drew on his sense of being Masotho as a responsibility to his country:

Sharon, look I'm a Masotho eh. Before I even become a researcher I am a Masotho and I'm affected either way by HIV/AIDS, so I mean, it’s a fact that HIV/AIDS in Lesotho prevalence is very high and maybe people know and maybe people do not know I won't judge on issues of dissemination of information. But I wouldn't want to have a situation where HIV/AIDS rates in Lesotho are escalating rather than decreasing because that effects our human capacity and also the responsibility I mean for me I think it’s the responsibility of every Masotho to try and make sure that we put in plans and policies and structures that will help decrease HIV/AIDS prevalence in Lesotho. And also I think, I mean, Sharon what's important going back [AIDS] it’s a worldwide problem. Being in that area does not open opportunities for me in Lesotho only but at least you know how HIV/AIDS issues are dealt with in Sub-Saharan Africa, in Africa, and globally. So I mean that opened an opportunity for me to be more involved on HIV and AIDS issues but also understanding, getting to know why people do what they are doing. Yeah. (Lebona)

While speaking about his sense of duty in doing something to curb the epidemic, Lebona also brings in ideas of the way the research experience opened up opportunities to be more involved regionally and globally. It is unclear if he is referring to “opportunities” for employment or to work against the spread of the disease or maybe both. In the next example, the participant draws the connection between his experience of seeing the difference between what people need and what is being done to educate.

I realized that there is still lots and lots of stuff that can be done to work against (HIV)for the prevention of HIV and AIDS in the country. People are willing to learn, people are willing to understand. But when we go to the most rural areas you found that as much as these people are all willing to learn there isn't that much that is being done to increase the [knowledge] of these people about HIV and AIDS. There isn't that much that is being done to help people accept that HIV is there and it’s living within them. Its either you're infected or you’re affected. There were still some of those people that would tell you that they wouldn't accept living with HIV positive people because it would also infect them somehow so it’s...it was all about seeing and realizing the need for educating people more for better interventions than just going around the country distributing boxes of condoms without educating people about HIV and AIDS. So back then there was less being done in the side of educating people about HIV and AIDS. (Khabane)
The above participant is describing what he observes as a real gap between what people need and want, education and knowledge about HIV with what they were receiving—condoms. He goes on to describe how the distribution of condoms and “education materials” became quite a lucrative activity. Unfortunately, enticing individuals who were more concerned with the profits than actually teaching and opening opportunities to discuss the reality of HIV in the community. From his perspective, the situation has improved in recent years. He explains:

Currently the interventions, the programs that are there on the radio, programs on national TV, the programs that have been taken by the AIDS directorate they're much better than the interventions that were there back then. I think back then there was lots and lots of sponsorships for anyone with a private company that is working, meaning an NGO that is working on HIV/AIDS related issues, almost each and everyone who had the know how was starting to organize his or her own NGO just to make sure that they work with issues of condom distribution they work with printing educational materials. Just to get lots of sponsorships to employ their own (incomp) I think the major focus back then was it wasn't necessarily on educating people it was more of people using the opportunity that was there of HIV and AIDS to enrich themselves. (Khabane)

This notion of using HIV to enrich themselves is further discussed in Chapter 10, it is a consistent and re-occurring emerging theme in this dissertation study. He explains that he believed the situation improved, less corruption, when the AIDS directorate also known as National AIDS Commission was given further funding and authority to monitor and evaluate the HIV activities throughout the country:

It has changed a lot. I think it also had to go down to the way government was monitoring. I don't think there was monitoring that was being done by the AIDS directorate. Because back then, they didn't have transport, they didn't have proper resources unlike now. Now they have lots of resources, transport, in terms of human resource they have lots of resources so it’s much easier for them to monitor all the NGO's that they've granted, that they've given funds to. (Khabane)

Unfortunately, right before the time of this interview in late 2011 the NAC/AIDS directorate he is referencing, as helping the situation through monitoring, had ceased functioning. Four participants, including former research assistants and some organizational representatives commented on how things were starting to turn back to NGOs doing what they want without coordination and proper evaluation.
7.6. HIV Prevention Difference

In order to understand research assistants perspectives on the value of the qualitative research experience, participants were asked: The first participant acknowledges the difficulty in measuring the effect of an interview or focus group discussion on an individual participant. However, he describes why he felt the process of remembering; reflecting upon sexual behaviors and then being asked directly about HIV may have had a prevention effect on those interviewed. As he explains:

Look Sharon, that's very difficult to measure, firstly, but what is important is for people to know, to understand, because I remember in one of the interviews and focus group discussions, I still remember very clearly when people left who'd spoken about their sexual history and stuff like that concurrency and blah-blah-blah-blah. And then there was the question on HIV/AIDS "you tell me, what do you know about HIV/AIDS". I mean people would say "OH WOW" they talk about their sexual history, they're promiscuous, they have concurrent sexual partnerships and whata-whata-whata-whata and then you get to the end of the interview and ask people, "tell me what you know about HIV/AIDS" so people can reflect on their sexual history. I think that was an opportunity that they may not have had before, which made them even more aware, I mean looking at the reality. You can hear about HIV/AIDS on the radio, you can read about HIV/AIDS but when you, when it's a reflection on your sexual history and how vulnerable you are at the risk that you are putting your life on and other people's on and engaging in concurrent sexual behavior without protection. I mean I think that really contributed a lot, but the difficulty, is for now I don't know if we would be able to measure how that has impacted or changed lives and decreasing the HIV/AIDS in Lesotho. (Lebona)

Like the above male example the following female research assistant describes the same process for research participants of talking, having someone listen without judgement and then listening to yourself provoking a type of reflection that may have led to behavior changes.

I think so it might have been, I am sure about the one-on-ones when someone is listening to you without judging you or you are talking, when you are talking you are actually listening to your own words and your own thoughts. You are saying them out loud and you are getting to listen to them and then you judge yourself, everyone has a conscious and then you'll say maybe I should stop doing this, this is not right, if you see that I have talked to this person about five lovers what is wrong with her having maybe two or one? What do I get from that? Am I just going to make myself sick? You'll think that it has something subconscious or I think it will even if it may not be fast somehow a person will begin to think and try to change their behaviors. (Neo)

Most participants were confident that the individual in-depth interviews had this type of prevention consequence. Some participants believed that the focus group discussions were also important prevention inputs, even if the participants were not talking and thinking about their personal behaviors. In fact, the
male research assistant all agreed that the focus group discussions made a difference with respect to HIV prevention. The following male researcher describes why:

Because it raised some consciousness in some of the people you know if a question comes up and its addressed or not necessarily addressed you know in a focus group discussion the flow of the discussion could give a certain understanding to a particular person in which case the one who didn't know much of the information could know it right then. Certain questions raised and answered by the very same people other colleagues would realize oh now this is how things are, this is how other people perceive this is the perception for other people. And probably in a situation where a group comes up and says no this is a social problem you know and they all agree, that brings consciousness for all of them that this is the challenge, it’s a social problem that we have to address so by itself it says we agree to this as our problem that we need to address so its directly having an impact on people. (Sechaba)

As discussed in Chapter 4 (section 4.3.2.1) the act of discussing, like the STOP AIDS program in California, naturally evolved into prevention interventions because it was a rare opportunity for people living through the same problem to be led through a process of reflection. A process that consequentially leads to problem identification and a realization, like the participant above describes that it is a “social problem” that can only be resolved through collective action. The next example, also from a male research assistant, emphasizes the importance of having an opportunity to discuss HIV and AIDS issues with a group of age mates:

Khabane: Focus groups did make a difference…There are hardly ever opportunities where people sit down and talk about HIV and AIDS issues and HIV related issues. Especially people within an age group. So with focus group discussions and the way we're holding the focus group discussions I am of the opinion that they actually made it easier for people to open up people to talk about that. After we were having those focus group discussions, as we were taking our stuff leaving the village, you'd leave people there like still sitting around in corners talking about the questions that were being asked, talking about the responses, talking about HIV and AIDS. And you'd realize that you have actually triggered something in these people to start talking more about the practices, talking more about preventive measures, talking more about their way of doing things.

Interviewer: And how did it make you feel?
Khabane: Proud you know. It would make us proud…it was really weird it’s like I think people don't, didn't really have a forum to kind of have that sort of discussion and you'd find that people are really apprehensive in the beginning but then you just get one person who says this one thing that's really controversial and it just fires off. It was interesting. Some interesting discussions and I think it kept going like after… I should think so cause they seem to be talking after they left.

Unfortunately, there is no way to know if the conversations that began during these discussions continued. Because qualitative research is seen as “research” and not an “intervention” no entities,
research organization or NGOs evaluate the effect of interviews and focus group discussions on participants. Obviously, this is not important in every setting. But like the unique situation in Uganda with Maxine Ankrah’s (discussed in Chapter 4 section 4.3.2.2) research team that “spanned across the country” the act of getting people to talk and think about a socially sensitive topic such as HIV and AIDS may have an effect that thus far prevention researchers are not measuring.

After asking their opinions about the prevention difference made on individual research participants I expanded the question about the value of the research experience in their personal opinion as well as its worth in preventing the spread of HIV in the country. In trying to better understand their judgments about the overall value of the research experience, I read two statements to participants and asked for their level of agreement and why they gave that rating (Figure 25).

![Graph](image)

**Figure 25:** Participant responses about the value of the MCP project based on money and time invested.

Two participants gave a value of three. One gave the rating because of her perception of the report and results not making it into programs and her suspicions about the mismanagement of funds:

…let me tell you why,’ cause I don't know what happened post study, I don't know what happened with the findings I mean I remember being like "hey is the report ready yet?” and finally seeing it and finally reading it but I don't know if anyone else took out the time to actually read the report. Which I don't think they did. And I know it was supposed to feed into all sorts of
different studies, and I heard now that the National AIDS Commission is shut so I'm just like, hmmm what happened with....there's a lot of stuff, again I'm going to go back into mismanagement of funds but it really didn't make sense to me that we kept flying people out, to come and do the most basic sort of training, who weren't here with us. I don't know if they were doing any sort of analysis later on but I was just like, what is the point of this? Yeah and then we have catering, we have morning tea, then we have lunch then we have afternoon tea and I'm just like is this really necessary? This money could be put to good use. That's how I thought about it. (Lebohang)

The second participant who gave the lower rating acknowledged the good that came out for each of the individuals on the study team but noted the limitations of the study design

I'd give it a four. Ok I'd give it a three. I'd give it a three because there were good things and there were bad things. Uhm the good thing of course is that we learned skills, how to do this, how to do that, you know our qualitative research skills we got to talk to people, we learned things that we wouldn't necessarily have learned, if we had not. But I also felt like the study itself was...I don't know...it wasn't... I felt like it wasn't designed right. Like, it was very mechanical, they were looking for what they were looking for. In a qualitative study of course you're looking for the in-depth thing, but I felt like, in as much as the in depth thing was being looked at there was so many other things that were not taken into consideration. Like people's social economic backgrounds, the fact that how much money do you earn. Do you know all those things have a very big impact on the type of sexual relationships that we get into to...because sometimes we do have sex just to get by (Tebello)

In her perspective, the research would have had more of an impact had it gathered systematic information about the social economic backgrounds of the participants. She believes that presenting sexual behavior results tied to peoples economic status would help stakeholders in Lesotho understand the dynamics of the epidemic.

All the other participants strongly agreed with the statement that the time and money was worth it in their personal opinion:

Mostly we gained a lot in terms of educationally, in terms of conducting interviews, in terms of analyzing, transcribing, translating we learned a lot of stuff we hadn't done that much at school. Secondly, I still believe that the information that was collected it was first class information from most interviews. (Khabane)

The reasons given for the study “worthiness” were linked to their capacity built in qualitative research, the quality of the overall research results and the changes they personally experienced in their ability to communicate in general and about HIV and sex. Another participant explains:
Because it made me part of who I am today, I think I am a better person because of being in that study. I would give it a five... I can do more work now because of that study. I can talk to people in a better way now and non-judgmental because of that study. (Mosa)

Based on participant responses the study had a life changing, long-term impact on their futures.

Revisiting points discussed in Chapter 4 about the qualitative methodological approach, it is clear that the anthropological role of the principal investigators and trainors not necessarily as “cultural expert” but rather facilitator for exploring cultural dynamics, helped participants to understand their own culture and HIV within their specific context. Learning to think about cultural and social aspects of the HIV problem does not occur when trained for biomedical and public health research or interventions. The next participant describes this type of learning about culture:

Well I strongly agree Sharon it was really worth it to conduct such a study. My reasons being one personally, the study educated me, to make informed decisions in my relationship both sexual decisions and other wise and most importantly to understand what people think about sex and sexuality and how different sexes view each other and how the misperceptions that people have about HIV/AIDS and Sex and I mean the whole lot of culture, culture being at the center of everything but it is one of those things that I am really grateful, I am really grateful to have been part of the sex team and I think this is an opportunity that I wouldn't have gained elsewhere so it was really worth it, it was really I am sure 110% agree on. (Lebona)

The second question asked in this sequence about the value of the research, “Given the amount of money and time that went into conducting this qualitative study it was worth it in terms of preventing the spread of HIV. (1. Strongly disagree, 2. Disagree, 3.Neutral, 4. Agree, 5. Strongly agree). This question in comparison to the previous question focusing on their personal opinion in contrast to its worth in terms of preventing the spread of HIV showed much more variance in perspectives.

For those who gave higher ratings of agreeing, or strongly agreeing, that given the amount of money and time that went into conducting the study it was worth it in terms of preventing the spread of HIV, the main reason given is their belief in the quality of the research (Figure 26). They noted it was worth it because it provided a knowledge base on the attitudes and behaviors that could inform larger preventative measures and programming. However, none of the participants stated feeling satisfied that the research fulfilled its potential. Three participants stated they did not know exactly what happened to the results, “I think after leaving UNAIDS I never really knew much about that except for the
Participant responses on the value of the MCP study in terms of preventing the spread of HIV.

Given the amount of money and time that went into conducting this qualitative study it was worth it in terms of preventing the spread of HIV. X-axis is the ordinal value. 1. Strongly disagree, 2. Disagree, 3. Neutral, 4. Agree, 5. Strongly agree. Y-axis is the number of research team members giving the rating.

Figure 26: Participant responses on the value of the MCP study in terms of preventing the spread of HIV.

fact that I still read about it on the internet on google. I don't know what was done about the information” (Khabane). The large majority of participants, including those who actually worked in HIV programming after the MCP project, were not satisfied.

In terms of preventing the spread of HIV. I'll give it a three. In the middle fifty, fifty. And the reasoning is the same. Because it was informative for prevention like the data we got out of it was informative. We knew the behavior, we knew it was happening we had the statistics but now it was the why, why is this happening. So if you want to do something about it and you know that for example, there is low condom use, then you know that that is an area in which to target for prevention. If you know that sexual dissatisfaction is a factor, but then it wasn't worth it on the flip side because interventions haven't been using the information. (Keromang)

This research assistant distinguishes the low rating on the “worthiness” from the quality of the research. She sees the quality of the research being informative, for example reconfirming low condom usage and sexual dissatisfaction as factors in the HIV dynamic. However, the lack of translating this information into practice in interventions dilutes the “worthiness” of the research as it contributes towards HIV prevention. Another participant describes this waste of potential impact:

I would give it a three because the amount of money and everything that was invested in MCP it was a very good study for that reason I would give it a four or five. The reason why I am giving it a three is because I don't know if it has changed people's lives the way it is supposed to. I think the study has or had so much potential into doing something totally different and BIG in people's lives, in terms of behavioral change, but I don't think the potential that I expected has been done. (Mosa)
Another participant gives a low ranking towards the research’s contribution to HIV prevention because of the directive that researchers were not allowed to intervene or give advice to research participants. This topic is discussed in more detail in Chapter 8. The female participant explains:

Three. Because we were not allowed to give advice, even though you can see that the whole group was agreeing with, like not good things, they were...we were not allowed to give advice of any kind. So the decisions that they made and they, if people are from Semonkong and in a certain area you'll find that they have their similar outlook towards something, so if you are not allowed to advise them or you'll find that they still, they go there (to interview or FGD discussion) with that type of idea and they go back with the very same type of misconception so it does not help. (Neo)

The next example points to the problem of politics and the lack of continuity in entities tasked to lead the HIV response in developing countries and especially Lesotho. In his opinion, the study was worth it because it provided quality research findings on MCP but the problem was in the next step. The government organization that was to ensure the information made its way into programming collapsed, taking with it the possibility for integrating the findings of recent studies in Lesotho. He explains:

There is a whole lot of politics of AIDS at the same time in developing countries but specifically in Lesotho example, when... I learned that National AIDS Commission has collapsed so it’s one of those setbacks that are taking us, we are not consistent, its taking us back and forth while we think we have findings that will inform policy and institutions like National AIDS Commission to try and enforce and ensure that HIV and AIDS policy implementation goes in accordance with studies I mean with the findings of the studies which include among others the MCP study. I mean to be honest with you I don't think a lot, the findings, I mean a lot is being done, in terms of intervening based on the research findings of the MCP based on politics and other challenges that especially in the economy our country is facing. (Lebona)

This chapter sought to identify the general and specific capacity building consequences in implementing a qualitative health research project. For instance, we found that the research team’s motivations for applying to this research project were overall economic in nature. Their perceived level of capacity in understanding, implementing, and conducting ethical research were viewed quite highly, and most team members went on to apply what they learned in future capacities of networking, other work opportunities, and HIV activism. One surprising finding was that many on the team had never connected before with the issues of HIV/AIDS, and the opportunity of working in this sector provided them with the
motivation to continue to work against the spread of HIV in Lesotho. However, similar to other campaigns in HIV education, many felt dissatisfied by the lack of application of the research to implement change at the ground level. The following chapter will expand upon this focus of how research team members themselves felt about the research they were doing, and their capacity to deal with an emotionally sensitive subject as HIV.
CHAPTER 8: PREVENTION SUPPORT SYSTEM: HUMAN RESEARCHERS, BUILDING OR EXASPERATING THE CAPACITY TO COPE?

Figure 27: ISF framework applied to describing the local researchers as part of both the prevention support and delivery systems, applying their capacities built through the research experience. Copyright 2008 by Springer adapted from (Wandersman et al. 2008) with permission.

8.1. Capacity to Cope

Using an ethnographic reflexive approach, which can broadly be understood as “turning back on oneself, a process of self-reference” (Aull Davies 1999: 4), the interview guide was structured to facilitate a process of self-reference for the original indigenous researchers’ own reflection upon their personal experience as a researcher (Sword 1999). This approach was utilized to further the body of research on the ethical implications of researching sensitive subject areas. While ethical implications are usually well thought out for the subjects of research, we need more focus on understanding the implications to the research members themselves (Watts 2008). This project builds upon the work of those studying the implications on the well-being of researchers and leaving the field with what may feel like “unfinished business” (Stebbins 1991; Taylor 1991; Burr 1996; Campbell 2002; Dickson-Swift, James et al. 2007).
This approach responds to the established need for more research and published accounts of investigators’ experience in dealing with the effects of conducting studies on sensitive and emotionally laden topics (Kinard 1996; Hubbard, Backett-Milburn et al. 2001; Johnson and Clark 2003; Rager 2005; Dickson-Swift, James et al. 2008; Watts 2008). Investigating the research team’s experience helps us to expand our knowledge of the emotional/personal elements that influence the conduct and output of research on sensitive domains, and of how these personal aspects go on to affect the dissemination of research. This chapter presents the results of some of the long-term effects to the local researchers. These results further our understanding of the different ways that “capacity” is built in local involvement. The chapter explores critical questions about qualitative research methods and ethics within a context of investigating a disease where everyone—researchers and the researched—are either infected or affected.

8.1.1. Transforming Statistics into Stories

In order to further understand the influence of the 2008 MCP research experience, I asked former researchers to explain what it was like being from Lesotho, interviewing people that could easily have been their friends, family and even lover and listening to these stories of love, betrayal, risk, vulnerability, etc? Five out of nine research assistants independently responded using the term “eye opener” to the above question. All participants described how the process of listening to people’s sexual history changed how they looked at HIV in general and how they saw themselves within the larger story of HIV and AIDS in Lesotho. The act of listening transformed statistics into stories. These stories provoked research assistants to take a look into their own lives, as one of them states:

THAT[participating in the research project] was the eye opener Sharon. Like this could actually happen to ME. This is how I’ve been living my life. Like I’ve had seven, eight, ten partners in a year and I didn't even realize it. Because we don't quantify things do we?...Turns out its eight partners in a year and this one made us realize that you could actually count how many people you had sex with. Put them on a chart...or seeing part of myself. I could relate. If things [do]n't work out, we don't necessarily stay in relationships. But we do things in those relationships and this is why you realize that, when the question comes how many people did you have sex with in the last year? How many people did you have sex with? And you’re like eight. It’s like a slap in the face. And then you realize exactly how many times you’re brushing with death. You see it was an eye opener. (Tebello)
The participant was referring to the Timeline Follow Back technique used in the original study, where the researchers asked participants to reflect on each month of the year and list their sexual acts and partners. By performing that series of questions on research participants, researchers inadvertently asked themselves the same questions. They ended up turning the lens back upon themselves, as another researcher explains:

You start first by taking a look at the life your living. Cause it's at times it’s scary when you start to look at what the HIV/AIDS the networks you know that HIV/AIDS makes for itself within one village. I remember we were in, Mokhotlong you know conducting this study, when we found out from two or three interviews that all the guys that we were interviewing actually were saying that they were sharing a girlfriend because they knew that they were sharing a girlfriend and they didn't mind. But probably there were others that didn't know but they were still sharing girlfriends with the same guys. So it was scary to see just how easy it was for HIV and AIDS to spread. I...we had to start looking at ourselves and asking ourselves and asking ourselves a few questions and I guess that's when I started you know...when I stopped playing around with girls and started being a sweet guy and started having one girlfriend, one steady relationship. That's when I started learning about being in a stable relationship. Because before that I guess I was just taking it easy and lightly seeing that I'm still young, why not have all the fun. (Khabane)

In the above discussion we see how this male researcher not only realizes how sexual networks operate in the country but how this knowledge sparks his personal reflection and actual behavior changes. Another male participant explained how the experience of listening to people in interviews and focus group discussions was “threatening”:

For me it was threatening. Because you know, realizing how people react to certain situations and how situations influence their behavior. If someone would say I would engage in MCP just to have an extra support that I don't have for my family. If someone would say that, for me it was threatening. To say I as a person, then if I don't have the means to provide all that would be required then it will make people around me could go out, for example my wife and seek some additional support from someone and engage in MCP. So it was fully frightening for me. (Sechaba)

Participants also described a sense of surprise against their own preconceptions that culturally, Basotho do not talk about sex and especially do not talk about sex with elders and instead finding that people are willing and want to talk. The environment of hearing other people’s sincere stories and then having the space at work to talk about sex, empowered the research team members to open up communications about sex, life, and relationships with people:
What changed mostly, was the way that I looked at HIV and AIDS, talking about sex, talking about problems, relationship problems, talking about relationships. With us I guess with me, basically I'd never talk to my parents about my relationships because I understood that I'd be disrespecting them. But I actually learned that the elders, the old people, the people who are older than us actually love giving us advice. They love talking about this stuff, it’s just not easy for them to open up. But when you start to open all those bridges for them it’s so easy for them to just give you advice. So mostly I guess for me it made it easier for me to talk about all that stuff with my parents, especially my dad and my uncles also. I have an uncle now who is my friend. I can call him now and I can tell him all my problems which I couldn't do before. (Khabane)

For the above male participant the realization in field work of seeing how people are not only willing but enjoy talking about sex and relationships helped him to open up bridges of communication with his own relatives. Female participants echoed the same surprise in discovering the openness of people she had always believed would be closed to talking about sex:

It was really an eye opening experience because even though you know the statistics of HIV/AIDS are that high in Lesotho but listening to peoples stories is a different thing all together because it shows you the reality and seriousness of the situation. There were times when it was interesting, sometimes it was sad because people would actually tell you very sad stories, but it was also interesting to see that people can actually open up so much about sex. Even older people that you would not expect….Because before I got into the MCP study, I was not as free as I am now to talk about sex. So for someone who has never been trained or talked about sex the way we talked about it at our team I think it is a totally different thing. Because to me sex is just another topic I can talk about sex to a stranger and be ok. But I don't think I would be like that, before. (Mosa)

Similar to what happens in many other research studies on sensitive topics, research assistants were touched by the stories they heard as illustrated in the previous examples. Participants used terms like “slap in the face,” “it’s scary,” “it’s threatening” to talk about their reactions. Studies such as this emotionally touch researchers:

I mean we know the impacts and implications of MCP in Africa and in Lesotho in particular. How this pandemic has hit us. And the support and the structures of support to HIV positive people this was not an easy, this was not a walk in the park. I mean although it did not traumatize me personally [long pause] …but I remember one of the team-mates who after her interview crying because she had a very sad story from her respondent. So yeah, this was a very sensitive topic that could have had some bad implications on me…but I mean as a young person it was a very exciting opportunity to get to talk to people and understand what their views and thoughts and ideas are about issues of sex and HIV/AIDS in Lesotho. (Lebona)
The above male respondent paused several times while recalling the difficulty in listening and transcribing such sensitive accounts. He seems to acknowledge that he could have been traumatized but because he was young and the research was so exciting he surpassed the difficulties. The next quote is from the female participant he was referring to as crying shows how the repeated act of hearing difficult realities cultivated empathy:

It was...torture at some point. (long pause) uhhm it was like other parts of the story couldn't be said. It was like you can tell me only the good things then when we had to, when we come to the bad things, but then I had to listen. But eventually, I got used to those conversations so much that I would even ask, I would even encourage you, I mean I would say, "no I know, these things happen" so that you can be freer then just thinking I am judging you. (Tumelo)

8.1.2. Research Encounters That Leave a Lasting Impact

As HIV and AIDS research continues to move from the lab to the real world, potential researchers and principal investigators must anticipate the types of ethical quandaries and the harm/pain they subject upon research team members. Research team members recalled the long lasting effect of particular research encounters:

….people had different reactions, some people were at the end of their hope. They were just hopeless just surviving and some people were positive about life. But it was all these different stories of people who could have...the things like when they told you the story, you were like if only you had KNOWN, if only you had, had a choice you could have avoided its possible you could have saved yourself. Or protected yourself, you wouldn't have to...’cause life is already so hard and your dealing with so much so…it was all these different stories and you don't forget them. You don't forget those faces, you don't forget those people. (Keromang)

Research members often, literally, shared the interview experience, because oftentimes the person who conducted the interview was not the same person to transcribe or conduct a quality assurance check on the transcription, “When you do quality assurance you come across, although I was not the one who was conducting that interview but there were interviews that I mean really got me thinking even when I got home, for a weekend, a week” (Sechaba). Despite the fact that none of the participants noted having unanticipated negative consequences, they all mentioned the emotional challenge of the job; as one participant notes, “the experiences we had in the field some of them were pretty traumatic” (Keromang). As a technical assistant responsible for upholding ethical standards there was always a delicate balance
between reminding the team of the importance of confidentiality, respecting even the voice and the story of a recording, and allowing them to vent and share the loads they were given. They were trained and retrained and reminded to always be careful, even among themselves, not to divulge too much information. They were cautioned to be extremely careful of how they spoke and who was around them during fieldwork and in the office building. They were allowed, and often did, code-switch into Sesotho. This had a dual effect of, one, reminding me of my outsider status, and combined with the immense amount of time spent together in travel and research, made me paranoid for the danger of breaching the reputation and trust of our MCP team as well as for qualitative researchers of the future. Even the study drivers and all study staff, including temporary transcriptionist, were trained with the same ethics curriculum and standards as those going out to the field. During interviews, conducted four years later, team members revealed a little bit about the Sesotho discussions where I was conveniently excluded. They revealed how much their “shared confidentiality” helped them to deal with the difficult stories they were hearing.

It was a nice but touching experience because I remember even telling Lebona after work. I know we didn't have to share the information that we had. But there was shared confidentiality, especially between colleagues. I just told him about the encounter. (Khabane)

Based on these interviews it is clear that the research assistants shared the funny, the good, the bad, and the painful creating a type of collective memory of their cumulative experiences. These reflections also point to the tendency in social science to underestimate the importance of emotional support for field workers.

In trying to understand how the research experience influenced their capacity to cope, participants were specifically asked to describe a particular experience that affected them most. Overall, the objective of this question is to further explore how we, as health researchers, think about our practice; we may formulate questions or design standardized guides, but in the end, the interview is implemented by humans, with humans. Their responses are presented here to reflect the depth of their encounters, and to illustrate the kinds of situations that they were left to deal with in the field.
8.1.2.1 Young Girl

Interestingly, there was one story, which came up in four out of nine responses to the experience that affected the researchers most. This story took residence as a sort of collective memory that deeply moved these research team members—male and female alike.

Tebello: There was this young girl that I did talk to and...she made me feel very sad. She was a girl growing up in the village and back in the rural areas I think it was in Mohale Hoek, ... And so, she married this guy he was working in the mines then he came back sick. When he came back sick because he was single, he was not married yet, he felt like let me get married before I die. And he married this girl and got her pregnant a couple of months after they got married. It didn't even last six months he was dead. So all this girl knows about this guy is that my husband was sick most of the time that we were married. And when she went to have the baby she found out she was HIV positive. And she was a girl who had not had sex before. Like she was eighteen, she was living and she fell in love with this guy, he convinced her "baby I love you I want to marry you" they didn't go for testing. And she's left with being positive, this guy is dead, she's alone raising this kid and she cried. You know she said...she said she is mad at God. Like how could he let something like that happen to her? ...and I remembered she looked so young and so innocent. And to think like she didn't go out looking for it. You know ahh come on this guy lived his life whatever he did it doesn't matter but, he came and he gave it to this...it's like being hit by a stray bullet and you die. Like you were minding your own business, that's how it made me feel. This thing is so unforgiving at least it would target people who deserve it, but then who deserves it?

The following example is from a male former research assistant who recalls the trauma of just listening while transcribing interviews:

There was this interview that was conducted by [a research assistant]And during the interview this girl ... was crying, she was sobbing... she was telling [the interviewer] about some of the abuses, abusive behaviors that her partner is instilling on her I mean some of the issues that I personally felt like "oh they were very traumatic" and guess what this young, young beautiful lady will turn out to be HIV positive and she was not getting enough support that she deserves. Yeah so those are some of the things that I mean really, I mean when I say, when I tell somebody it’s easy to ignore, but when you listen to the audio, I mean the whole conversation how the nature of how this young woman explained her life experiences were very traumatic, Sharon, that is why I felt that her crying during the interview and the interviewer perhaps crying or trying to comfort her was really justified, yeah. (Lebona)
8.1.2.2 Shocked by the frequency and normalcy of rape and abuse

Several research team members noted how the research experience placed them into situations where they had to face the reality of the frequency and normalcy of abuse be that in “live” interactions or in the stories recounted of sexual experiences:

We had an interview with one … girl, and she was just like, oh no, no, no, please come in and tell my husband that I was with you and that I had the interview, otherwise he's going to hit me before and we had to go to like the house and tell her, and be like oh sorry we're doing this study and this is why she came here right now. Because she was like he's going to get really angry, he's going to get really angry. Yeah there was a lot of that, that was happening (Lebohang)

Like you know there is that woman, the woman we met at Ha Thesane, remember the one whose boyfriend used to beat her up and she stayed in this relationship it was just crazy. And I thought she needed counseling you know, because it wasn't healthy under any circumstances, and she was sexually assaulted by this so called boyfriend who loved her. (Keromang)

8.1.2.3 Forgiveness

Several participants gave examples of the love and forgiveness in which many people faced HIV and the suffering of their loved ones. For example, incidences of taking care of a relative who had gone away neglecting the family and returning sick and in need of care or between partners suffering together supporting each other regardless of who is to “blame”. Professional AIDS response narratives often recount stories of HIV stigma and discrimination or the sacrifices and support for children. However, stories of forgiveness, love, and support among adults seem to be a narrative neglected. These stories deeply touched research participants. One of them explains:

The lady I met in uhm Butha-Butha who was also HIV positive that very talkative one who was positive, it was like she was very bubbly but she was in this relationship and what happened with the guy who was a soldier and she loved him and she was faithful and whatever, and then it turns out that he...he...he... passed it on to her. But even after she found out she forgave him, because you know he was a soldier, so that whole mobility thing, and him having other partners, but she still forgave him and she was the one who nursed him when he was dying all the other ones were not there and she was still positive about life and you know because she had a child with him, she had a son (Keromang).

Stories, such as this, of strength, love, forgiveness, and the heroes in the epidemic may provide more of an initiating point into behavior change discussions than prevention professionals realize.
8.1.2.4 Ignorance, risk and keeping your mouth shut

Another common response by participants was the difficulty they faced in listening to people’s stories of risk, misconceptions, and ignorance and not being able to intervene as they would in a normal conversation.

But some of the experiences and I mean they know about HIV/AIDS but they do not protect themselves and yet they HAVE, I mean they are promiscuous. You really ask yourself but you do not want to perceive or make an impression to the respondent that he is promiscuous and he is just ignoring the risk of HIV. You just need to be neutral and listen to the story and ask questions and whata-whata-whata-what… (Lebona)

Another participant recalls the difficulty in not advising people, of feeling selfish but at the same time learning not to judge:

Mosa: I remember that sometimes I would hear very strange things that I didn't believe…But I would just keep quiet maybe because we just wanted to, sometimes you felt selfish because it was like we just wanted to hear peoples’ stories. And it wasn't really about advising people at the end. I remember one lady from, was it Mohale's Hoek I think. She was telling me all about strange things about how she takes her blood and puts it in a bottle and puts it somewhere under the bed so that she does not contract HIV/AIDS. So that experience particularly... Yeah...yeah. Some of the stories in a way taught me to be appreciative and talking to people about those things sex and all that taught me to be nonjudgmental and I could see things in a different way… I could understand that sometimes people do certain things because they are ignorant not necessarily because they are stupid. Yeah.

8.1.2.5 Personalize it

Participants also repeated another theme of taking what they were hearing and personalizing it into their own life experiences and relationships:

Sechaba: But having transcribed and translated some of the interviews there is one interview that was done for a lady who was you know saying why and how does she engage in MCP. And you know all those dynamics of how she would do it. While the husband doesn't know, and you know he is trying to do all the things for the family. I think I personalized it (laughs). So yeah that interview stayed with me for a long time. You know I never forget it….It haunts me (still laughing) that one it doesn't go off. I think even the voice I can recall the voice of the lady who was speaking. You know the honesty she had. And really realizing how happy she was, on the other side the husband is here struggling … he goes out to fend for the family, the lady remains with HIS business people and you know how it runs about. And actually how that affects her emotionally…she wouldn't really feel bad, for it altered all of how she would feel for the husband and now her feelings were going towards these other people. And I thought, "oh this is haunting”…you see now I see I think I personalized it. I know ethically I couldn't go out and say
anything about it but internally you know that is what I felt. I think I always had a problem with MCP consciously or unconsciously that is why I did this study, I didn't understand why people could do it. So now having a clear picture, I think that was revealing to me to see this is how it happens and these are the reasons why it happens so I think having answered all the questions that I have had for a long time, now it stayed with me.

As part of the MCP project, the research team always had weekly debrief meetings, and probably, more importantly, the members of the team had each other to lean on, to laugh and cry with. The need to vent with each other seemed to trump the attention of who may be hearing their conversation. The team leaders provided each of the research assistants a reference number and a list of counselors and resources specific to each of the field work districts in the case of coming across participants in interviews or focus group discussions who seemed be in need of help. Yet the team leaders did not provide a counselor or psychologist for the research team members.

8.1.3. Research Experience Effect on Personal Sexual Relationships

![Changes Reported in Personal Sexual Relationships](image)

*Figure 28: Theme frequency on how the MCP research experience affected their own sexual relationships.*

In Figure 28, researcher responses to the question regarding how their experience affected their sexual relationships are presented. The most common response revolved around having better communications with
sexual partners. Researchers also connected the experience to improving their test seeking behaviors individually and within partnerships. All three of the men brought up how the study helped them to go against the MCP trend and be a “one woman man.” While there was no direct message of “fear”, participants brought up how the experience motivated them to change by forcing them to reflect on their own situation and invoking a bit of “fear”.

8.1.3.1 Female Participant Examples

Participants, especially the women, explained how the research experience improved their ability to carry, discuss, and use condoms. One female participant explains:

Tebello: I think, before I participated in this study I wouldn't have had the confidence to tell my partner if you don't test, I won't have unprotected sex with you. That was the best thing that ever happened to me from that study. The fact that, as a woman, I got assertive, "like uhuh, Ok, if you want do this, let’s go there" I went there myself before and I got myself tested and I realized I have to you know be possessive of this status, because if it changes, it changes. So I felt like the next guy I was going to be in a relationship with, I at first said, "hey, listen to me, no test, no unprotected sex, no test, no unprotected sex" that's my new slogan.

Interviewer: So what was the source of the confidence that assertiveness?
Tebello: I think I talked about this to people all the time. Have you ever tested, did you ask your partner to test. Remember there were questions like that in the, in the interview guides. You can't ask people like...you see when you interview somebody, you learn the guide yourself. Isn't it? So you start internalizing these things whether you realize it or you don't. You know you...even if you do have unprotected sex it helps you so much, it’s like you killed you somebody or...it’s like an illegal activity. It becomes that, it gives you, you can't sleep at night. "OH MY GOD I did it!"(imitating a terrorized voice) that's what happens. So even today, if I have unprotected sex with my boyfriend at the back of my head its always there. I could very well be positive right now. So you see, that's what it did. It made me AWARE, it’s like smelling salts, it wakes you up. Smell it, smell it. Yes.

The effect on the researcher of taking ownership of her negative status and new found assertiveness for HIV testing in relationships lasted through four years after the MCP research experience. Other female researchers also noted the long lasting impression and a similar mix of fear and protection of her negative status with her partner:

I was really paranoid yeah for a long while afterwards, really paranoid...yeah I mean for a bit after I finished I was just like we need to go for a test, we need to, we just need to be more careful but I don't know where you've been, I've been away for so many months...and he was like, "where is this coming from?" and I was just like, "I work with this every single day" but it was really weird because that's all I used to talk about sex. Seriously, not just with him my parents, with like
anybody who was willing to listen. At university...that's all I talked about (laugh) all I talked about. (Lebohang)

Like the above examples, the next example is from a researcher in a long-term relationship. She points out the way in which the MCP research experience helped her to mature as an individual as well as in her love with her partner:

Tumelo: uhmm my own sexual relationships I think I've changed. I HAVE, not an I think, I have changed. Before I joined MCP I was already in one steady relationship to the one I got married to...I learned to appreciate myself I learned to appreciate my partner and I learned to love my partner. Uhmm you know you can be tempted and then you have to think of the consequences it has matured me in a way it has made me a grown up woman. Honestly (laugh)
Interviewer: what do you mean grown up woman?
Tumelo: well I think like a grown up not like a teenager not like a baby not like, you know a youngster anymore. I don't know if the MCP together with the marriage thing, something happened. I just changed, I just became this responsible person you know I think it comes with the responsibilities you have a child, you have a family, you are not living for yourself only. You have to behave in a certain way that you will not disappoint other people so that on its own will bring a positive change in you. I like it.

The research experience also influenced the sexual relationships of female participants who were not in long-term steady relationships. Research assistants noted their empowerment to bridge conversations about sex, past relationships, HIV testing and condoms with new partners:

Keromang: Now when I start a relationship with somebody even like, way before anything happens, I have a "talk" I've got THE TALK. We have to have THE TALK and THE TALK has sometimes chased potential boyfriends away but I always think well I'm glad I did it because at least now I know and I didn't have to make any mistakes. And I wished I had, had THE TALK my entire life. Like I wished I had known This is like my new thing in my life. That when I meet a guy we have a couple of dates we decide ok we're starting something, we're gonna see where it goes. Before we get to the bedroom...when it starts to lead like it's about to go there...we have THE TALK like I put on the brakes and I'm like let's talk. Have you ever been HIV tested, how often have you been tested, do you know your status? Do you go alone, did you go with your partner, do you know the status of your previous partner, like that is my THE TALK. And then I start talking about other stuff like their goals other stuff what you want, do you see yourself married, do you not see yourself married stuff like that. So now I have THE TALK. Yes and it always cracks me up it shocks people. Like my previous supervisor was so shocked we were talking about this and she was in a relationship the guy she was with for like over ten years and they only recently was she starting to try having the talk. She asked me, how do you even begin to have that conversation? Like how do you start? I don't have a problem it just comes out, its natural I don't have to think about it.
In consideration that nearly all of the research participants explicitly stated an improvement in their communications with their sexual partnership there seems to be a difference in their way of communicating with that of the general population. She points out her supervisor, who was in a ten-year relationship, shock at her boldness in initiating and ease in talking about HIV with her partners. Of special note, the participant’s supervisor was working in an HIV prevention organization. The research assistant goes on to describe her “the talk” within the context of what she learned in the original 2008 MCP study about the cultural interpretation of “faithfulness” and “trust” being attributes that were not necessarily linked to sexually having one partner, that people could “trust” and be “faithful” to their partners despite having multiple other partners. She explains:

Whenever I feel like we're moving towards that next phase, like before we get there and its, its...I'm very comfortable about it. Like if you don't know your status why don't you know your status? Don't you want to know it? How do you feel about condoms, blah, blah. For me it’s a big deal I'm not I know my status I get tested regularly...I'm like ok so you know your status, but I don't. I'm at a stage where before trust was you know we had, remember the thing with the faithfulness that we discovered in the study. The faithfulness trusting thing. And the whole Sesotho whatever, so now it’s more like, I trust you I have faith in you but we are going to get tested together. We are going to be in the same room and get the result together so that I know your status and you know mine. As much as I can tell you I'm positive I'm negative and then we will decide on what happens like what kind of relationship. Like seriously I have scared away potentials. So I'm like ok I'm single but at least...I'm glad, imagine if I'd found out after. Like I don't know why, a person should be scared about something like that. I mean we live in a world, and in a part of the world where this is a big deal. You cannot tip toe around it. And it is part of our...we might not have had to talk about this ten years ago, or twenty years ago, or thirty years ago but now it’s here. It’s kind of like deciding if you’re going to be with somebody, if you're going to marry somebody who doesn't want kids if you want kids. You have to know. So I have THE TALK.

What is also evident in the research assistant’s discussions is that talking about testing and HIV status was not only about protecting their own negative status but it was about realistically facing their high HIV prevalence reality and taking the needed steps to create a healthy future, even within an HIV discordant relationship. As the participant above says “I’m positive, I’m negative and then we will decide on what happens like what kind of relationship”.
8.1.3.2 Male Participant Examples

The 2008 MCP research experience had life changing impacts on the male participants. The experience helped them to challenge their own cultural notions on the normality of MCP as well as take steps in adopting less risky sexual behavior patterns:

Lebona: …that (the research experience) showed me how people handle their relationships and most importantly helped me inform my decision making in my own relationships. First of all, I mean as a boy you have, as a man you have that feeling especially growing from a rural background like me you have that feeling that men is like a pumpkin, you remember that Sharon?

Interviewer: I cannot forget it.

Lebona: yeah that man is a pumpkin and needs to put his concurrency and multiple relations sexually. I mean there is a whole lot of things and being part of this team kind of tipped my perceptions from my background, as a man you don't necessarily have to be in concurrent relationships. And the risks that come with it, the implications of putting your own life at risk and your partners at risk, and your partners, partners, partners, partners, partners at risk, so the whole AIDS network and how it spreads it made me more aware and made me more careful and most importantly encouraged me from time to time to use protection when I engage in sexual relations but please know in capital letters, Sharon, that I am not promiscuous I am a one man, one woman.

Like the women the effect of the research experience lasted long into the future for the male participants.

In moments of temptation the research assistants recalled various experiences or research findings that helped them to avoid risky situations. As the following participant describes:

Khabane: (still laughing) I've...let's say being in serious relationships, I've always been a serious relationship guy I guess…I'd be tempted to do stuff but I would never really go into it. So it did change my understanding, it probably even helped prevent me from in engaging in multiple partners you know, as I grow up. Even now I do still remember such stuff that we came across back then that, that I would never ever think of getting involved in such stuff. Besides the fact that, besides the love that I have for my wife, you know.

It is clear that for each research assistant the experience effected their personal relationship with their partners and with their own HIV status. The experience influenced each person in their particular season of life to take control of their HIV status and open up lines of communication

Sechaba: You know it (the MCP research experience) highlighted the importance to know (your status), I, following the study I know for sure that me and my wife tested. We began discussing a lot around issues that we never discussed before, even finding out about her feeling, my feeling around the issues of MCP how they could affect us what could influence that and so forth. It has helped bring a lot of understanding between us. Which was followed actually, by consensus following testing and counseling and let me tell you this…Ahh Sharon you know some of the information that we used to come up with in these discussions was so sensitive but having been
engaged in this you know I am just free having realized how people can be free to just talk about some of their personal, MOST personal issues.

This participant emphasized that it was not only the field experiences but also the training and team discussions that helped him to be “free” to talk about personal issues. He goes on to describe a specific incidence during the 2008 MCP training when we were going through the interview guide question by question and trying to help the team to internalize the questions and prepare for a wide range of possible responses during fieldwork:

You know I can recall while we were doing, I think it was the qualitative methods training or ethical considerations or something, just before we started the project, you had, YOU personally had asked the question "who is married" then we said yes I'm married married or I'm not married. And the second question was who is constantly using condoms and people came out "no I can't use a condom with my wife" and some are constantly using these (condoms). And then the third question was what are the reasons you know for using or not using. You know those issues, people became, I mean we answered, the research team people, began to answer to say it is because of this, this is because of this, I can recall that because now I looked at the reason, why was I one of the people who was using condoms constantly? Now the question was WHY? I can recall that very well and the reason was I didn't know my HIV and AIDS status, you know, and neither did she know her status. And so that was the reason (laugh) so now after the study and opening up and so forth, we have tested and so there is no need for the constant condom use you will ask why? We don't need it (laugh)

Interviewer: Yeah I don't even remember asking that. Well I am really happy for you that you were able to discuss things and get on the same page with your wife, it’s not easy.

Sechaba: it’s not easy and for long I’ve been doubting, you know I was doubting, I had been doubting (now talking in a whisper) "my what would I" then you know testing wasn't easy eashh oh then YEAH (in a grunt tone whispering) being conscious and we have done it then I am free, you know I am really free.

According to the 2004 and 2014 DHS, the HIV prevalence within couples is approximately 66% both HIV negative, 20% both positive, 9% man positive, woman negative and 5% woman positive, man negative (DHS 2004; DHS 2016). The above example shows that despite having worked in the HIV sector, being college educated, urban, and using condoms within a committed relationship there existed a barrier in testing and communicating about HIV within the relationship. However, the excerpt also demonstrates the difference made when an individual is urged to critically think about why they do what they do. For this individual, the urge was provoked as part of a specific training experience about questions on the research guide. Once again demonstrating the inadvertent ways that the process of
conducting research on a sensitive subject as HIV, also becomes a prevention intervention moment. Like this participant other participants noted how the MCP research experience helped them to seek testing and increase communication within their relationships. The “ownership” they took in protecting their negative status (once they knew) while others highlighted how knowing their own status and that of their partner, even if discordant, helped them to strategize on how to stay healthy or take steps to conceive a negative child.

8.2. Keeping or Crossing Over the “Researcher” Line

During the original MCP study, training, and piloting team members had many discussions about their roles as “researchers” and NOT as educators or interventionists. It is important to note the complexity of the ground situation and the relatively scarce level of training and experience these young research assistants had to address the myriad of issues that could and did come up during data collection. From a research integrity perspective there were three fundamental components to defining this kind of “line” during research: the need for being nonjudgmental, the need to not introduce bias into the way people respond, and the need to provide appropriate support & accurate information when called for. Taking the lead from the principal investigators, the researchers were taught to maintain their role as researcher, not to cross the line, but if they came across an issue in the field they all had a list of local services, for each study site, to which they could refer participants. Four years after the original study, I asked the original research team members what it was like to be “personally, listening to people stating misperceptions, describing their own risks, how they may be exposing many others, and maintaining your role as “researcher” and not as an educator or interventionist?” The following section first presents results from research assistants who never went beyond their researcher role. Then the section provides the perspective and examples from, those who crossed the line providing more than what the research protocol dictated. The last part of the section delves into the research assistant’s reflections about the difficulty in balancing their sense of responsibility to the long-term benefits of the research and the immediate needs of their participants.
8.2.1. Did Not Cross The Line

Only three of the nine participants stated that they did not ever cross the line beyond their researcher role. A fourth researcher acknowledged crossing the line once. They all admitted to the desire to cross the line, the frustration in not providing more information, but understood the rationale of the principal investigators.

Keromang: The thing is she[research participant] was saying were born out of ignorance, of not knowing and it was because she had no opportunity. How was she going to know that information? She had no opportunity to learn. We were like the first, they were so happy because we were the first town people to ever bother with them. You know. To come to them and.... and bother talking to them, and asking them questions and asking them about how they feel, and what they know. So how were we expecting her to have, to know. And so yes, times like that when it was really, it was like ignorance is not bliss under these circumstances. This person needs information I have the information I could let them know, I could tell them but then I’d be crossing the line...and also I might taint the information the data so yes, there were times. but it’s because we had an outlet. I think, like that's why we developed the relationships [with in the team] that we developed and we ended up even being friends afterwards. Because we had, you had somewhere where you could go and vent. Immediately after you could go and sit with somebody and you could talk about...you know what just happened? Like and just let it out. And that practice, the talking about, the constantly going over it, the complaining, the whining, yeah.

As discussed in the previous section, the informal support of sharing with each other the difficulties provided an outlet that helped the researchers maintain their researcher role. They kept in focus the need not to “taint” the research or to make participants “uneasy” by sharing information that these participants would not have otherwise been exposed to:

Neo: YES, I wished I could cross the line but after the ethics training you know that you are there as a researcher you are not there as a counselor or advisor so you have to stick to what you are going to do there. But then you think that NO this shouldn't be happening, this shouldn't be happening I should say something to this person but then you know that saying something to that person it will make them uneasy and then it will be against your research ethics. But sometimes... Interviewer: Do you think that was fair of us to ask that of you?
Neo: Yeah it was because you wouldn't know how to go about it correctly. Like, you are not trained to do that. So you could like be biased, you may want to impose your beliefs onto that person. And in that way you will be telling them that they are wrong, and you are right and then you see how it will...it couldn’t be nice. I understood why we shouldn't do it but then as a person you somehow feel NO this person these people are still....
Within the conflict of wanting to say something but knowing that one should not, were also doubts in “knowing” enough to convey the correct information about HIV to participants. There was often a worry of doing more harm by spreading misinformation. The next example makes reference to the problem of getting messages and information from various sources with rapid changes happening in international directives and national policies, thus not feeling adequate in their knowledge. The ever-changing information seemed to make HIV education something for “professionals” out of the capacity of even college degree researchers working for the National AIDS Commission and UNAIDS:

Lebohang: I guess I would say it was really hard, because there were a number of times where you had to actually, actively stop yourself from wanting to correct someone and be like, can we just stop this tape right now, what your doing is actually not very good for you or its bad for you, you really shouldn't do this. There was the temptation to do that.

Interviewer: Do you think that was fair?
Lebohang: I guess yes and no. yes in the sense that I kind of like one of the reasons that we may have problems with sort of like HIV is because of the way in which we mismanage. There's no, how do I explain it, it's not like there is any sort of central institution or place that disseminates information. You have so many people coming in doing their own different projects. And telling you so many different things. So for example, we came into this study and we had to do some training on like the basic HIV knowledge. And we'd be doing some stuff and you know some very, very, very basic stuff, like I think one of the things we had with Dr.[name omitted] is when we were talking about breast feeding and we were initially like breast feeding, no you can't breast feed your child if your HIV positive and then he was like ACTUALLY in the last couple of weeks we found out this particular thing [the new WHO recommendation to breastfeed even if HIV+]. I think it's just like the mismanagement of information so I think to kind of curb that, in some ways it was good to be like, please don't say anything. But on the flip side it was a bit like, this person is actually doing something that's really totally crazy and you want me to carry on as if nothing is wrong with this, that's a little crazy.

Interviewer: and I just wondered how did that affect you?
Lebohang: it was such a long time ago, but I guess your conflicted on the one hand your like I'm gonna get into trouble but I should really tell you this...but I guess you just kind of had to leave it, and be like, I'm sorry I mean this is kind of what I've been told to do...it goes against everything I believe in but...sorry.

Interviewer: why didn't you go against us?
Lebohang: every time, do you know how many people I would have had to correct!! (laughing) And have it get back to you? It just wasn't worth it...(laughing)

All of the participants acknowledged not feeling “good” about leaving their participants without intervening. The researchers who did not cross the line made the connection between their silence in the research process, and their belief that the research would go on to practice application, returning to provide an intervention for the people they left in ignorance:
Sechaba: you would not feel good that you were not able to say "no that's not the fact" "that's not how things are" but I think for the fact that I already knew that there were interventions going on then I didn't have much a problem about that because I knew those are the issues, whatever issues were coming up would be addressed sooner or later and I believe that is what is happening now. The issues that came out from the MCP are the issues that are informing the interventions, the national interventions now. That are being done by various role-players including us. So I really didn't have a problem at that time because I knew these were the issues that would be addressed. Interviewer: And when you said it didn't feel good what did it feel?
Sechaba: Yeah. It felt like well maybe I could be saying no this is the situation but knowing that you couldn't say that well it didn’t feel so much good. But also for the fact that ethically I knew what my role was. I wouldn't really combine the roles which ought to be well delineated and set out. So to a very small extent it didn't feel too good that someone will go out without the information or not all the information on issues…. While maybe we could try and provide you know interventions at that particular moment we could have missed it in that maybe we wouldn't be the right people to give the information based on the specialties, the level of knowledge and time…

The participants also connected the frustration of not intervening during the interviews with their awareness that not enough was being done in education and prevention. Two of the three individuals who reported never crossing the line were still working in the field of HIV/AIDS at the four-year project follow-up. This is in contrast to the six individuals who crossed the line, where only one of whom was still working in the field of HIV/AIDS. The non-line crossers linked their motivation to continue working in HIV prevention to their personal need to ensure the information they gathered actually influenced change:

I wanted to be part of, if it [the interventions utilizing the 2008 MCP research] was going to make a change it was going to alleviate the circumstances of the situation. I wanted to be the one who was doing something. And like WHAT NEXT, WHAT NOW!....Things like those missed opportunities kind of helped me and guided me into deciding that now that I have this information I'm going to go into this thing because it’s actually using the information. It’s getting it back to the people who need it most because where are they going to access it? Like we expect people to access it...WHERE? Where? And we saw first-hand that it’s not accessible. (Keromang)

8.2.2. Crossing the line

As the technical assistant guiding the team, responsible for reinforcing the rule of maintaining the researcher role and not of interventionist or social worker. I too had my moments of doubt about this being the correct approach. When I left Lesotho, I still struggled with this memory, especially because living there I witnessed how many people did not talk about HIV and how many people did not know
their risks. And it was difficult knowing that the research assistants had these one-on-one intense moments of encounter and an opportunity to change the life of the participants they encountered and I was responsible for keeping them from crossing the line. An opportunity I knew, knowing the prevention programming situation in the country, study participants were unlikely to have again. I felt guilty. Having conducted this follow-up research I was almost relieved to find that six of the nine researchers admitted to crossing the line beyond their “researcher” role. As one researcher blatantly explained:

Tebello: No, no don't worry. We never stuck to it anyway. We broke the ethics...you know sometimes the people would tell you, I want to talk to you again can I take your numbers and you'd be like, yes of course take them. I'd get calls until the calls stop coming. And these people would call "hello Me Tebello how are you? you know I took my sister it turns out she's pregnant, remember when we were talking about that, I thought she was pregnant" because we got to talk to them up to the point where they felt like they were free to talk to us. And I've always, always, always, always regretted that we never went back to those particular people to talk to them, you know. Not to the community, to the individuals. To check up on them, yes. I feel like I don't care about the community, I didn't talk to the community, I talked to a particular person. And I feel like it would have been good for that person to be accorded the respect cause they took an hour, two hours from their time to talk to us honestly about these things. I felt like we should have gone back and had conversations with those people. Like hi how are you, how has this affected you, how had...it would have been good for your study as well to go back. Not talk to us...how did it change their lives? YES because they had charts and everything. Maybe the study should have been designed to tell the people, if you want, I'll come back in six months and talk to you.

The research assistant emphasizes the individual and not the community because the 2008 MCP project did include a dissemination component. However, the meetings were at a central location in the district and not necessarily in or near the villages from which we recruited. Furthermore, to conserve privacy, the study protocol required research assistants to destroy participants’ contact information so there was no official means for inviting individual participants to the dissemination meetings. It is within this context that the researcher above argues for the importance of going back to the individual both in terms of the short-term follow up as well as the long term to know how the research experience changed research participant’s lives.

Another researcher explained how at the beginning of her researcher employment she was careful not to cross the line, but as time went on, her sense of responsibility grew, and she started intervening turning off the recorder at the end of interviews or focus group discussions:
Mosa: yeah and sometimes after the interview I would just shut off the recorder and tell them the actual truth. "no you're not supposed to do that. When you have unprotected sex you'll have AIDS". There were times when I would cross the line.

*Interviewer: And why did you do that?*

Mosa: Because I thought it was my responsibility. Especially when I talked to younger girls I felt like it was my responsibility to tell them the actual truth. But I would do that after the interview. But there were times when I crossed the line. I would switch off the recorder and tell them, "look this is not how the world operates you know"

*Interviewer: Were there times that you didn't cross the line that you wished you had?*

Mosa: Yeah there were times when I would just be ok. And then I would leave. Especially after focus groups. But on one-on-one interviews...I would. Focus groups I left them...I wish I could have told them the truth but, I couldn't because it was easy when it was one to one interview you just tell the person "no it is not like this" but when it's a group it's a different story all together. And YOU [pointing to me] would know at the end. But after that when I worked at [name of organization omitted] I would keep all the ethics but after I remember that primary school I went to in some area of Maseru, we were talking about sex and all those things with some little girls and they were talking about ALL kinds of misconceptions and after the focus group we were also told the same thing that "no you should not tell them all whatever all those ethics and you know" but after I had the conversation with them we talked about everything, during the focus group discussion I didn't say anything. I would listen purely to what they would think and all those things but after that I would switch off the recorder and talked to them nicely, "no look young girls this is not how I think" you know. Because really I think we are doing an injustice to a lot of people... Because they are supposed to know the truth and sometimes you are the only person who can tell them the truth or you can change people's lives but you are just there to ask questions. It is important to get the actual truth, the way they think, but the intervention sometimes comes after a very long time.

*Interviewer: And in some cases not at all.*

Mosa: Yeah in most cases.

Research team members brought up the sense of responsibility they felt to say something that would help the participants they encountered. They described how they perceived a unique space for the participant having a professional outsider present. One researcher described her encounter as if the participants were actually expecting and wanting the researchers to say something:

Tumelo: It was a bit difficult to separate the two [respecting the protocol of not intervening and responding to a sense of responsibility to say something]. Because sometimes you are listening to this person she is telling these things and you want to tell her NO you don't have to do that (laugh) it was way difficult to separate the two. I think one time or the other we stepped over the line, because you were there to take information out of her, the next thing you know that she is doing these things and she is not even aware that what she is doing is not good. Ok. You can't just leave her like that you have got what you wanted then just go. You just can't. Other things you just have to say just one word. I think it was difficult…I think many times. I honestly think we crossed the line many times.

*Interviewer: so do you think it was fair, unfair, ok that we tried to make this distinction between researcher and educator and interventionist.*

Tumelo: I think, for us as researchers it was fair. But then, for the participants it wasn't fair because, they were expecting us to say something to them. And here we are just asking them
questions. Then after we are done say thank you. I think to them it wasn't fair. They wanted us to say something...Just to say, ok even though you know you are having nyatsi and you think you are happy it is not good. Something like that.

**Interviewer:** *why do you think they wanted you to say that?*

Tumelo: I don't know but I have this feeling that, I mean I think they think we are professionals, so we know, we know too much. Maybe if we can tell them. They will change or something. I don't know it’s my thinking. …The other thing is I don't think, I don't know if other people are as free as we were. So if you are not that free people cannot confront you. That is the problem. Even if you are a peer educator, but if you are not, people are not comfortable talking to you, then they cannot come to you that is the problem.

This last example also points to the precarious balance in the nature of keeping the researcher vs interventionist line. In this case the researcher went beyond simply correcting misinformation to attempting to provide life counseling. The necessary training and skill set to provide this type of help is different from that of HIV education or testing and counseling. The research team members were college educated with a social science degree, several of which included psychology and social work. However, the information and counseling they gave to participants, who were strangers, had the potential to change in remarkable ways participants’ lives. While the intention of the researchers who crossed the line was that the guidance they gave would help, there is also the threat that without a greater understanding of the context of the participant’s life, the guidance could create unintended anxst and harm to the participant.

Thus revealing the complexity of minimizing damage control by creating a clear boundary or line not to be crossed and the opening of the door to crossing a blurry line between providing HIV information, clearing up misconceptions and life changing counseling.

### 8.2.3. “A difficult battle between ethics and humanity”

Several of the respondents used the same words to express how they felt about the researcher vs interventionist dichotomy. Ironically, they often put in juxtaposition their humanity with upholding ethics.

Khabane: It was a difficult battle between ethics and humanity. We were human but we had the ethics to abide by. There were stories that could just break you and you'd break away from your ethics, like the one that I'm just giving you know about this guy who was HIV positive. I couldn't just refer him to all those local hospitals or, local HIV/AIDS offices. I mean he was from there, he had already tested, he knew the situation he was in, all he was doing I could see, as a [profession] he just wanted to talk. He just wanted to confirm what he knew and that it was what
it was. So all I had to do was just to instill confidence in the guy. It was a difficult battle between ethics and humanity.

*Interviewer: But what do you mean by ethics and humanity?*

Khabane: Uhm ethics it's like I'm saying the ethics go by what you have been told to do right. When I'm talking about ethics I am talking about the roles and the regulations that we were also given at work. We were not there as counselors, we were not there as problem solvers and all that. We had to refer people if they had problems and they had questions. But this guy in the middle of the interview, he didn't have questions he was telling me of his situation so I wouldn't tell him go talk to this person, go talk to a counselor at PSI, go talk to a counselor at NEW Start. No I was there and all I needed to do was to pause the interview, break one ethic and then get back to work.

He makes the distinction of ethics as following the roles and regulations he was given at work. I probed him more about what he described as a battle between ethics and humanity by asking him what this distinction means in light of the intention of ethics being to protect human subjects. He responded:

Khabane: What I mean by ethics and what I mean by humanity? The human part of me not the researcher in me. I felt I had to talk to this person. But I also had in mind that we were not allowed to talk to people about issues outside the interviews, right. About personal issues that are not involved in any way with the interviews that we have. But like I'm saying those were the rules and the regulations that were also guided by the ethics that we had, but this was the situation. As a person for me it was extremely difficult to just refer this person without playing a little bit part of...of giving him the information that I felt would be a right for me to give him, which is why I'm saying it was kind of hard, it was a battle between work ethics and the human part in me. There was a battle between the two.

*Interviewer: Did you think that was fair of us? To have asked you to do that?*

Khabane: Yeah it was. Because the kind of advice you give to someone is not always the right advise. It's not always the proper advise, it’s not always the best advise we can give. Sometimes you'd be thinking you’re giving someone advise only to find that you're actually taking him the other way around. And at the end of the day all the stuff that you advised people to do comes back to bite you. So yeah, the ethics have to be there at work. The rules, the operational guidelines have to be there, they have to be there it was fair.

This above example also demonstrates the fear of misguiding people with the wrong information.

In 2008, there was an incident during an interview which seemed to reveal a case of sexual abuse on a minor; during our debrief meeting we discussed the incident. Drawing upon an American perspective, I made the connection between the illegality of the act and the need to break confidentiality in order to protect the child. The following 2012 example alludes to that discussion with the researcher justifying breaking the operational rules surrounding their researcher role:

Tebello: you cannot help intervening...you cannot help it...Well it sounds like something that could be done...you now you were told don't intervene, don't, don't, don't. Remember there was a
case where you felt like this child was being abused and we were wondering if we should tell the police, remember? And I remember you specifically saying, you know if it’s breaking the law then I will disclose. If this child is being hurt, sexually I'll have no choice but to tell the police about this. So you see what I mean. The delicate balance you must keep the confidence of this person but if something really is wrong than you have to intervene. So sometimes we wouldn't intervene, intervene, but you'd give somebody advice. Stop doing this. Go and see a doctor, stop drinking the herbal medicines they don't work, go and see a doctor, get yourself tested so that you know for sure if you have it or you don't have it, stop praying, GO see the doctor. Pray yes, but...please

Interviewer: Do you think that was fair of us? To tell you you’re a researcher and not an educator, you’re not an interventionists? Don't cross the line.

Tebello: Ahh come on...I mean it’s the ethics isn't it. But we're all human you know.

A common thread that researchers brought up in the discussion of crossing the line was that of being “human.”

Lebona: [really hard laugh] Sharon look you know, yeah I mean before, before you became a researcher I mean you have to understand that you are a human being and that you are a guy and you are interacting with other guys on other pertinent, very pertinent issues that confront our lives, I mean that I think me as a researcher at some point but I think quite honestly YES I did cross the line I mean informally, yeah I did.

Several researchers described their role as researcher as being extractive, like an “instrument” or “tool” used to get stories. The following participant compares the pain in hearing misconceptions and not conveying information with the relatively better experience of participating in the dissemination of the study findings:

Mosa: it was a painful experience at times because after people tell you certain misconceptions it’s like you can switch off the recorder and tell them the actual truth so that maybe they can change their lives for the better. So, sometimes it would just feel like you are even though the job was that important but sometimes it would feel like you are just an instrument that is used to get peoples’ stories, that is why the actual dissemination of information was better in many ways it was better than just [drawing] information from the people…It was good at times to hear peoples stories but that part of not being able to make a certain impact in terms of intervention or telling them it was painful.  

Interviewer: do you think that was fair of us?

Mosa: Fair? [pause] yes and no. Yes because we had to take people's perceptions just as they are, you know, so that they don't, they tell us the actual truth but then because we did not go back to them and tell them about the reality or corrected them on their misconceptions and...but I don't know a better way...
8.2.4. “I couldn't just disassociate”

Ethical quandaries exist because there is often no black and white, clear solution to the problem presented. A few of the researchers conveyed situations where they seemed caught between the struggles of the participant and the need to do the “right” thing by saying or doing something, even if they were told not to, because it was not their job:

Keromang: The experiences we had in the field some of them were pretty traumatic. For me personally I...don't like...I wasn't aware but I think I'm a hyper-sensitive person you know. Like I take things on, I get emotionally involved. And I don't dissociate easily. So some of the stories, some of the things that people we interacted with and the things that we saw and how that had a personal, for me it was like, AND then what? We went out there we got this information, we'd go to a place and you'd be talking to somebody and you'd interview this person and you'd find that your sitting at their house and interviewing them and they're sitting there and they have babies, they have all this and these people are living in abject poverty. You can see that they haven't eaten like the whole day. And you're sitting there, fine we would have snacks and stuff, I would feel guilty, I would feel bad, like I have nothing to offer this person. And we, didn't say anything, we but if I had ten rands on me like after our interview I would say go buy some flour for your children. Because I'm sitting with this young girl who maybe she's slightly older, she's like a thirty-something year old woman and there are her children and I can see that they haven't eaten they didn't last night, they didn't eat in the morning, you know and she doesn't know where she's going to get the next meal. I don't...I have nothing to offer her, I don't even have money myself, I'm not even making so much, but if I had ten rands or five rands on me like we would do that and we wouldn't come back and say, "ok I gave somebody ten rands can I get compensated for it?" we didn't because it was MY personal choice to say I can't just leave, ok I got what I wanted which was information it’s great, and she gave it freely, but I can't just walk away, you know, I have to at least....ah... comfort her somehow and say I acknowledge that you are a person and...don't give up...I acknowledge that. So that personal interest like we couldn't, I couldn't just disassociate.

It could be argued that the researcher here is setting a bad precedent by providing more than just the symbolic gift of a bag of chips and a juice box for participating. However, in the bigger picture, field research of this nature sends people crashing into each other’s worlds whose paths may have never crossed. Many of the middle class researchers were forced to enter into the homes and stories of the poor. Their response should be taken in the context of them wanting to know what was next, being dissatisfied with keeping quiet and not exchanging anything, no information or knowledge or compensation with the people who were actually giving freely of their time and life story.

Keromang: Like seriously, my number is changed now because I had to stop using my number some of the people still had my number and they would call. And I would talk to them and I realized I have to break these relationships I cannot continue encouraging these types of relationships because they are not healthy for me. It emotionally overwhelmed me and it's making
me cynical like I'm already kind of a practical, like let's look at life its black and white but I'm
coming, I'll end up becoming very cynical and very...its debilitating for me because I can't...I
can't do anything for them. I'm powerless, it's starting to make me feel powerless, like I am
incapable, I'm inept, you know and all I can offer is words and they're not enough and these
people are looking to you for MORE. Because you were the face, you were the voice, you were
the person that sat down for two hours and listened to them and encouraged them to talk. And
sometimes they said some really personal stuff, they tell things they'd never told anybody. And
that whole, we're supposed to build rapport, we're trained to "build rapport, build rapport"
[imitating trainers voice] but you build trust with this person, even your leaving and taking this
information and going away, there was that trust and inherent in the trust is expectation from
YOU, they expect something like ok something is going to come of this, and they expect to have
a DIRECT benefit they're not thinking about the bigger picture and how this will go on to
inform...strategies and whatever...they're thinking about YOU to ME. Like ok I'm going to
receive something, my life is going to be better, so like when am I going to get the turnaround for
this, when is it going to happen?

This excerpt brings to the fore the complexity of long-term expectations at the personal level and false
expectations about direct benefits. Despite informed consent documents explicitly saying “you will
receive no direct benefit” these in-depth intense human interactions begged for something more. Common
IRB practice asks researchers to say to participants you will receive no benefit but the research may go on
to inform future interventions. An individual participating cannot help but to hope that the future
intervention will be near them. And research assistants who repeatedly build rapport and see the
expectations of participants often cannot resist feeling responsible in ensuring some kind of benefit. For a
few of the research team members this meant giving their phone numbers and providing ongoing
information and advice and for others this meant continuing to work in the HIV prevention sector.

In contrast to the previous example, the next example is from a line crossing researcher who felt
that sharing knowledge was indeed part of his job, even if not officially. His educational background
included social work, yet during his academic career he maintained doubts about the efficacy of
“counseling” interestingly it was a research field experience that changed his perspective on the role of
counselors.

Khabane: I was interviewing someone and he disclosed to me that he's HIV positive. He had
never disclosed it to anyone else because he had just tested. So it was touching cause he told me
that I'm actually the first person that he has ever told. It was scary. At the same time it also made
me aware that it’s much easier talking to a stranger than talking to someone you know. And it
changed my perspective about the understanding of counseling, whether you do it individually or
in a group. I used to underrate counseling a lot...But after talking to this guy, I think it changed
because I started understanding how easy it was to open up to a stranger whom you know will
never judge you for who you are because they don't know you, they've never seen you. Basically
talking to a stranger I realize that it's one of the best things that a person can do when you are in
distress, because they don't know you. They will probably never come across you they will never
even recognize you again someday… you won't be comfortable telling your problems to your
neighbor. To go for counseling it’s easy to open up to someone that you've never talked to, you've
never seen, you've never met, you'll know you'll never need stuff from. You're just there to open
up. Because mostly you'll find that in counseling you, you as the person with problems you end
up coming up with the solution. You just don't know, you just need someone to confirm it for you
that this is the solution.

He goes on to describes well the contrast between the presence of peer educators from the
community with that of the comfort provided in talking to a “stranger” or a person that “you'll know
you'll never need stuff from”. This example demonstrates the unique difference between a researcher and
a typical counselor. First, the individual doesn’t seek out the researcher it is the researcher who recruits
and opens the space for dialogue, thereby many people who may never have sought out a counselor or
physically go to an HIV resource center found themselves with a young educated professional who
seemed to know more about HIV than themselves. Secondly, community outreach workers and HIV peer
educators are often immediately associated with testing, or delivering medicines to the HIV positive, a
community members association with them can lead to later problems of stigma. In contrast, these
research assistants were perceived as neutral the interaction was completely random, which opened doors
to people that may have otherwise remain closed. He goes on describe the uniqueness of the interview
moment to exchange information rather than referring a participant to a counseling center.

Like for example that person had just tested. He knew the solution. But I was a stranger coming
from Maseru in Mokhotlong, first time in his village, probably the last time in his village. There
were a lot of experiences there. This was my first time to meet this guy. I'm there interviewing
this guy he tells me his problems, I give him examples of friends and family members who are
HIV positive who have lived probably ten or fifteen years positive and they are still living a
healthy life. He was rich because he had lots and lots of sheep. So eating for him was not a
problem. All he needed was to confirm the knowledge that he had gained from the pre-counseling
that was the case. And after talking to me, he, the second day when we were going past the
village we met he told me he was coming from the clinic to go get his anti-retrovirals and all that.
But before we talked he was kind of scared of how people are going to look at him when he starts
using ARVs and some pills and HIV medication and all that. But after we talked I mean I gave
him my attitude the never care attitude, the never mind attitude, you're living for yourself, you’re
not living your life for anyone else and after that he told me that the words I told him were
encouraging and they were the only thing that made him go for the medication. It was a nice but
touching experience because I remember even telling Lebona after work. I know we didn't have
to share the information that we had. But there was shared confidentiality, especially between colleagues. I just told him about the encounter I had and he was scared. He was telling me that he would have probably have cancelled the interview and just changed the topic. But I felt that since I was there I had the knowledge, I'll just you know, pause, the recorder, give him a few tips and then go on with the interview.

The questions asked on the original MCP study guide were designed to gain information about risk perceptions and norms surrounding MCP to inform prevention efforts, not to be a prevention effort. While it may not have been the intent of the principal investigators, it is clear from the interviews in this case study that the unintentional consequence of these types of questions is a form of intervention. The questions provoked reflection and interactions by and between researcher and participant about their individual risks and behaviors creating a type of prevention moment. Most qualitative researchers are probably aware that these types of interactions are a form of intervention but as discussed in Chapter 3, there is no empirical evidence demonstrating the interview interaction as an intervention benefit.

The following example demonstrates, like the above example, this grey area, where immediate risks are identified and a researcher goes beyond providing information to providing life changing advise:

Ok there was this lady I think we were Tha...Mokhotlong or something. She was young, married and her husband was working in Durban, I think. And she was having extra-marital relationships with men in her village because she needed money to live. And so after, you know there was a question do you receive gifts? Remember? And she said yes, I sleep with this particular man because he makes sure I live, I have sanitary towels every month. I was like, Sharon, you know. She's basically a prostitute [said in a whisper] because her husband has left her destitute in Lesotho. Like he's in South Africa he's not sending enough money home or he's sending money and the mother-in-law takes the money, something like that. But for her she didn't have money and she was a bride. Literally they didn't have a child. So imagine if the husband is being faithful in South Africa and she's not being faithful here, because they didn't use condoms, that's the thing. They don't use condoms. So she was like she has, she's worried she has this discharge. And I was telling her go to the clinic. We talked about this off record anyways. She said I have this, I said, no, no, no go to the doctor, but stop, stop doing it, your mother-in-law won't let you starve. She said, yes she would. And I said, just go home then, go to your home. Forget this marriage because now you’re putting yourself at risk for so, so many things. (Tebello)

The next example goes back to the story we began with, the story of the young widow was recalled by four of the participants as the research event that affected them the most. The following excerpt is told by the researcher who actually interviewed the young lady in response to the question of which experience effected her most:
Tumelo:....the case of that girl in Mohales Hoek. The one who, who was a virgin then she got married to a man who was way older than her and who was already sick and then that man forced himself onto her, and then she ended up being HIV positive. It always haunts me. It always haunts me...[pause] I usually stay and think about her what is she doing how is she coping, the husband died. At one point in time I wanted to call her to come and be my nanny and then I didn't have her contacts I didn't have anything else to call her. But I wish there could be something I could do to help her actually, but it frustrates me. I still think about it, even today. She has a child.

During the dissemination when the research team went back to the districts to discuss the findings, the research assistant asked the team driver to take her to the girl’s village which was far from the dissemination meetings.

We were in Mohales Hoek where I told them, I would really, really, really like to see that girl. I would really like to see how she is coping or especially because she told me that the child was breast feeding I wanted to hear if she had stopped breast feeding the child because she was about six months. And so I went there, we arrived there late when she was not home but she came running when she saw the car. Yeah. We talked for some very short time. But it was great.

This sentiment of wanting to follow up, to know what happened to respondents even years after the project is probably quite common amongst qualitative researchers. Yet, professionally the institutional review board (IRB) ethics norm is to sign a contract that you will destroy all contact traceable information implying that after a professional qualitative interview the relationship ends there. The examples in this chapter, put into question the expectation to not follow-up or to not intervene. In the end, both researchers and participants crossed the line in their behavior towards each other. These examples demonstrate how the application of research in the real world is not easily contained within operational guidelines or the life of a commissioned study.

8.2.5. Alternative Research Solutions Provided

In their discussions about the frustration in not correcting misconceptions or not having a chance to educate their participants, some of the researchers provided suggestions on ways future research studies on sensitive topics like this could be improved. The following participant is explaining her difficulty in listening to misconceptions and not having the authority to intervene:
Keromang: Hard. And horrible. And really, really uncomfortable. Yes. Very hard. For emphasis I'll say it again, very hard... First of all, we used to have these talks. Like you would have to be impassive you cannot pass judgement you have to sit there and listen and be like, "hmm" "ok" and try to get people to explain how they feel and what they think. And you couldn't...and sometimes you think..."HOW CAN YOU THINK LIKE THIS? HOW CAN YOU DO THIS OR HOW CAN YOU NOT SEE THIS?" and you want to say something, in normal human conversation if somebody says something, really, really, careless, really, really flippant and show lack of care for other people and lack of responsibility, you would call them out on that. You'd be like "ok stop....who do you think you are?" You know, or if somebody is saying something really dumb, like "yes I know that my boyfriend has other girlfriends and I know some of them have HIV... and yet I choose to have unprotected sex with him" you know and you're like, you would be like "what's wrong with you? Are you daft?" But you can't. You have to sit there and go "hmmm so let us trace, this is the graph you're going to take them and then you're going to place their names here, you can give them whatever name you want" [imitating a researcher professional voice] you know you had to move on and...so yes...it was really, really, really hard because you are not a computer, you're not a machine you are a person you've got...and some people NEEDED to be told. There were some people who really needed like a shaking...

I asked the participant what she may have done differently in the implementation of the 2008 MCP research she responded:

Keromang: NO. I would definitely have that outlet. I'm talking about getting the information out there. You know, I would take the extra day and give the green light. Like do the data collection, finish, but then maybe take an extra day or two in that same community with the same people and start sitting down and having conversations and giving them an opportunity to ask questions to clarify for them things that they needed clarification on. Things that you picked up during the interview. Things like misinformation and myths about information taking those one or two days immediately, while you're still there...And you already, you don't even need to actively work to recruit those people to participate like you let them know after the interview, ok like tomorrow come back we will provide you with lunch we are going to have just a talking session and we are going to look at some of the questions we didn't answer and you can ask me questions. They were already there...so they would come back, and bring their friends...It's like you're already there, there's already stuff you can do right then. You've already started, you're...you're human. And you don't need to wait for a year to analyze the data you're getting the data right then you are already seeing the gaps so why can't we...

At the time the research was implemented in 2008, the only way it made sense not to take up the rare opportunity encounter to talk and educate people about HIV and MCP was the expectation that the information gathered would live on in prevention interventions targeting MCP throughout the country. Without that guarantee, the hindsight perspective of the reality being that a lack of funding and political will (as described in Chapter 5) would mean that interventions never happened in these communities and
people were not educated about HIV and MCP. When this question was posed to the participants, Lebona offered the following answer:

Lebona: It was very difficult, Sharon, it was very difficult I mean, although, we were trained, but practically it is not something that's easy to maintain. I mean listening to such stories and you had to be neutral. You knew as a researcher hearing the stories would perhaps make life better for themselves or I mean then you at the same time you are not an educator you just need to refer them. And when you refer them some of them they really do not trust the service that they would get. With others, this was an opportunity for them to, one of those opportunities that they don't get if ever they do to try to talk about issues of sexual, sex and HIV/AIDS.

Like other research assistants he too emphasizes the uniqueness of having an opportunity to talk about HIV and the lack of trust in the competency of the services in which he was to refer participants. He goes on to explain that he understood and agreed with the lines that were dictated in the protocol between researcher and interventionist but points out that before becoming a researcher you are human:

But I mean it was really not easy to maintain your role as a researcher. Every research has its own way it has to be conducted it has to comply with certain standards. So I think it has been fair of you guys to train throughout the research and remind us that we are not educators which is true we were not educators and we were not interveners we were not politicians, we are researchers. But I mean every research has limitations., Like I indicated Sharon, even you before you even become a researcher you are a mother and there are instances where you act as a mother and a researcher but you, and then it clicks after some time, I shouldn't have done that! [laugh]... I mean that's the honest truth as human beings that social interaction with other human beings there are other things that we cannot ignore but I mean, professionally yes it was good to have those kind of trainings. Where it was mentioned that we do not have to intervene that we are not educators we need to refer because our area of interest is research and as a researcher we need to comply with certain research ETHICS.

Similar to what other research assistants repeated he makes the connection with the fear of providing wrong information of not being “expert” enough to have the authority to provide information or correct misconceptions as a justification for following the directive to not intervene:

Lebona: look Sharon, I mean an area like HIV/AIDS it is a very huge area, and I mean it’s not an area that you can know EVERYTHING and nobody knows everything even if we were educated. I mean on how to intervene and how to respond to certain questions, definitely it’s not all questions that we would have answers to. There could have, I mean, come across other questions technically, medical questions about HIV/AIDS and you, you as a researcher become an educator which is going to be very difficult. I mean there has to be specialization we need to specialize in our area of research and that is all. We need maybe, we may be educators but we need to be very careful what we are educating people. Because I mean, Sharon, come to think of it, you have been in Lesotho you have seen the kind of resource centers that we have that are accessible and not accessible to people you have been to those kind of areas in rural areas where people when they
see you, you talk about issues of HIV/AIDS they say "wow this guy knows everything" ok so if you, I mean, really become educator would be a risk, you'd feed people very wrong information and that can be very dangerous to interventions in a place trying to curb HIV/AIDS.

As he continued to explain why it was dangerous for researchers to overstep their boundaries and educate he came back to talking about the basic HIV training the research assistants underwent before conducting field work. Three other researchers made reference to the training and its way of providing information that made them doubt their ability to talk about HIV and acceptance in maintaining their researcher role and not educator. The major point of confusion during the training was the new WHO protocol to breast feed even if HIV positive after years that people in Lesotho were told, by health professionals and national protocol, to not breast feed if you are HIV positive because the virus lives in breast milk. The research assistants found the recommendation to breastfeed nonsensical. This confusion ebbed their confidence to provide advice, as he explains:

Lebona: I mean you can give people tips not a FULLY, educator because, look Sharon, I mean you can't know everything. I mean we had training for whom we could ask questions and some of the responses were technically, medically unsensible they were not making sense to me as a social scientist. Then how could I go and explain that which I did not understand. I think that would be a very huge risk. On the topic that we are tackling on HIV/AIDS I think when you are dealing with other things like poverty, like human trafficking and many other social aspects, I mean its ok, when it comes to issues of counselling you can provide people with basic, basic counselling which I think is ok. I mean look what happened to Tumelo and that girl. That girl needed immediate counselling you wouldn't say I will refer you to so and so's counseling center or whatever. When we are thrust in the middle of no-where, there was a need to provide some basic, basic counselling as in the case of that girl who was really, really traumatized. Going back to my response in one line is that we can, there can be such training [to prepare research assistants to answer questions about HIV] but we need to be very careful on which area we are dealing with, otherwise, no such training should be provided because I mean we would be putting our lives and lives of other people and policies that are already in place in DANGER and defeating the whole purpose of curbing HIV/AIDS in Lesotho.

In Chapter 8, we showed how the use of an ethnographic reflexive approach could help to pinpoint and understand the ethical implications for research members themselves in conducting research on sensitive and emotionally laden topics. The chapter highlighted the importance of dealing with investigators’ emotions and their capacity to cope, and how these influence the conduct and output of research as well as its dissemination. The chapter explored critical questions of what it was like for
researchers to interview people whom could easily be neighbors, friends, or family members and asked about cases which stood out in particular, or had lasting impressions on investigators. Finally, the subject of crossing over the line between researcher and educator/interventionist was addressed. Several research members felt that while they understood the need to conduct research according to certain guidelines and ethics, their ‘humanity’ often intervened, and they were left feeling that the research had not done enough for follow-up communication of information for the participants involved.
CHAPTER 9. PREVENTION DELIVERY SYSTEM: TRACING HIV AND MCP

COMMUNICATION DIFFUSION

Figure 29: ISF framework applied to describing the role of researchers in prevention delivery as they diffused the knowledge gained about HIV and MCP in their communication networks. Copyright 2008 by Springer adapted from (Wandersman et al. 2008) with permission.

As outlined thus far in this dissertation, quality discussions about sex, HIV, and MCP are not readily available or necessarily natural subjects of discourse in Lesotho. To describe how the results and experience of the research process affected local researcher’s ability to incorporate health knowledge in their life, this chapter traces the way that information regarding HIV and MCP has been communicated by original research team members and a small comparison group out to the general population. As described in Chapter 1 (section 1.3.3) the Communication diffusion network diagram assesses if the local researchers spread the innovation (i.e., , the knowledge they acquired about MCP and HIV) and if that was the case, to whom and how; if they did not spread the knowledge, the research seeks to uncover the reasons behind that decision. Respondents were asked to recall with whom, when, and where the conversation took place and to explain what made them decide that this particular conversation was a
“quality” conversation. They were also asked about attempts to have conversations that were not successful. I investigate the context surrounding how these conversations started, and how this type of diffusion of information varies from informal contexts to formal mechanisms. This information can be applied in training sessions for future research and programming capacity-building efforts.

In order to protect participant identity, all participants are assigned a number that corresponds to their diffusion network diagram. Participant numbers one through nine are from the original research team while participants ten through thirteen are from the comparison group of individuals. While in other sections of the dissertation these individuals are referred to by a pseudonym, this chapter uses numbers to add a layer of ambiguity in putting together information from other chapters with their network activity so as to prevent the identification of individual identities.

9.1. Communication Diffusion Network Activity

During interviews, I used the below text to transition into the diffusion network activity:

Here, at the end of the interview, we are going to finish up with the activity I told you about during the informed consent process… I am curious to know if during your time on the research team, and afterwards, if you ever had any quality conversations with people about HIV and MCP. Where you used in conversation some of the knowledge or ways of talking about HIV, MCP, and sex that you learned from the project. It could be a family member, friend, acquaintance, employer, someone you work with, a stranger, someone you met during recruitment, chat room, etc… where you've used the information you learned to talk to other people and that you walked away and you were like, ‘They don't think the same way that they used to.’ Would you agree with this definition or how would you define a quality conversation?

Most participants agreed with the definition of quality conversation that I provided. In other words, a conversation in which information that one learned from the project was shared with others in an informal setting and that this allowed the diffusion of information producing a clear sense of having changed someone’s attitudes. Some participants further elaborated on what they thought a quality conversation was. These elaborations, as well as in other text segments about conversations they had, stressed their role as personal actors sharing what they know even if the conversation was uncomfortable or perceived to be futile. As one participant describes a quality conversation:
I mean quality conversation is always about sharing and feeling like you got heard, you've made a positive contribution to the conversation even if you don't necessarily agree, at least you get your point across that this is what is happening and this is what is not happening. Of course you always have quality conversations with friends, because you're more open with them and relaxed and yourself, so it doesn't necessarily have to be a power point thing, like point one you, but there are things that can be gotten across. (Participant 2)

In addition to stressing the informality, that a quality conversation does not have be a “power point thing”, participants associate a quality conversation with the ability to be open:

Quality. When you talk about everything openly. And at the end of the conversation you know that someone will definitely think about what you were talking about and implement it maybe in their lives or they'll just make choice but you know you know you talked about everything. (Participant 7)

One participant distinguished a quality conversation about HIV and MCP as one that is personal and typically seen as taboo in Basotho culture.

I think… being able to be personal, being able to talk about issues that are normally uncomfortable. Basically, basing ourselves on our culture, because you know that Basotho, here in Lesotho it’s a bit awkward to talk about that. (Participant 10)

This “being able to” may reflect the antithesis of the norm of conversations about HIV and MCP being formal and impersonal. Thus, quality happens when a person is able to break this norm and talk about what is perceived as not culturally acceptable in a personal, informal, open way.

The following example reflects the depth of the type of knowledge research assistants had about HIV and MCP, and the ways in which they were able to teach and discuss this with others. This is important because it demonstrates how an initial large investment in educating research assistants can raise the general capacity on the topic of HIV and MCP, furthering knowledge, versus streamlining information to quickly get the research or intervention project implemented (specific capacity). Such an investment, promotes knowledge that can be articulated and presented to others so that they can make informed decisions about their lives, as opposed to only offering superficial HIV trainings, “assuming” that any college graduate working in the field of HIV has a proper HIV education, or that these details should be left to the “specialists.” The difference of general capacity built versus a superficial
understanding of HIV and MCP is quite clear in this respondent’s description of a quality conversation about HIV and MCP:

…based on what I have been doing and what I have been working on I have specifics. I had like specific topics that I made sure that we talked about so it was, basically what is HIV how do you get it, what do we understand about HIV and that also included ARTs and to the point where I explain it like what do ART's do. And then MCP and then what is the correlation between MCP and HIV... so specifically looking at the acute infection spike and understanding sexual networks and how those kind of things work. Those were the core and then for me it was risk perception was the next thing... what do you understand about risk and what's your own risk. And stuff like that. And then it was about ownership and personal responsibility. Personal responsibility was my big thing. So like I said what is your responsibility to yourself, to protecting yourself, and then your family. So if you're a mother what's your responsibility to your children to making sure they're informed so they can protect themselves are you going to talk to them. And then to your community do you have a say in what’s happening in your community. So those are my core and then anything else that would come up, in the conversation, move on to beliefs, and faith, and myths and sometimes it would be disillusionment. And stuff like that. So, yes. That was my thing. (Participant 4)

The reference to ownership, personal responsibility to yourself, family and community was part of the evaluation of research assistant’s sense of empowerment right before the 2008 study projected ended. I as a technical assistant in creating the evaluation drew upon concepts from my own Community Health course with Dr. Romero-Daza and applied the Scale for Measuring Perceptions of Individual, Organizational, and Community Control (Isreal et al 2002). Years later, it was interesting to hear these same concepts of empowerment verbalized in how this research assistant supported those around her with HIV information. As discussed in Chapter 4 on researchers and a praxis approach to work, this is another example of the long lasting difference academic anthropology makes in various practice setting.

9.1.1. Communication Network Diagrams

In 1997 Robert Chambers, published, Whose Reality Counts?, which reflected the insistence internationally by donors, governments and NGOs on participatory approaches in assessing needs and in implementing programs. The basic doctrine is to start with people’s knowledge as the fundamental basis for planning and change (Chambers 1997). But stating it is one thing and monitoring and evaluating the outcome is quite another. Estrella points out that “as institutions became more inclusive in the ‘front-end’
of project development that is in promoting participation in appraisal and implementation—then
questions of ‘who measures’ results and ‘who defines’ success become critical. ‘Who Counts Reality?’
may prove as significant a question as ‘whose reality counts?’” (Estrella and Gaventa 1998: 3). These
theoretical considerations sparked the merger of the “people’s knowledge” and enumeration of reality
which is known as participatory monitoring and evaluation (PM&E). The creation of the communication
network diagram procedure is inspired by this participatory framework (Chambers 1997) (Estrella and
Gaventa 1998: 3) that combines visuals, tangibles, and numbers to facilitate the creation of visual
synergies to represent reality and relationships. The network activity is an experimental procedure
created for this dissertation but intended to be simple and useful for ordinary people or organizational
representatives to evaluate the spread and long-term benefits of an intervention or dissemination effort.

As discussed in the introduction of this chapter the communication network diagram and in
Chapter 1 (section 1.3.3) Rogers and colleagues outline the importance of knowing “who talks to whom
and what they say to each other about the innovation” (Rogers, Vaughan et al. 1999: 193). I trace if the
local researchers spread the innovation (e.g., the knowledge they acquired about MCP and HIV) and if
they did, to whom and how if they did not spread the knowledge, uncovering the reasons. In order to
make “visible” their communication networks I reconstructed a communication network of who they have
“educated” about MCP and HIV. The format of this activity is quite similar to the “Time Line Follow-
Back (TLFB) method” that the research team members used to document the sexual histories of
individuals they interviewed in the original study. The technique uses a combination of open-ended
questions with memory aids to help the respondent in recalling detailed behavior patterns over an
extended time period (Carey, Ceray et al. 2001). For the communication network activity the “behavior
patterns” or outcomes studied are the research assistants’ quality conversations about MCP and HIV. The
activity asks participants to recall if during their time on the research team and afterwards if they ever had
any quality conversations with people about HIV and MCP. I asked respondents to recall with whom,
when, and where the conversation took place and to explain what made them decide that this particular
conversation was “quality.” I also asked about attempts to have conversations that were not successful.
While participants were talking, I drew out concentric circles that each represented a year from 2008 to 2012 and wrote out abbreviations of names and contextual information they were giving for each year. The chart drawn while they were talking was more of a memory aid than a data collection tool. The diagrams in Figures 30-32 were created after each interview was fully transcribed and coded in MAXQDA by; category of persons (partner, friend, family, work colleague, acquaintance and trainee/student), number of people, conversation trigger, and content of conversations. The center of the diagram shows the sex of the respondent and each radii represents a different category of persons in which the number and type of person are represented by different symbols. The diagram was created using Microsoft Word and Adobe Photoshop.

Drawing upon the stated need for more qualitative studies incorporating networks and retrospective cohorts to understand the diffusion process, I purposively selected thirteen individuals for this objective of the case study. All of the participants were between the ages of 21-32, at the time of the original study (26-37 at follow-up), self-identify as being Basotho, live in an urban area, have a secondary degree, from either within Lesotho or in South Africa, and have worked for an organization addressing HIV and AIDS. The focus of this study is on nine individuals (3M/6F) who spent between 8-9 months on the research team. I also recruited a comparison group of four individuals (3M/1F) to understand if and how the firsthand experience in conducting qualitative interviews, discussing sexual behaviors, HIV, and multiple concurrent partnerships influenced these individuals. The intention of this design was to try to compare a group of individuals who all had similar innovation-specific capacity built, pertaining to the capacity necessary to complete the specific project objective with those that had a chance to engage in ongoing practice based training and application. Two of the comparison individuals were hired by the project management team but resigned from the MCP research team before having a chance to go out into communities and conduct interviews and focus groups. The two comparison individuals shared the initial pre-pilot training with the “exposed” team, approximately three weeks of innovation specific training on talking about the body, sex, and HIV, qualitative research methods, and ethics. However, these individuals did not experience the six-nine month intense period of conducting and transcribing
interviews and focus groups, they had approximately three weeks of innovation specific training on talking about the body, sex, and HIV, qualitative research methods, and ethics. Another two comparison individuals were recruited using the eligibility criteria that they had to have worked for an HIV organizations targeting Behavior Change Communications (BCC) around 2008/9, had training and experience in environments where sex, HIV, and multiple concurrent partnerships were part of their professional repertoire; they were Basotho, had a degree from Lesotho or South Africa, and within the same age range as the original MCP team members (26-37). One of these comparison individuals had experience with these topics in an office environment while the other participated in a project similar to that of the MCP research team members going out into different communities and facilitating dialogues.

Comparison of communication network diagrams between the original research team members and a group of non-research team members indicate several important findings (Figure 30-32). First, three out of the four non-researcher comparison group (11, 12, 13) show none to very little communications about HIV (Figure 32). All of the original team members indicated more communications about HIV than the comparison group individuals. From the non-researcher comparison group individuals, one indicated that he never had a conversation about HIV and sexual relationships outside of the professional realm, another only had one conversation, and the third had conversations that were either initiated by a health professional friend and relative or prompted when faced with a moral hazard (i.e., a younger brother pregnancy scare and bar acquaintance discussing sexual relationship with a minor). A fourth person from the comparison group (participant 10) appears as an outlier as the communication diagram is more analogous to the original research team members’ (Figure 31). This can be explained because, unlike the other comparison group members, this person previously worked for a social behavioral program that facilitated conversations about sexual relationships and HIV. This finding may indicate that people who have the specific capacity for facilitating these types of conversations are more likely to go on to use their skills beyond the professional realm and into their personal spheres of influence. Similar to the control group individual, two additional participants from the original team members indicated having, prior to MCP team experience, conversations about sex and HIV initiated by a relative who is in the health
profession. These preliminary findings may imply the more generalizable finding that this type of training about how to talk about sex and HIV, is not unique to only this project, but has a quantifiable long-term consequence associated with building solid educational and communication skills about sexual relationships and HIV. These findings further support the importance of expanding HIV awareness training for clinical health professionals to include social, behavioral, and communications components.

It was not possible to consider the differences of communication networks by gender and exposure to research experience, since there was only one woman in the non-research member comparison group compared to six in the original research team group. All of the men in the non-research members comparison group had had experience working with HIV, but did not have experience in probing and facilitating conversations about sex and HIV. The contrast between the men in the original team and those in the comparison group, however, reveals significant differences. All of the original male team member reported conversations with partners, family members, and friends, whereas only one comparison male reported a conversation within these categories. Two of three original research team males reported conversations with work colleagues, while one out of three of the comparison group reported similar conversations. Original research team males indicated conversations between work colleagues (outside of the HIV sector) three times more than the comparison group of men, four times more with their partners, and 10 times more with family members and friends. The largest number of persons they reported having conversations with is work colleagues, both in the original team and comparison group. None of the original team member males reported conversations with acquaintances or discussions initiated during non-HIV teaching/training opportunities, and only one comparison group male reported a conversation with one acquaintance. This is in contrast to the females in the research team group, where six out of seven reported these types of encounters and their approximate outreach was with over 1,355 people. These findings may reflect a gender trend of discourse, where men are less likely to seek out opportunities to teach or train about HIV and sex or to recognize the occasion to discuss this type of topic with mere acquaintances. These results seem to imply that men, when trained about how to talk about HIV and sex in a professional context, go on to diffuse their knowledge mostly with close friends.
Figure 30: Communication network diagrams providing a visual representation of the category of persons and quantity of people with whom the participant had a quality conversation about HIV or MCP (1-5).
Figure 31: Communication network diagrams providing a visual representation of the category of persons and quantity of people with whom the participant had a quality conversation about HIV or MCP (6-10).
and colleagues rather than family members and acquaintances.

Through the interviews and diffusion network activities, it was possible to classify conversation triggers into a few dominant categories:

1. Immediate crisis that makes initiating an HIV prevention conversation imperative
2. Health professional friend or relative who brings up the conversation based on an experience they had at work
3. Constructive gossip a conversation during lunch break with colleagues, at the gym or bar with friends, office gossip about a celebrity or another person that opens up the discussion to MCP or HIV

Figure 32: Communication network diagrams providing a visual representation of the category of persons and quantity of people with whom the participant had a quality conversation about HIV or MCP (11-13).
4. Life transitions, both their own and that of people in their personal network like getting a new job, starting back at University, new relationships, new pregnancy, a death, these life transitions created opportunities to discuss the MCP research experience as well as HIV and MCP in general.

5. Work-place HIV orientations and HIV trainings with people who had not participated on the 2008 MCP opened doors to conversations about MCP and HIV.

The next few sections of this chapter go into more details about these encounters providing examples of these types conversation triggers, with whom and the content of the participants quality conversations about HIV and MCP.

9.1.3. With whom did they have conversations?

All of the original research team reported having quality conversations with a partner, family member, and friend while only half of the comparison group reported having these conversations. In looking more closely at the actual number of reported encounters with a specific person, the difference between the original research team and the comparison group becomes even clearer (see Figures 30, 31, and 32). Likewise, the magnitude of the actual number of persons who engaged in conversations with colleagues at non-HIV workplaces is higher in this group as well. When looking at the raw data the largest number of persons with whom participants conversed were acquaintances, including those people they trained on the matter of HIV and MCP for work, random people, and people who were in their classes. Of the seven people who reported conversations with acquaintances, only four were probed further about the number of people they had a “quality conversation” with. Thus, the number of persons networked is likely to be much higher than the 1,355 approximation.

Another interesting finding relates to, conversations held with work colleagues, who are outside of the HIV work sector. This category of persons differs from other categories. Work colleagues are people with whom the participants interacted over a long period of time, with whom they are in relationships of social connections (not just a one-time encounter) but with less relative social obligations (compared to friends, partners and family members). Additionally most work colleagues have no direct element of power such as found between teacher/trainer and student/trainees. Numerically speaking, participants had more conversations with non-HIV sector work colleagues than they did with partners,
friends, and family members. From a gender perspective, while only one male reported a conversation with an acquaintance, the highest number of conversations for men occurred at work between colleagues.

Pertinent findings were not just limited to whom the participants had conversations with, but also with whom they did not have conversations. Regardless of how dense their communication diagram seemed to be, none of the participants report initiating conversations with older siblings (especially older sisters). They reported initiating conversations with younger siblings, nieces and nephews, and the friends of younger siblings. There is also a pattern of having had very few conversations with broader extended family members. All of the comparison group, including #10 who had the most populated communication diagram in this group, maintained that talking to elders or parents about sex and HIV was not a cultural norm and something they did not and could not do. This is in contrast to the original research team members who reported that their role on the research team had changed their cultural expectations; thus, they were now able to have conversations with elders and their parents (1, 3, 4, 5, 8), thereby opening up a space for intergenerational knowledge transfer. For these participants, the practice in recruiting and talking to elders during study implementation helped them to open up and talk to their own elders. This ability to bridge the gap allowed them to receive and divulge a wealth of information that otherwise they would not transmit.

Sometimes we would talk about, they have support groups at home where people are either affected or infected with HIV and AIDS gather together and sometimes she (mother) would share with me what they have discussed and then I would talk to her as well with the experience and knowledge that I got from MCP...(Participant 5)

All of the original research team members noted having conversations about sex and HIV risk reduction with their partners. This includes all three of the male respondents from the original team. Of the three male comparison group individuals, only one had reported having this type of conversation with a partner. His conversations specifically about risk reduction and testing resulted from his partner’s pregnancy and ongoing choice for breast-feeding. The association of compulsory testing during pregnancy and the suggested policy of women to stop breastfeeding was cited by all of the participants, both male and female, who had children after 2007. This finding reinforces the importance of utilizing the
clinical encounters of child-birth and early feeding as an intervention point for not only mothers and babies but also fathers and pertinent family members.

Two participants made the connection about their fearlessness in having conversations about HIV status and testing with potential partners with that of “scaring” potential partners away. Participants had more conversations about MCP and HIV with friends than they did with family members. Several participants highlighted how these conversations with friends were not just a onetime event, but part of an ongoing dialogue. They noted how they would bring in their MCP and HIV knowledge into the conversations during different life situations that their friends were facing. This is the type of outcome that if only quantitatively measured by person contacted would not reveal the repeated encounters over time nor the depth of the relationship that allows the information to be tailored to the life need of the recipient. In other words, 25 acquaintances contacted may not have the same long-term value in raising consciousness or behavior change as the repeated and higher quality encounters with five friends or work colleagues.

9.1.4. Content of Conversations

The quantitative and qualitative analysis of the diffusion activity provides several key points for application. People trained with capacity specific basic HIV and AIDS prevention information, including how to talk and get others to talk about sex and risky behavior, take this information with them and apply it in various spheres of contact with people in their personal and professional network. People who are trained with basic HIV knowledge but had no practice in talking or getting other people to talk about sex and risky behaviors are less likely to have conversations about HIV with their partners, family, friends, work colleagues, and acquaintances. Based on the results of the activity we can categorize participants into high diffusers and low diffusers. High diffusers are those who reported conversations in at least three different interaction groups, were able to provide details of conversation content, and recalled more than one person in the interaction groups. Low diffusers were those with less than three interaction groups,
with only one person in an interaction group, and had a lack of recall about conversations. The next section highlights the ways in which these groups talk about HIV and MCP.

9.1.5. Low Diffusers

Conversation content from the three comparison group males does not reflect the same level of detail, quantity of persons, or repeated contact interactions as seen with the original research team. Participant 12 explains how he perceives people sterilizing conversations about HIV and MCP for professional discourse. He explained this sterilization as cleaning the personal connection with HIV and MCP and leaving it at purely academic and professional level. He noted how conversations about HIV come up in passing but could not give one example of an in-depth conversation:

I've had...a lot of conversations with people in different situations, I don't think I recall myself particularly initiating anything to do with HIV and AIDS. I think this one may not be so easy to approach the reason I'm saying this is that you know, Sharon, sometimes you learn something and you learn it when you already have your own firmly established you know opinions and so forth about this particular thing. (Participant 12)

This participant is the only person who exhibited an inability to recall the details of even one quality conversation and admitted to never “initiating anything to do with HIV and AIDS.” The other comparison males were able to recall in detail the few conversations they remembered. The above participant is in contrast to the high diffusers who recalled multiple conversations and had the ability to describe details about the context and content of conversations. This may confirm the methodological assumption that these conversations are an exceptional event and that if a quality conversation had taken place an impression remained so that, when an interviewer probed, an individual could recall the details.

Participant 13 only recalled one quality conversation at work with approximately eight of his colleagues:

Interviewer: do you remember those conversations?
Participant 13: [pause]...what was happening, because what I remember there were a number of us. I think there was something happening and I was surprised by most of the people there were not aware...I think early 2011 cause that was after [Name of organization]...we were in the work place or something but they didn't know about MCP. Yes because I remember I was telling them that an average man has three, three concurrent friends and they were like "uh uh" [Sesotho sound of surprise shock] and some were saying no, no that its more the number is more we know of some people with more than that.
Interviewer: and then did you actually get to talk about why this is dangerous?
Participant 13: yes, because it ended up being like a debate because some people were for it and some were saying no it is not good. The ones who are saying its good were saying that the number of women is higher than the number of men so what are they supposed to do? If we are saying that men should only focus on one woman, yes then we try to talk to them about the dangers of that. I remember I even referred to [Name of organization] did a study… the focus was on the gays and lesbians, yes they also presented the study to the national forum. So I was also telling them that I was surprised that most of the lesbians and gays are married. I was saying that you can just imagine if somebody is a gay and he is married the wife has three concurrents then look at the chain if one of them is infected what is going to happen. I remember I referred to that study.

As discussed previously, this participant had worked within the HIV sector but had never had an opportunity to facilitate interviews or discussions about sex or HIV. When he transitioned to a non-HIV working environment, he seized the opportunity, when it came up, to convey his research knowledge. However, this encounter is the only quality conversation the participant could recall. Also noteworthy from this example, is his surprise at how people were unaware and did not know about MCP. This may speak to the level of ignorance about concurrency and HIV still present in the general educated middle class population up into 2011.

The last example from the low diffusers is from participant 11. He reported conversations with five different people: his wife, a friend, his friend’s physician wife, his younger brother, and an acquaintance at the bar. Participant 11 and his wife initiated conversation during life transitions such as an AIDS related death of a family member and decisions surrounding pregnancy, childbirth, and breastfeeding. As mentioned previously, his physician friend who was conducting research herself initiated one of the quality conversations about the prevalence and risks involved with MCP and HIV in Lesotho. The last two conversations initiated by participant 11 with his younger brother and an acquaintance at the bar were provoked by facing a moral hazard. The example below demonstrates several interesting points. It shows the type of settings where opportunities may arise for conversations about HIV prevention and what type of misconceptions are present in college educated working people who can afford to be at a bar and afford the upkeep of a young girlfriend:

Participant 11: yeah he's [male participants friend name] thirty-four actually. And divorced, twice, and well I don't know but I wasn't really comfortable with the whole thing. Mainly because
this girl will come to where we are sitting, she will, you know. So my wife was actually upset cause she thought that maybe I might be doing the same thing. 'Cause what she was saying was, "I don't understand the logic behind a thirty-four year old man dating a sixteen year old girl" And then you are out with this person drinking almost every Saturday. You know, but then I decided to face up the reality and ask the guy, "Why are you dating a girl of sixteen" and he told me, "You know what I'm trying to run away from HIV and AIDS." He says, “I'm trying to run away.” Run away like I don't want to get infected because, in his mind he thinks well, having a younger partner will actually safeguard you. You won't get infected. I don't know it’s a misconception. Most of the people do have that...so I tried to convince him he was wrong.

Interviewer: what did you tell him?
Participant 11: A lot of things morally…Well I actually told him that according to our laws a sixteen year old is still a minor, you cannot have sex with someone who is younger than 18. Well then he said I didn't see anything wrong, because apart from me nobody knew that the girl was sixteen. ‘Cause she looked mature, but she wasn't and the fact that the matter is I think the girl is only interested in the guy because...she gets a lot of money from him. Buys her some expensive cell phones, some clothes sometimes, so I think that is the whole point. But then, I can't remember exactly what we talked about but I found it wrong.

9.1.6. High Diffuser Conversations

High diffusers are those participants who reported conversations in at least three different interaction groups and provided details of conversation content. Conversations from the diffusion activity of these high diffusers point to five key trends for consideration:

1. All in the Family—Intergenerational Knowledge Transfers. Individuals who have a high-level capacity in talking about HIV prevention and sex in the work place use their skills to open culturally appropriate HIV discussions with family members.

2. Time and Transition Sensitivity—The opportunities for initiating and continuing quality conversations about HIV prevention and sex are time and transition sensitive. “Time and transition sensitivity” refers to periods of time or life transitions when it is more likely for an opportunity to initiate a prevention conversation.

3. Men Talk—Male participants from the original team all describe “man talk” with close family or friends where they bring up their HIV prevention and sex knowledge with the same men in their inner circle, numerous times across several years.

4. Non-HIV Sector Work Environment—Individuals who transition out of a working environment where the specific capacity for explaining and making others talk about HIV and sex as an
essential competency go on to use this competency with colleagues in various non-HIV sector work environments.

5. Teaching and Training—Participants apply their research knowledge and examples gained from the research experience in teaching and training positions including university courses, HIV prevention, and general education programs.

The following section describes in further detail, and provide examples of, these dominant themes.

1. All in the Family—Intergenerational Knowledge Transfers

Individuals who have a high-level capacity in talking about HIV prevention and sex in the work place use their skills to open culturally appropriate HIV discussions with family members. Intergenerational knowledge transfers took place as adult child to parent conversations and where they could utilize their cultural role within the family to talk to other family members, such as big sister/aunt, brother/uncle. Despite the cultural assumption that children do not, and will not, talk to their parents about sexual matters, such as confirmed by the comparison group, original research team members reported that their role on the research team had changed their cultural expectations, and they were, in fact, able to have conversations with elders and their parents (1, 3, 4, 5, 8,).

As discussed in Chapter 7 several participants mentioned how the practice of recruiting and talking to elders during study implementation helped them to open up and talk to their own elders. This ability to bridge the gap allowed them to receive and divulge a wealth of information that otherwise they would not have transmitted. Three participants mentioned how they were able to share what they learned from the MCP project experience with their parents and how their parents went on to share the knowledge in their spheres of influence.

I have a lot of conversations with my mother. And because my mother filters the conversations the information out to other people. So the people she talks to, I mean this I would give her pamphlets I would give her female condoms and she would be distributing them to other people, people she interacts with from like church ladies (Participant 4)
Several participants repeated this theme of providing “materials” and information to their mothers. Even the comparison group’s high diffuser, participant 10, despite not being able to verbally talk to her mother said, “Not my mother! Oh you know our culture...I just can't imagine myself talking about...no, no, multiple concurrent partners...No I'll bring material, I'll bring material not talk.” Thus, adult children’s transfer of information with parents may be an under-utilized intervention point. Parents of adult children are often out of their reproductive years and not perceived as outreach targets, however, given their age, they have a broader network of various types of relationships with younger and older adults. Giving materials to young adults with the awareness that they may share them with parents, who then can diffuse information, could be a potential way to increase the spread and diversity of prevention knowledge recipients.

The western paradigm of a “quality prevention conversation” often places great weight on details around a specific sexual act. ABC’s and “Safe Sex” messages softly imply ‘Have sex but use condoms.’ Negotiating this type of conversation with “at-risk” siblings is not that simple. Participants describe their “quality conversations” as ongoing and holistic, taking into consideration the specific context of the risk taking behaviors within a sexual relationship.

Participant 2: No, no, with my sisters it’s more like, do you know this guy what are you doing? I think you’re taking this relationship too quickly, don't be like me, don't be looking at the financial aspect of the relationship, look at the quality of the guy. That's how I talk to them. It’s not about, use condoms, have sex, I don't think I'm quite comfortable with that yet.

Interviewer: But you do talk to them?

Participant 2: YES of course I do, you know what I mean. My sister is very money oriented and I tell her you'll regret it. One day you'll look at your life and... yes I remember one time I saw an SMS[phone text message]. Like can I borrow your phone and then when I look at the phone I realize oh no, "ok baby only if you want to have sex" and I was like WHAT? And I said to her, you know I said, " I saw the SMS that you sent to so and so, you know it’s your life, I realize that...but you must really look at other things in your life right now other than for you to be actively talking to this boy about sex. She was so embarrassed and for days she avoided me, you know what I mean. I felt bad, I felt very bad but at the same time I felt like I did the right thing by making her aware that I was aware that she knew that I knew that I knew that she knew that I knew. Yes.

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Diffusion activity conversations reveal how HIV prevention information, disseminated by participants, is not formulated in a unilinear pathway from “target” potentially sexually active persons and their direct exchanges with their partners. Instead, the quality conversations discussed by participants built up a social awareness, a cultural translation of information that creates an enabling environment. These conversations repeatedly show the special dynamic of kinship relationships. People hear the same information differently because it is coming from a person in the family that is respected and that is socially sanctioned to call on when in need of help in fulfilling social obligations for marriage, inheritance, death and respect to the ancestors. People in key kinship roles can facilitate this type of conversation. However, study results also revealed the consistent trend of not talking to family members of certain kinship relationships. Most of the time, for instance, younger siblings did not initiate conversations with the oldest female sister in the family. Participants also drew an invisible line of who was “close” enough in the family to have conversations about sex and HIV.

2. Time and Transition Sensitivity

I use the term “Time and transition sensitivity” to refer to periods of time, or life transitions, when it is more likely that an opportunity presents itself to initiate a prevention conversation. During study implementation, participant conversations within their network were stimulated by family and friends asking questions, (that they otherwise would not) because they knew that the individual was part of a team working on issues about sex and HIV. Other time and transition sensitive examples include ex-research team members initiating conversations around either their own life transitions, whether new positions or relationships, pregnancy, marriage, affairs, etc., as well as those of other people in their life.

My friends we talk about it all the time. Because I keep insisting on the talk. Every time a friend of mine has a new boyfriend I am like, "have you had the talk?" you need to have the talk. And every time a friend of mine was to get, some of them were trying to get married, some of them having problems, a friend of mine would be like oh I'm pregnant and I'm like "why weren't you using condoms?" (Participant 4)
One participant discussed her role in her friends’ circle as they were getting married and moving into the role of daughter-in-law and mother, supporting her friends to move from engaging in irresponsible sexual behaviors to “how we can change how we could focus on important things” (Participant 9). Repeatedly, these descriptions of conversations from high diffusers bring to light how their unique access to HIV prevention information and awareness was put into practice in the everyday reality of people around them.

The next participant example demonstrates several aspects of the concept of time and transition sensitivity. People around the participant, her friends, family and neighbors were interested in her “new work” and thereby got involved in learning from her and her “interesting” study. Curiosity may have been the initial opening, but it created an ongoing space for dialogue about HIV and sex that otherwise would not be present. In fact, this type of window opened up during project implementation as well as when participants moved into a new job or university setting and they had to talk about their previous work experience. Similar to other conversations, people in her network used and provoked the “high-diffuser” to bring to the table her knowledge about sex and HIV. Her life transitions and that of those around her stimulate the exchange of sexual health information:

Participant 8: because I think our study was very interesting. So much so that everyone was interested in my study. They will be asking you what have you been up to? This is while I was working with MCP I think that's what initiated the talks about HIV because I will always be having stories to tell. I think everyone was interested in "what is happening in your study?"

These conversations took place during the study implementation in 2008. She also gave other examples of people she talked to about HIV and MCP in the years after the study had ended:

I always talk with my friend, a very good friend of mine, we talk every day every time, even after birth... have you gone back to it [sex] yet? You see things like that [laugh] what contraceptives did you use? What isn't it painful, blah, blah, blah. We talk almost every day. And then in my office. It’s almost like another sex team.

Interviewer: In your office the [non-HIV Government Department].
Participant 8: yeah we talk, we talk about everything. MCP I used to tell them how we used to, how MCP was, how we use to interact in the office, what we used to talk about and sometimes they were like, "huh you did that?"

Interviewer: So were you the one to initiate those types of conversations?
Participant 8: I think so, I think I had a very like big, big influence, on initiating those topics because we used to talk with my friend and then she used to say "hmmh [Partipant 8’s name]
where she used to work they talked about this and this and that, weren't you too ashamed, weren't you" And then we ended up having those kinds of conversations there in the office, almost natural. So right now it’s not even like, it comes when someone is talking about something you just put it on the table.

Chapter 8 illustrated how the research team members changed the way they talked and negotiated their own sexual practices following their experiences on the MCP project. A particularly key time to do so was at the initiation of a new relationship. One participant explained the content of her conversation with a new partner about, “HIV and AIDS, use of condoms, MCP, why we have higher prevalence here in Lesotho, the impact and blah, blah, blah. Luckily enough he was more informed than this one. So our conversation was much more.” She also described how she would attempt conversations with not only her new partners but also with the friends of new potential partners:

Participant 10: I had a boyfriend…and even with his friends, “UH OH [participant says own name] is coming she is going to talk about sex and AIDS UH OH she’s coming!” I think there were four of his friends.

*Interviewer: Who dreaded your arrival?*

Participant 10: Oh they knew if I was around that I would talk to them, "Guys, guys, please [laugh]"

Another single woman and high diffuser talked about how she felt strongly about the importance of having “the talk” with potential partners but feeling as if her “talk” actually scares off potential partners, “I'm very...I don't have a life. When I'm gonna get…seriously, it has made them run away so what does that say. The TALK has made them run away” (Participant 4).

3. Men Talk

Male participants from the original team all describe “man talk” with close family or friends where they bring up their HIV prevention and sex knowledge with people in their inner circle, numerous times across several years. These conversations included explaining and bringing to light the risks in multiple concurrent partnerships, supporting each other in decisions to avoid risky behavior, and providing a place for alternative practices:
I mean we would talk about sex, I mean boys conversations sex and HIV and sexuality and we would advise, give and get suggestions from some of us. I remember a friend of mine who when we talked I mean, I learned that he had...had...he was an MCP PRACTITIONER [laugh]! And when we were talking in a more relaxed way trying to understand what are the reasons why he is having multiple and concurrent sexual partnerships, and the risk that he is putting his life in and his partners in. I think that is one of the conversations which I think I would regard as a success story for me towards the information dissemination to my friends. Because I mean, from time to time you would, although I am not an expert on HIV and AIDS related issues but from time to time he would ask me "so what is this? Do you think this is a wise decision? Do you think I should part ways with this woman?" I was more of a reference he would use from time to time,, I think it’s one of those stories that I am saying it’s a success story, that of the information I gained from MCP team and disseminated it to one of my friends. Slowly he started changing his behavior, his sexual behavior so which is good, which is good. And as we speak now he is a one man one woman gentleman, I think he is planning to get married in a year or two.

Interviewer: wow, so how does that make you feel?
Participant 5: I mean, man, it feels really good, it feels very good, I mean it’s one of those things that, although, I'm not the only one who influenced him or who played a critical role but I KNOW for sure that I played a MAJOR role towards him changing his behavior.

All of the male high diffusers noted how they do not hold back if the subject of HIV or the danger of MCP "comes up," however, if it does not come up, they will not initiate conversation. Further studies should be done on understanding what constitutes “the topic coming up” and opening the way for sharing sexual health information. Three men said they talked repeatedly to their male core group of friends but not to extended family because the subject “never came up”. Participant 6 described his conversations as critical "guy talk" where he is purposefully trying to inform those around him of MCP, how it comes about, and how to eliminate the possibilities through behavior change:

…the floor of the discussion [about MCP and HIV] it’s not like to say "hey man don't do this do this" it’s all about saying "why, why can you do that?" you know that in the process you are advocating you know...cause in the process you will find, ok well if we agree that this is a challenge then how do we go about it, against it. Then we will conclude ok when its Friday guys lets go to the gym...instead of moving around you know (Participant 6)

Here the participant is not using accusatory language with his friends but rather an approach for the friend to better understand his own behaviors. The example also shows how men support each other in seeking out alternative activities like going to the gym instead of “moving around” or sleeping around.
4. Non-HIV Sector Work Environment

Individuals who transition out of a working environment where the specific capacity for explaining and making others talk about HIV and sex is an essential competency go on to use this competency in various non-HIV sector work environments. These individuals did not shy away from sharing their knowledge about HIV and sex, but instead took the opportunity to spread what they knew in settings where most people had either a superficial knowledge or grave misconceptions. In fact, participants reported more people contacted within the category of non-HIV sector work colleagues than they did with partners, friends, and family members.

Participant 9:…before MCP, we used to talk about everything else besides HIV everything else besides sex. But then after MCP we just talk about it…I just transmit from one conversation to the other, I think they are naturals, [laugh] since...I think the free-ness, I think the free-ness and how we learned to talk about it, not putting other people's lives in danger, or whatever, I think that's how we managed to gain that experience. Just like, yesterday we were talking about all other things, and then one friend of mine told me we were talking about this other man, who has many wives, and then one of them said, "how come he doesn't have HIV?" And then the other one said, "it’s because he is doing it concurrently" [imitating their voices]. Another one said, it is my first time to hear about this "concurrent" thing. I laughed and I was like, "where did you think I was working when I was working at the UN" and then she said, were you in that group and I said yes I was in that group. And it was great, and we started talking about concurrency, we started talking about HIV, we started talking about all those things, it just comes from one conversation to the other.

5. Teaching and Training

Participants applied their research knowledge and examples gained from the research experience in teaching and training positions including university courses, HIV prevention, and general education programs. Both male and female individuals report having applied aspects of the research and research experience in their future careers. However, it was female participants, more than males, that reported the connection between their application of knowledge and their perception of having stimulated quality conversations or new ways of thinking about HIV and concurrency by those they were teaching/training. As discussed in Chapter 4 teaching and training opportunities are unique spaces for engaging in critical thought about HIV, sexuality, and social realities. Several respondents described how they brought in stories, statistics, ethical examples, and ways of talking about HIV and MCP that they gained from the
original MCP project, into their teaching and training employment. Despite the prevention outreach in Lesotho, most of these high diffusers commented on how it seemed like their students had never heard the story of HIV told in this way:

Participant 7: … [my students] were really interested to hearing what I was saying as though they had not heard it or seen it on TV because I think I taught it in a, even though it was a class, I think I taught it in an interesting way and I see from their faces that its different from what they hear or see on TV. I made examples, of us in the class. You know sometimes I have such a person and suppose this person…it would be more interesting but at the same time I could see that they were really thinking about it.

Interviewer: How did you feel after having that?
Participant 7: I was actually proud because I, it was something that I learned somewhere and it was good when you teach people later in life about something that you learned that you were part of... and I could actually tell them, you know I was once part of this study the MCP study and have you seen it. It is there on the internet so they could go and see it.

Thus this participant not only diffused information during her courses but also continued the process of diffusion by referring students to the original MCP report.

Several of the original research team members, who went on to work in the HIV sector, were recognized and associated with the MCP study regardless of their current employment in another organization. For some, this meant past participants actively calling to “continue” the conversation and asking for counseling and specific questions about HIV and the resources available.

9.1.7. Feelings After Quality HIV and MCP Conversations

In looking into the question about how participants felt after having a quality conversation about HIV and MCP, I found that participant responses vary greatly. Feelings ranged from feeling happy, content, good, fulfilled to feeling bad, frustrated, judged, shaken and fatalistic. Some participants experienced several diverse feelings in different encounters, sometimes even with the same person. I did not determine a pattern according to male, female, research team, comparison group, nor high diffuser or low in how participants felt after a conversation. However, some high diffusers talked about how they worked through the nervousness of bridging the subject of HIV and sex to becoming comfortable, regardless of how others may react, to it becoming a natural “something that I just do”:…[laugh] right
now it feels just normal but at first I would be left with the shaky kind of feeling like "did I just do that?" "did I?, DID I?" but right now it comes and goes. It is no longer difficult. (Participant 8)

It is important to remember that this is actually a second layer of feeling comfort when talking about HIV and sex. Research assistants first increased their comfort when they developed expertise in interviewing and conducting focus group discussions during the project. This second layer is the additional stratum of using the fact that the researchers know how to talk about sex, MCP, and HIV, as well as having the toolset to get other people talking, that they can actually apply these skills in real life situations.

Several participants noted how many Basotho stereotyped people who work in the HIV sector as being hypocrites; that when it comes to “risky” behavior, these people were worse than the average Mosotho. In many cases, this perception served as a way to block further conversation about MCP or HIV. One participant who worked in HIV prevention outreach described how community members would reject her attempts to talk to them about MCP arguing that people working in the HIV sector were hypocrites:

‘Cause the argument was that [name of participant] you just come and tell us or talk about that topic [as in HIV and AIDS] ‘cause you people who are working with HIV and AIDS you are more promiscuous than us, you practice MCP more than us so I mean, you CAN'T! No no go to HIV and AIDS workshops those people are just so…NO you can't tell us anything! (Participant 10)

Some of the participants provided responses that seemed mixed between feeling content that they said something to make a change and that of feeling frustration and resignation that their words could not make a difference, one participant stated: “Yeah well, yeah I felt like well, I have done my part I don't care. Yeah the reason being the reaction I got” (Participant 6), the reaction being negative and dismissive. Another participant explained how having gained the knowledge and experience from the MCP project she could not talk to her friends and could not understand how anyone in the same position would not go on to share their knowledge. When asked if she thought her words made a difference she said:

Participant 3: I think they [her friends] still carry on, their behavior certainly hasn't changed, I don't think. I can't really control what it is that they choose to do cause I think they kind of know
the risks involved but I think a lot of them it’s kind of circumstances so...it’s a bit like...I think they know the risks but I think it’s kind of in the potential kind of situations that they’re finding themselves in. Which is why they've decided to take certain paths

Similar to this participant, all the other participants who risked initiating or speaking about what they knew about HIV and MCP put themselves at risk of feeling frustrated, judged, and ridiculed, yet they still put that information out there. These individuals made themselves vulnerable hoping to not only be heard, but also to plant a seed of change, knowing they had done their part towards ending the epidemic.

9.1.9. Conclusions

The goal of this methodological approach is to compare a praxis-centered model with a specific practice-oriented approach to capacity building. In other words, attempting to look at the difference between the comparison group who are trained to have a practical professional proficiency of HIV sexual transmission knowledge to achieve a specific objective associated with their job. As oppose to a praxis-centered model where in addition to the specific objective of the larger project research assistants from the 2008 MCP study were treated as agents of change and time, space and authority were invested towards building their specific and general capacity. In transitioning to a post-development reality, where knowledge creation and production are truly collaborative with a shared end-goal, research assistants/employees must be seen as not only project implementers but as agents of change. This shared goal can be implemented in the individual “funded” project and also by individuals who have the power to go on and synthesize health information in a real world setting, where it can have more meaning far beyond a specific project. What if the good of a project could be measured not only by the original specific objectives, but in the myriad of potential networks that each individual can harness? How might our everyday practices change during a project if we saw each other not only as implementers to an immediate end but implementers of long-term change? Would we take the time to ensure that all levels of our staff know the problem we are tackling, can clearly articulate how their work feeds into a larger goal, can respond and explain if interrogated, and know how to listen and learn from alternative perspectives?
The findings in this project support the general finding that a praxis type of training about how to talk about sex and HIV, while not unique to this project, has a quantifiable long-term consequence associated with building solid educational and communication skills about sexual relationships and HIV. These findings further support the importance of expanding HIV awareness training for health researchers and clinical health professionals to include social, behavioral, and communications components. In discussing the individual in relation to society in the study of social change, Boas, points out the importance of this dynamic relationship, he argues:

Similar considerations may be made in regard to the important problem of the relation of the individual to society, a problem that has to be considered whenever we study the dynamic conditions for change. The activities of the individual are determined to a great extent by his social environment, but in turn his own activities influence the society in which he lives, and may bring about modifications in its form. Obviously, this problem is one of the most important ones to be taken up in a study of cultural changes. It is also beginning to attract the attention of students who are no longer satisfied with the systematic enumeration of standardized beliefs and customs of a tribe, but who begin to be interested in the question of the way in which the individual reacts to his whole social environment, and to the differences of opinion and of mode of action that occur in primitive[sic] society and which are the causes of far-reaching changes (Boas 1920).

This chapter, through the use of the communication activity, demonstrates this dynamic interaction of the ways in which an individual reacts to his social environment and the role the individual plays in stimulating social changes. The communication activity helps to visualize the personal impact that working on the MCP research project had on the researchers’ ability to talk to their families, partners, acquaintances, work colleagues, and students/trainees. The results indicate that there are particular life moments where the opportunity to have a quality conversation about sex and MCP may arise. Individuals in the comparison group who were not trained in talking about sex and HIV reported much fewer conversations. While individuals with this type of general capacity built in building rapport, listening and talking about culturally sensitive topics such as HIV, sex and MCP had not only significantly more conversations but also had much more variation in the categories of persons in which they had discussions. Thus far the results of this dissertation show the difference made in organizations, policy, programming, and individuals following the implementation of a particular type of HIV project, a
qualitative research experience. Participant discussions have revealed why this experience and the results had such an impact, often making comparisons with other types of HIV projects in the country. Research participants have also pointed to what has hindered the potential difference the research could have made indicating the general reality where HIV is not a subject of normal conversation, something done for research or work, and furthermore how HIV has come to be associated with fostering inequity. The next chapter discusses the general way in which the AIDS response has been implemented in Lesotho, and the consequences this deployment in terms of its influence on the ways in which local leaders, and everyday citizens, define, communicate and conceive solutions to the problem of HIV.
CHAPTER 10. HIV RESPONSE AND THE DYNAMICS OF SOCIAL, ECONOMIC AND POLITICAL CHANGE

**Figure 33:** ISF framework applied to highlighting the macro policy, funding, and social climate complexities in diffusing and translating HIV prevention information. Copyright 2008 by Springer adapted from (Wandersman et al. 2008) with permission.

10.1. The HIV/AIDS Response

The previous chapter illustrated the important feedback mechanism for social change that exists between the individual and the social environment. Moving forward towards solutions of getting what we know about HIV and MCP translated into actions will no doubt require multidisciplinary combination prevention approaches that draw on biomedical, behavioral, and social knowledge. Thus far, in Lesotho the scale is heavily tipped towards the biomedical. However, as anthropologist Kate MacQueen (2011) reflecting on 20 years of experience as a social scientist working in collaborative biomedical projects argues that we need “to move beyond a critical framing of the social in opposition to the biomedical” (S37/8):
HIV transmission is not simply an event but a dynamic, evolving process that sends its roots into our complex human systems over the course of years. As a chronic treated condition, those years become decades. HIV is now rooted in the social ecology of thousands of communities and it has demonstrated its capacity to propagate through human generations. As social scientists, we need to move beyond a critical framing of the social in opposition to the biomedical. We need to ask how the dynamics of social change can be combined with our increasing understanding of the biomedical dynamics of HIV transmission to create, evaluate and implement highly effective HIV interventions. We need the opportunity to work with the complexities of social systems with the same degree of nuance and rigor that biomedical researchers work with the complexities of genetic systems, immune systems and population-level transmission dynamics. Our understanding of each of these systems includes attention to the idiosyncratic as well as the generalizable, the random along with the patterned, the mutable together with the stable. All have much to offer in this endeavor, and much to learn (MacQueen 2011:S37/8).

Part of looking at the complexities of social systems requires that the lens be placed on the social changes caused by HIV research and interventions themselves. In this chapter, turning towards solutions, I look at HIV as part of economic, social and health development in Lesotho supported by the aid industry. With this perspective, I present my own discussion and that of the research participants, on how the investments of money influence the ways in which local leaders and everyday citizens define, communicate, and conceive solutions to the problem of HIV.

There is indeed an in-country HIV/AIDS problem, context specific, culturally grounded, geographically isolated, and then there is the AIDS Response, the local and global institutions harnessed to respond to the problem. A new reality is created at the interplay of what is often left invisible between the AIDS Response and its conjoining with the local HIV problem, most research is inspired by the imperatives set by professionals in the Response and rarely takes into account the influence of the Response itself (Epstein 2007). The AIDS industry Response, which includes the local and global entities, tasked and financed to measure, research, control, treat, prevent, and coordinate the HIV/AIDS reaction, falls under the umbrella of “Development”. I categorize it as development because the transfer of aid, technical assistance, and technology follows the traditional trajectory from “wealthy” nations to low or middle income countries. This approach follows the anthropological shift towards understanding the discursive and institutional construction of client categories through studying the institutional apparatuses doing the “developing” (Ferguson 2001: xiv). Escobar describes this shift as turning the development
apparatus itself into an object of anthropological study. Within this context a form of “Institutional Ethnography” was established moving from studying not only the textual and work practices of institutions, but also the effects of these practices in the world, “how they contribute to structuring the conditions under which people think and live their lives” (Escobar 1995). Escobar argues that the work of institutions is one of the most powerful forces in the creation of the world in which we live.

In trying to understand the diffusion process of the MCP research findings and the way in which the experience affected the research team, it is clear that the full story cannot be told without consideration of the larger institutional forces at play. Many people working within the HIV Response see the problem of high incidence HIV in several Sub-Saharan countries as a confined public health response, using all the bio medical and technological means necessary and working within funding cycle packages. Some professionals in the Response do not consider how the Response itself may be exacerbating the local HIV problems. I am not arguing that the entire AIDS Response should come to a halt, but rather that it is important to take a praxis approach of reflecting on how everyday normal research and intervention practices may aggravate or help communities to cope and resolve the epidemic.

Academics and practitioners oftentimes treat the issues of governance, democracy, corruption, race, and inequalities as separate categories of intervention from development issues of health and especially HIV. This chapter demonstrates how these issues have very pertinent consequences in Lesotho’s rapidly changing social, economic, and health systems. Furthermore, in a systems perspective, these issues are tightly linked to how people perceive and define the problem of HIV.

10.2. Development AIDS Employed for HIV in Lesotho

A category of “outsiders” within Lesotho are the relatively numerous expatriates who come specifically for “development” purposes. They have been a consistent presence in Lesotho since independence, but increased in number with the growth of HIV initiatives (BTI 2016). These individuals are deployed from their organization or country for a typical period of one to five years. Some of these outsiders work for organizations in rural areas and live in the “trenches.” However, a large majority of ex-
patriots who are paid in dollars, Euros, or Pounds live in elite neighborhoods behind guarded fences, driving nice cars, having plenty of house help, dining in restaurants, playing at the casino, hanging at the hip bars, and spending more in one night than most Basotho make in a month (Watson 2008a). In fact, many of these individuals live better and save more than they would if they were working in their country of origin. Their experience in “developing” Lesotho literally builds their resume and their wealth. When the average donor country citizen thinks about how much their country gives to “aid” in development, they most likely think of the idealized recipients of aid (e.g., hungry babies and young women) they are helping. They have no knowledge of how little of that money makes its way down into communities, but neither do they consider how much of it makes its way back to “donor” countries through the high paid salaries and benefits of ex-patriot workers, through the strings attached to aid to buy products from the “giving” institutions, or even through the overhead for Universities conducting research on behalf of the donors.

The reality that development projects are accompanied by a development class of colonizers/expatriates/missionaries is often taken for granted. Arguments of modernity, or political economic inequality, do not capture the long-term subjective ideological terrain of identity, power, and race. Outsider interventions, whether for security, religion, development, or HIV, rely on the assumption that without someone economically supporting the intervention, change for the better could not happen. This assumption implies that the insiders, left without intervention, would not be able to secure what is good for themselves. Every development worker sent abroad must carry this justification (for their presence and salary) that they are able to provide some service, knowledge, or enterprise that the “natives” cannot do themselves. This assumption implicitly and explicitly has consequences on the subjective reality of both insiders and outsiders. The ways of thinking about self-identity in Lesotho are constructed in an ongoing interaction between ‘white’ outsider wealth infusing more wealth into the system. In this system, the development outsiders typically stay in the Maseru capital city center and accumulate more wealth before their next international appointment. Meanwhile they pay, through their organizations and projects, a type of tax to the local powerful and high paying jobs for the middle class. A
seemingly win-win for everyone, nice intervention projects, more jobs, and money that trickles its way into all parts of society. Unfortunately, it does not work that way. As examples in this chapter will demonstrate, instead of trickling down, wealth is often diverted and accumulated in personal accounts.

The ongoing cycle of projects formulated and mandated from foreign donor supported development, create the effect of inverted brain drain where intellectual and physical resources are diverted from long-term visioning that can create sustainable change, to short term lucrative but unsustainable development projects. Indigenous intellectuals are often stifled from exploring their own research agendas, finding only funding attached to donor prerogatives. Basotho frustration and resentment for outsider intrusion and dominance may play itself out in subtle forms, for example, the code switching by Basotho bilinguals from English to Sesotho when in mixed company of “experts” who only speak English. The switch to Sesotho simultaneously reminds the outsider of their status as a foreigner and unifies the real Basotho. Discussions with research participants reveal that for many professionals and intellectual Basotho there exists a type of latent resentment where these individuals know how the system works, are able to exploit it, but feel an ongoing frustration towards the powerful role of outsiders in the country. Some internalize the outsiders’ perceived superiority and believe without outside intervention all would crumble, while others become increasingly frustrated and want to break the dependency cycle. As one female respondent explained in her response to being asked if the MCP experience left her motivated or disillusioned for change for the better in Lesotho:

I think it was just I became disillusioned by the people, it was seeing the different sort of partners or people that are given the authority, that are given the power and the money to be able to affect change and the way they kind of misuse things…there was so much dependence… it’s like this is the problem, this is the project we want to implement and then the next slide is what’s the solution? And they kept being like, we'll keep asking the global fund for money, we'll keep asking the global fund for money, we'll keep asking the global fund for money, and I was just like we seem to be incapable of coming up with our own sort of solutions and just being dependent on aid. And then being given money, and, mismanaging it. I guess on the part of donors I would say you would have to put in specific kind of accountability mechanisms like to hold people to account.
In addition to the problem of dependency, the respondent quoted above connects the mismanagement of aid funds with the lower level capacity of foreigners placed in management positions by virtue of their donor nationality:

I dislike foreign aid because of the mismanagement of the funds. Secondly, I feel like we're kind of being put in a position where, a lot of people that have come in to run certain projects, I don't feel have been very competent that I've met who have worked for a lot of NGO's, particularly ones that are based here. But the vibe that I kind of get from donors is a bit to say, you know you're poor, unfortunately you don't have the resources so you know F you, like you’re giving me rubbish services, by virtue of the fact that I'm poor. ..Again this sounds like I'm being like, racist or what have you not, but I was just like a lot of white people who worked at the agency, barely had any seeming experience, and then you look at the Africans who came into the office it was like they’re doctors. They've got like two masters degrees, they seem to be a bit more accomplished so why are they working at the same level as people who are… I understand they're donating money to the agency but, how did these people get this job if there are people, I'm sure there are people who live here who are probably cheaper to hire that you could get to do the job, but you want to fly in some foreigner who just finished university to tell me to oversee projects...no that doesn't work for me. So, that's why I'm just not a fan.

For this participant the concept of race and the sentiment of a type of injustice based on color and nationality are part of the problem. This dynamic plays out in outsider to insider relationships but also amidst insiders. As a middle, class, well-educated, fluent and articulate British English speaker, she felt that foreigners treated her less “Basotho”:

...and I also don't like the way foreigners kind of interact with you when you’re sort of like a local person. Which is what I was saying to you earlier it’s like people are almost condescending, it’s like they expect you to be a certain, I guess we kind of play up to it as well. I don't know if it’s like the after effects of colonialism if you have someone who’s a foreigner, who’s a white person and you want to go out, and you want to do something, people are willing to listen to you. But if you come as a black person and you’re trying to tell people something here, people are not interested in hearing what you have to say to them. But they'll listen to what a white person tells them, but they won't listen to what a black person tells them, seemingly. And then you talk to other people who are foreigners who come from outside and they're like oh but come on you know, you’re not really like the same as everyone else, you know the average person in Lesotho, they wouldn't be the same as you, they wouldn't have the same kind of educational background, they wouldn't be this, they wouldn't be that. And I'm like, that's not the point. So yeah, I just don't like the whole begging sort of...mentality that we kind of seem to have here. And yeah it almost means that people don't take you seriously but at the same time I was a bit like, we don't take ourselves seriously so why should anybody else coming from outside take us seriously?

At the end of the conversation, when asked what she would tell the donor community, this respondent stated:
I'm really tempted to say “go away.” But that's not really good for people in sort of like emergency situations, but I think you need to give people things that are a bit more sustainable instead of giving people that are sort of short term which is what they kind of give. But yeah in all honestly I would tell them to go away.

In contrast to King Moshoeshoe I, building wealth and power by how much he could accumulate, protect, and share with the population, current leaders and politicians exploit development for private accumulation. Current leaders build wealth and power by the quantity of what they have and how close this mirrors modern perceptions of what a wealthy and powerful person should do, dress like, eat, etc. Unsustainable development continues because it economically benefits the outsider ex-pats and the insider elites. What does it mean if a certain way of practicing development makes certain players extremely rich but diverts resources and attention from sustainable development?

10. 2.1. Problems with Interventions and Development Programs

Lesotho, is in a perpetual state of intervention. Intervention money for food security, HIV, World Bank loans for hydrodams, and various projects continue to flow despite rampant corruption and mismanagement. One telling example is from a construction project funded by the Millennium Challenge Account (MCA) under the American bilateral foreign aid agency Millennium Challenge Corporation. The MCA provided $362.5 million in funding for ‘Health Systems Strengthening’ the construction project for this example being one of several projects in the country under this umbrella. Between 2010 and 2014 six construction companies “fleeced” approximately M14 million (approximately US $2 million) by “misrepresented contractual information relating to the construction of healthcare infrastructure” from the MCA government account (Nysukunyane 2015). The project was to design, renovate, and construct 102 health centers across the country. All payments by MCA Lesotho were to be made upon submission of an Interim Payment Certificate by the certified Engineer of the project. The project was to buy all the supplies necessary for construction—plumbing, solar panels, batteries, etc. and keep the stock at the Maseru depot. In a convoluted process, “under false pretenses” and over a three year period, Interim Payment Certificates were signed and money was released by the MCA for stock that was either already
bought or for unaccounted stock. The auditors emphasized, that when MCA-Lesotho entered into a consultancy agreement with Aurecon (Engineer presenting the certificates) one of the obligations of the consultant was to “always act as a faithful advisor to the MCA entity” (Nysukunyane 2015), thereby turning responsibility to the middle consultant rather than to MCA. Civil and criminal lawsuits were recommended against the six companies to recover the money and the case was referred to the police and Directorate on Corruption and Economic Offences. It is easy to stop and point fingers at “corrupt Africans,” but, in this case, the culpability is also on the organizations and financial institutions at higher levels. How is it possible that after three years into the process the problem was finally discovered? Did no one at higher levels ask to visit some of the health centers or the supply depot to verify reporting? The audit report noted that “no stock-take was performed after provisional sequestration…there were various stages where custody and control over stock changed without a stock-taking being done” (Nysukunyane 2015). After the case made headlines “20 health centers again put out to public tender” and as they “started to hand out materials to the newly appointed contractors in order to complete the works. At this stage, once again, no stock-taking was done” (Nysukunyane 2015). In other words, in the middle of the controversy when these companies should have been taken to court and forced to pay back, the MCA replenished the lost money and continued construction. What kind of message is being given? Even the most basic elements of evaluation and accountability should have been able to catch the situation earlier. It begs the question of what type of entity would permit corruption and keep paying for health centers. One could argue that the money continues to ensure that people get the health centers they need, regardless of corruption, but if the health centers were the priority, there would have been closer monitoring, preventing corruption, and ensuring efficient construction. Examples like this feed the flames of doubt. Does money pour in without consequence in exchange for something else? Who benefits from foreign donor presence in “helping” Lesotho? The problem of a corrupt system is not only material, of the rich continuing to get richer and the poor continuing to get poorer, the problem is also the subjective reality of being dependent on this system of aid having serious ethical implications that impact the “poor” recipients of project activities. These development projects target little niche areas that lend themselves
easily to description for justifying need and measuring impact by outside funders rather than on the real holistic development of a community. As a result, projects focus on construction and target groups, rather than on a homemade coherent vision for the future.

The above example is one of many where money is scattered to appease rather than to build something that builds jobs, food security, and opportunities. Development discourse focuses on the poverty that exists, but it takes attention away from asking why it is that a country that produces hydroelectric energy sold to South Africa does not have its own water for food production, Lesotho has diamonds, casinos, heavy border taxation income, not to mention the numerous pockets of project funding all over the country. If the money from these sources had been invested in such a way as to produce sustainable change within the country there would probably be less blatant inequalities and less programs based on need qualifications that infuse a sense of injustice and inequality in communities suffering from larger level inequalities.

Unsustainable development in Lesotho is fueling the inequality of "oh you don't qualify for that." Development continues to feed itself rather than make a sustainable change. The following excerpt from a male respondent with experience working in HIV and food aid programs describes this phenomenon:

….a number of initiatives it’s just that we are talking about HIV and AIDS here but there are a lot of other, initiatives that have got the same challenge, if I have to put it like that, but coming to HIV and AIDS… we come across these kinds of cases a lot here. Where you'll find that for example, there will be a building initiative somewhere in Mohale’s Hoek, there is also WFP [World Food Programme], targeting vulnerable groups and so forth, there is also UNICEF. You will find that all these three provide some food packages for those that are taken to be or are classified as vulnerable. But you find that vulnerability maybe some would concentrate on those who are aged and physically not able to do things for themselves. Another will concentrate on households that are child headed, and another one that concentrates on those people who are HIV positive. Let’s say for example it’s food packages for those who are HIV positive. This is a live case that I am talking about in Mohale’s Hoek where people were complaining that they are being refused entry into another program that exist in that particular village because they are not HIV positive. In addition, that one was meant specifically for those people who are HIV positive and apparently the food packages that are received by the beneficiaries for that particular program are better than the food packages offered by these other two organizations.

Thus, multiple organizations working in the same area but with different eligibility criteria inadvertently create divisions. But because the economic situation is so dire for so many people, there are
additional unintentional consequences of these attribute-based eligibility programs, as the participant goes on to describe:

in order to qualify the only way of proving that you are eligible of course, is to get tested and they look at the results and if you are positive then you come and you are eligible for food packages for this… specific program. But… in these mobile clinics for mobile testing centers you will find people who are devastated that they have failed this test. FAILED you know, they have been found not to be HIV positive. They are devastated.

In the Lesotho context of high unemployment, inequality and a plethora of a non-profit organizations helping people based on “need” or “disease” categories, health itself becomes an economic opportunity. Another participant who worked on part of an HIV project evaluation team also explained:

I wish you can speak to some nurses you know so that you get some of these stories from people who deal with patients all the time. Where you find that, Sharon, a person will actually you know, when they go to check people for TB they will want (TB). They give you a small tube where you provide some sputum and so forth. You know people will actually purchase such a sputum that has been tested positive, keep the sputum in their mouth so that they'll be symptomatic and so that of course they can be diagnosed as positive also. Just so that they get into a beneficiary role of TB patients for some one thing or another. You know there are actually mothers who deliberately malnourish their children just so that they are eligible. [pause] So all I am saying is this is tough I don't even have a suggestion on what to do but at least, I think, it’s really about time we people who work with things, issues like this, HIV and AIDS it’s really about time seriously, on making sure that the effect, the desired impact is appropriately realized… Programs that are sensitive…

As many anthropologists argue, the long range gross problems of HIV and AIDS are intricately linked to broader social, political, and economic dynamics (Farmer 1992; Romero-Daza and Himmelgreen 1998; Schoepf 2001; Green 2003; Schoepf 2003a; Himmelgreen, Romero-Daza et al. 2009; Whelehan 2009; Green and Herling Ruark 2011; MacQueen 2011). AIDS is a disease that hibernates for long periods of time and, without treatment, kills off adults in the prime of their responsibilities as parents and workers. It is a disease that we know is more easily passed in malnourished or under nourished bodies. Inequalities and the desire for modernity place those who have money as seductive vectors and those who desire money as making themselves willingly vulnerable. In national documents, often written with a large amount of outside consulting, there is an awareness of the need for holistic planning, cross sector visioning to curb the current and future implications of HIV and AIDS. However, in practice, support programming by many agencies focuses on the emergency response to those seemingly most
“needy” rather than larger communities or social support networks. In other words, change agents tend to focus on individuals or families rather than structural changes in the broader system. We should not turn our gaze completely away from these immediate responses, but we need to widen the gaze and the investment of resources into broader initiatives creating supportive environments. Such arguments, which call for broadening the scope of interventions, however, are usually countered by those working in development or health professionals as being beyond the scope of their vision or deliverables. The messy work of holistic planning is too time-consuming and too difficult to measure change in the short term, something that funders and political election cycles do not like. However, interventionist who deem their work as an immediate and emergency response in a long-term disease like HIV and AIDS often do not realize the long-term harm and consequences this approach has on the recipients of aid and the broader community. As seen in the above example where the desire to access short-term emergency food packages had detrimental long-term impacts on the health of individuals (acquiring TB, starving children) as well as creating local competition and social division.

10.2.1.1. Artists Selling Out

Financially sponsoring the involvement of “homophilous” leaders to create a semblance of social mobilization may be doing more harm than good. As discussed previously about inverted brain drain, where intellectuals were stifled by research funding tightly tied to foreign identified prerogatives, the same process is evident with local leaders and artists. Paying artists and leaders to publicly support HIV initiatives inadvertently undermines their authenticity in transmitting the message. One participant describes indigenous distaste for HIV “champions” for hire as follows:

We were talking with this guy one time he did things, related to film making and things like that so he was so angry he was saying "no, no, no my brother you know we are so backward here at home". How come? "No, no, no you know can you believe that everyone is prepared to fund whatever if it’s a documentary, if it’s a film as long as it deals with HIV and AIDS but if it’s something else, nobody is interested in funding it" and I could see it. There is a lot of funding to do with HIV and AIDS campaigns and so forth and you see this guy is already negative for the fact that why can’t we get other funding for some other projects. Why do we have to always, you know, talk about that [HIV]...there is an advert for example that is inside a massive HIV and AIDS campaign and we see a very good musician getting wasted to speak on singing on things to
because I mean if you are commissioned to do a song on HIV and AIDS or even a commercial I don’t think it’s the same. I am not a musician, but I don't think it’s the same as you know, the FREEDOM of doing whatever it is that you feel and producing whatever music that you like, I don't think it’s as artistic, like coming from the SOUL that sort of thing. So you may find that here is this guy, I so love listening to his music, but because he has no other alternatives he is on TV and all that he can play are commissioned adverts about HIV and AIDS…That advert is actually itself sabotaging itself. It’s to say that it is not achieving what it is setting out to do, it is actually KILLING itself, it’s what do you call it suicide. The advert itself is committing suicide because instead of affecting the type of changes that you are hoping for… that the advert is actually making the audience, this guy [filmmaker] HATE all campaigns to do with HIV and AIDS. So much so that sometimes once he sees an HIV and AIDS campaign, whenever it is coming up on TV he’s looking for his remote control (laugh)

Thirty years into the epidemic in Lesotho, this process of hiring “leaders,”, using marketing and diffusion principles, and of getting universally liked figures who are emulated, to talk about HIV, seems to have backfired, they might indeed be “sabotaging itself” as the above respondent describes. Those dealing with Behavior Change Communication and media in Lesotho probably are not aware that some people actually, “HATE all campaigns to do with HIV and AIDS.” Hired leaders, musicians, champions are seen as if they have sold themselves out, where not only research and employment are dominated by outside HIV funding, but the arts as well, “very good musicians are getting wasted”. What does it mean when people feel that they are no longer able to express themselves freely? The large amount of funding for HIV projects alongside the lack of funding for other types of projects seems to unintentionally create an atmosphere of resentment towards HIV messaging. Furthermore, the fact that after thirty years of prevention work leaders and artist must be commissioned rather than organically rising up is reflective of the extent in which the response has been professionalized in the country. Speaking out about HIV has become something one does because it is their job or they are getting something in return. HIV interventions and programs are not only compromised by this practice of hiring “champions” and leaders but also by the general rejection of the topic by the general population, its unpopularity, and the association of HIV programs with insincere political will and corruption.
10.2.1.2 Elections, Political Will, and Corruption

The roads and potholes in Lesotho are notoriously bad, but for a few short seasons, they suddenly improve. The momentary joy of “things are really getting better” is curbed by the realization that political campaign season has begun. The smooth roads accompany a strange silence on the issue of HIV and AIDS. I was in Lesotho during the 2007 and 2011 elections and watched from the outside during the 2015 elections. Each time, activities and discourses that had to do with HIV took the back seat. One female participant described this:

I think politically we are going for elections in a few weeks’ time. So local government is concentrating on building roads, bridges, things that people can see they are not interested in HIV and AIDS to be honest. That is my opinion. They are interested in doing projects that can be seen...People are not, I am not going to vote for you because you have come up with an HIV and AIDS project they want the people to say, oh she has built roads for us so we are going to vote for her, that is the biggest challenge for us now, I think.

While I did not ask directly, “How would you connect local politics, corruption, and inequality to HIV and AIDS?” all of the participants brought these issues to light during the interviews. A male respondent described his frustration:

The politics of this country sucks, sucks. All so much corruption. I can't stand that. I hate corruption. It really saddens me to see, Sharon have you really gone into those villages? Looked into the villages and seen the level of poverty. Jeez... it makes me mad knowing that they're not even asking for too much they're just saying they need a little. The struggles the pain, it’s so sad. One girl that I went to school with we were together in primary school she was working for these Chinese factory jobs now. And I can tell you she is dying as well. She is infected. She told me she met this Nigerian guy who promised to marry her and she discovered after she was pregnant that she's infected and the guy has left. And she's staying in such poverty, you wouldn't believe it. And she is the only one working, and sometimes she tells me she's too sick to go to work but she has to go because that's the only way to survive...if you listen to all those politicians. You know we are going to the elections on the 26th but you sit down and you listen to them talk, My GOD. They're making mockery of these people, because I know that after the 26th nothing is going to change. Very few people are still getting rich. There is still a big gap between the haves and the have nots. And it's widening apparently, and then a selective few people are getting rich and IMMENSELY rich. There's this one guy whose just got some airplanes, getting government tenders. I'm telling you and all of these people who have money they don't seem to be really caring much about those who...people just keep on...And that is what makes me really sad. I wonder why, when will it ever change, IF it will ever change. I don't think it will. Not any time soon. Not in this lifetime.

Interviewer: Don't say that. Without hope what do we have?
Participant 81: Nothing. Yeah but hope is a big word. About myself, so much about it...the sad thing is a lack of role models in this country, so even the younger generation will look up to the wrong people as their role model so they still keep on doing the same things as well. You know a
lot of people who are rich they've gotten rich out of government tenders in a corrupt way. And you see the people who emulate these people. I am still going to do the same mistake, so there is no hope. Well I shouldn't be so negative but, seriously, I don't see anything changing any time soon, that's my problem. So that’s the problem with our politics today. But look at all Africa it’s just the same thing.

This excerpt clearly demonstrates that people are very cognizant of the growing inequalities. The respondent also points out the connection between underemployment and the employment that exists having deplorable conditions and pay. Furthermore, it is shared knowledge that part of the rising elite is getting rich from using government tenders in corrupt ways. The MCA example discussed previously is only one instance of the many corrupt schemes taking place in the country, where the sources of money can be traced to aid coming from outside the country.

As documented in Chapter 4, in 2011 the Honorary Prime Minister was budgeted $200,000 to kick off the “HIV Prevention Revitalization” initiative (Team 2011). The original name of the initiative was “Revolution” but stakeholders argued the political and economic climate was not suitable for such provoking language, reflecting the rising tensions in the country (Watson 2012). The “buy in” of politicians in Lesotho is undermining solutions to the HIV problem. As interventions are largely driven by outside donors, politicians and organizations receive large sums of money. This type of corruption contributes to the ongoing suffering of people and is corroding genuine ownership and collective consciousness in the general population. Applying the diffusion principle of getting a leader “on board” and having them attract others to change is viable when it is clear that the leader is benefiting from the innovation, but in the case of HIV in Lesotho this is only a façade. This façade does not work to diffuse the actual innovation into the general population; instead, the general population is left to interpret the deluge of funding with disingenuous leaders. Some people are left baffled by outside donors who continue to give politicians money, while others praise politicians for playing the game well and getting rich. For other people the reaction is to throw out the HIV message because they link the message to a sense of injustice where foreign funding is fueling inequality. One participant complained that there has yet to be a politician in Lesotho who consistently sustains, with financial transparency, the issue of HIV
and AIDS. As another participant highlights “all Africa it’s just the same.” There is an inherent idea that corruption and inequality are a characteristic of Africa without acknowledging how past and current corruption and inequality are intricately related to the concept of “development” and racism.

The industry of HIV and AIDS has unfortunately become a “money making machine” as one participant describes:

Indeed the funding that is involved in HIV and AIDS initiatives, does have that kind effect where you find that the incentives that you get working with HIV and AIDS related whatever it can actually affect even in the minds of people. Especially because sometimes you may be ignorant, despite the fact that we are educated, you may be ignorant because you are not conscious of it. We are ignorant of some of these things that you find that you resent HIV and AIDS initiatives for the fact that no, no, no this is a machine, this is a money making machine. Maybe even some consciously might even believe that even statistics can be blown out of proportion just to keep the funding coming. The funding is not all bad. It will be doing a lot of good things that need to be done if we are to address adequately the scourge of HIV and AIDS. So we are not even saying let’s do away with funding, no, not at all let us get even more funding yes, but let us at least be sensitive of the fact that, for the efforts to eradicate HIV and AIDS to be positive we want to avoid, also, to give those efforts characteristics of them being lucrative.

Many times, the misconceptions put forth by those such as former South African president Mbeki(Cherry 2000) and other politicians are blamed for creating doubt in people’s minds about the truth of the science and statistics surrounding HIV. As discussed in Chapter 2, activists (and some scientists) are thus, fueled to convey statistics in a particular light in order to facilitate communication of the situation as well as to harness resources. There may however, be another angle of culpability for this doubting statistics stemming from how “do-gooder” institutions seem to be a wellspring of wealth for the outsider and insider employed dependents. On the one hand, individuals see people who are employed and getting rich “helping people” while on the other they are looking around them and seeing that the HIV prevalence does not seem so bad within their own social circle. Everyone knows someone with HIV, but the one out of four ratio is hard to believe for many, and not helped by the long-term nature of the disease. People are living better thanks to the employment, services and opportunities that HIV-related initiatives bring, harkening back to the idea of “it’s for the people”. The money making machine of HIV response formalizes the energy and work of its subjects as a profitable pursuit; individuals pursue money and/or benefits rather than a critical consciousness of what the disease is, how transmission occurs, and
what the best sustainable solutions for curbing the epidemic in specific communities are. Furthermore, the reality of outsiders and insiders getting increasingly richer but no sustainable change or programming visible at the community level is a ripe recipe for accusations of corruption and scapegoating, as the examples in this section demonstrate. Thus, there are many people going into the “business” not because they believe or understand the disease or problem but because it is lucrative. Even the best thought-out evidence based interventions, if not implemented by people who understand the point and the message, becomes a waste of money. The following example is a description of a large-scale well-funded intervention project, deemed successful because it enumerated teens present and tested. The following participant offers another perspective on the “success” of the numbers achieved by the organization:

I worked with that [organization], we were supposed to, they used sports as another way of talking to teenagers about HIV, people should be occupied so that they can get their minds away from sex and whatever and then concentrate on…well that was not what they were doing! What they did they would organize the tournaments instead of transmitting the information they would just play soccer eat some brye, so there is no point you didn't do what you were supposed to be doing. So and then at the end of the day, we are back to square one…no conversations, just have a good time. That is the problem.

Several participants echoed this notion of people going through the motions in the money-making machine. Below, a participant describes her frustration of not understanding how Multiple Concurrent Partnerships are not being researched by others, given that it is such a serious aspect of the epidemic. Yet, in her opinion, only a few are actually addressing the issue:

I don't know about other organizations but PHELA [PHELA Health and Development Communications] is the ONLY organization that I know that does that[addresses MCP] I don't know about these other AIDS organizations if they are just about getting the donations but I haven't heard anything that is MCP related or I think people just do research for money here and pack their reports in…

This sentiment can also be projected into the realm of researchers themselves, where money is often a motivation to apply to work in this field. In Chapter 7, I highlighted that all of the researchers mentioned money in their motivation to apply. While many note the beneficial effect of having worked for large international organizations like FHI and UNAIDS for building their personal careers, most evaluate the “difference” made by such research with ambivalence.
You know it [2008 MCP research study] is good because these kind of studies make a difference in an individual’s life. Like for us, they have opened a lot of doors for us as individuals yes, and yes we have talked to some people but they don't make the impact that they are supposed to make on the nation as they just open doors for individuals unfortunately, because people see UNAIDS on your CV and think "ooohh she must be good" so they don't make the impact that they are supposed to make….It is not just supposed to be a job it’s not about us getting something at the end of the month and at the end it’s just a waste of time.

After proven corruption in various parts of the country and seeing that certain areas were left unreached while others were overly saturated, the National AIDS Commission was given new vigor and support to ensure the coordination, monitoring, and evaluation of all HIV and AIDS work in the country. From 2005 to 2010, the NAC did this with some amount of success. However, in a wave of accusations of corruption and political moves in 2011 NAC itself was left immobilized. Despite questionable financial practices the NAC in theory and practice served an important role. Prior to their institutionalization, storefront interventions and corruption were at a profitable high and since the demise of NAC it is likely on the rise again, this is illustrated by participant interviews as reported in Chapters 6 and 7.

In a system where funding success is measured only by short-term quantitative outreach numbers rather than by measuring how the integration of short and long-term quantitative and qualitative indicators has benefited communities, things will stay the same. Based on the repeated complaints by participants about indicators, it seems as if almost any organization can be funded and will produce numbers by myopically asking how many people or how many events hosted but they are rarely asked from the funding source, how is it coordinated with other activities and how the project fits into a holistic system of change. The next participant describes her experience with an HIV prevention project after her 2008 MCP experience. She describes the “pain” in working for an organization and with people who squandered the resources and opportunities given to them to educate people:

It [the work experience] was painful, because, you know we come from, we know the reality, I think my position, I know the reality. I know that these people are suffering and then I can't do anything about it. And here I am, I have the opportunity to do something but I can't. I am given the job to facilitate, but I can't because someone has taken the money, because someone is not [pause and sigh], it was very painful. I remember a time when I went to work and we were supposed to have a short course to educate on breast-feeding and HIV. The only thing they are interested in is how many people are coming, what are we eating, and it was very painful. It was very painful because they didn't engage people who are qualified to do such trainings. People are
qualified, yet the facilitators were not qualified. They just take one nurse and then tell her just do the facilitation and I will pay you. Those people [participants] go out of there not knowing what is the right thing to do or what is the wrong thing to do I mean they are messing up with people. I didn't like it at all. It was very scary, and it taught me if you are carrying on like this we are not going anywhere. Yes, the project was all over the country, every other village in the country, but what was happening?

In this example, she explains how the concern of the facilitators was more about how many people they could get to the event, what food they would provide rather than taking the time to identify a person who could teach and explain well the new national HIV and breastfeeding recommendations. Several participants mentioned this type of disjuncture between the types of projects that were of high quality and connected well with local needs but desperate for funding, and other projects that looked great on paper and websites, well-funded and had a large spread in the country yet were relatively worthless.

10.2.2. “We think we are speaking the same language, but it turns out we're not”: A Story About How One Person Can Make A Difference…If you let them.

Individuals within an organization can make the difference. The best organizations with the wrong people or the right people with the wrong motivations will have difficulty fulfilling the mission of the organization. This last section brings together several lessons on how organizational and institutional structures retard the difference that a well-intentioned, “right” person could make to end HIV. The story is formed by excerpts from a conversation that took place after an eight month crisis of disillusionment and cynicism due to mismanagement and corruption where the participant had left the HIV prevention sector. This is the same individual who refused employment opportunities and volunteered for a year to help see that the research findings made their way into MCP programming and who had one of the highest density diffusion networks. The participant was recently re-employed in HIV prevention work after her hiatus. Like many other young educated middle class professionals employed within the AIDS response work, this participant was implementing projects with strings heavily attached to donor institutions and under management personnel that were “placed” in the position oftentimes with less merit or experience than their subordinates. These young professionals find themselves caught, having one foot serving their
country in suboptimal conditions and the other privileged with the option to leave and seek better opportunities for themselves:

"I was like very demotivated and very cynical and very angry. And so, I had to sit and reflect and...do I still believe in the same things? Can I still make a difference? Do I want to be involved? Do I want to be here? Do I think I should do it from here?"

In the process of implementing the research, the dissemination and intervention research assistants included in this research project became more and more entwined with the lives of the people they encountered. For logistical purposes, research assistants often gave out their numbers for recruitment, setting of appointments, and organizing community engagements. The people they encountered continued to seek out the research assistants following the project:

…and people have said… like after the project, "I'm so glad I met you, I wish I'd met you before" like when we developed the strategy, we developed the manual we had it now it was in a nice package and we were starting to work with people. And women would say you know 'I used to be this lady, I'd drink, and the guys would buy me, and I thought I was this and that, and now I wish I had known you before, I wish I'd met you before and known, but at least now I'm living positively. Like, ok I know I'm HIV positive but I'm living positively, I feel like...and I can help others you know I can be a testament, I can say to other people I'm driving the project.' Because it was a community based project. We wanted ownership from the community and we wanted to encourage people to do, you do, DON’T wait for somebody to come from Maseru or to come from the States, and come and DO, we're giving you the skills and the tools where you DO for yourself. We were using a peer educator sort of structure. So when people said those things, like after years of working with them and you come back, like a year or two years, three years and they're active, they're the ones who are pushing and driving the [HIV prevention] message then yeah. It’s like OOHhhh, it’s like a baby growing up, that sense of...yes I MADE a difference.

The respondent highlights her own proof of the difference she made through the teaching and empowering local leaders using the community communications toolkit, “Relationships Without Risk” program that built upon the original MCP research results (comprehensive description of project in Chapter 5). Part of her proof that she had made a difference was a sense of gratification in hearing community dialogue participants realize their role in creating change at the personal and communal level. She underlined and emphasized how the project team implementing the discussions wanted to encourage people not to wait for outsiders but to take ownership of the HIV response. At the beginning of the question, series about the difference in HIV prevention made by the original MCP project and the
proceeding interventions she was ambivalent stating that it did make a difference but in many ways did not make a difference. I continued the interview by probing about where she felt the results and programs had not made a difference:

This is an internationally funded project, this is USAID money. There is money to do stuff but sometimes the bureaucracies and the rubbish of organizational structures, you wouldn't be able. They would hinder the work. I had a goal, my bigger picture was, this has to get where it’s needed where people can use it [the community dialogue based on the MCP findings], then I would have to end up to use my own funding, my own time, my car, my money to get things done. It was such a hassle, the politics the down side to development. It never does enough. It’s almost, it’s ALWAYS almost, it’s like it’s done on purpose, you know, like we want to ALMOST succeed but we don't want to succeed. We want to just...look like we're going to succeed but instead of crossing the finish line we're going to fall out of the race. Like why not go ALL the way? That process it’s institutionalized, that we don't, WE the NGO's, we the donors, we the funders don't want to do that. What we want to do is come and say to people here is a program that worked in California, or it worked in Vietnam or we developed this nice tool when we were working in Paraguay and now you must, you're going to do this. One of the things that I liked about this project [community dialogues], I stayed in this project I am complaining a lot about it, and I always complain about it, and I was mad towards the end, but I stayed in this project, for what three years and I stayed because of the specific methodology that WE developed, that I as part of the team developed. That what we're going to do instead of telling people we are going to let people decide what is best for them. Remember during the dissemination [2008 MCP research project] one of the things we had people map out there intrinsic and their extrinsic goals, what they wanted, and the hierarchy of what was most important. So we took that and we continued with that, what is important here, what do you want and how do you want to get it. What's stopping you? We didn't want to dictate, which is what most implementation projects do.

This example demonstrates how institutional management from abroad constrains local agency and creativity by promoting pre-packaged “evidence-based” solutions. There is indeed a delicate balance between using what is known from other sites and stifling local initiative. There is a need to illuminate the effect on quality and continuity for translating knowledge into practice by fostering participatory methodology both at the level of creating programming as well as at the level of community delivery:

So this is the thing that kept me there. I thought for once this program has a good shot of succeeding not because of the donors, and the institutions and all that rubbish but because it’s when people start owning their program, the information the tools, and appreciating our taking the time out and like being there. ...We all had the same goals, the same science, we pushed really hard. But you have to remember that this is donor funding first of all. So you have to have numbers. You have to SHOW the progress, the reporting and the mechanism we used it was all quantitative data, the numbers, hit numbers, it was all numbers. How many people did you reach. Meet the targets and meet the indicators. Obviously, it limits you because you’re not evaluated by other qualitative long-term measures. The thing about this is that change doesn't happen overnight. And for some strange reason we developmentalists seem to forget that like no smoking
person or alcoholic person quits drinking overnight. It takes time. It’s an investment and you have to have reinforcements, you have to have things in place, structures that help that person.

The formal review and evaluation of the project that the participant is discussing most likely did not include elements, such as the dedication of the implementation team, the personal investments—time, energy, money, passion, collaborative synergy between implementers; and rather makes it seem like project management could employ anyone in the community, just by following steps 1, 2, 3, using the same funding, and get the same results. These are the background stories that do not make it into official reports or articles but oftentimes without which “success” or translation would not have happened. During the same discussion the participant described herself as being “a tool” I asked her to explain why she felt this way:

because the distance between Sharon whose sitting in an office in Washington and making decisions based on whatever Sharon knows, and Sharon's expertise that this is how we are going to do this and this money is going to be spent this way. Because its money, and we live in a monetary world. I am the ground piece the one who is actually doing the work but there is a communication gap, a space, the LAYERS in between management and I. That creates the disparity of knowledge of understanding of compassion. And that's where you become a tool, because you're not, you might have all these ideals and you might have your own goals you want to achieve but they might not actually necessarily be in line with the decision makers ideals. I have had a very rare and privileged experience. Not many people get to participate from the beginning in something, usually people get hired. For example, I just got hired into a project ALL of that stuff like proposal writing, objectives, indicators it was already done. This is a package I'm just here to implement, to follow the work plan. But I was fortunate in that I was there [from the original MCP research through community programming]... even up to the campaign when we had the One-Love campaign everything from the foundation from when the baby was conceived. From that process having been involved and having had an opportunity to say, let's not do it like this, let's try this that's why I say it was an ALMOST success because we came so close. I mean there are success stories we have those, we really did reach people, we really did make a difference there are things that I am very, very proud of.

Another aspect that the respondent stressed is the way in which funding and project timetables erode long-term local visioning. In fact, the need for regional uniformity, according to directives given from abroad, actually undermines looking back at, using what is known, or even thinking beyond what is to follow the project, campaign, or initiative:

… people were like condomize, abstain, know your status (voice of announcement) and you had those BIG campaigns like the Know Your Status campaign. A LOT OF MONEY, went into it but it was a total waste of money. What did it do? You had those big campaigns like that with
incentives for people to get tested and then what? What happens after people test? There was no follow up. There was no OK so you tested positive what happens? You test negative and then what happens? It is donor driven. Another big problem is that you're getting BIG BIG donors like most of the donors are like USAID right. And USAID likes uniformity, the process, regionalizing things, so if we're talking about the SADC region like all the Southern African Development countries have to have the same communications strategy, the same campaigns, the same, you know and tailoring things… that doesn't really work! Like it looks like it can work, it looks good on paper because when you look at us all we're the same on paper but that thing remember when we were talking about the ownership, the drive, it has to be intrinsic it has to be within me. So if I don't feel like this belongs to me and its good for me, I'm not going to push for it to succeed. That has been the problem; we know that the best way to do it is to get people to want to do it themselves. So you need to understand the people, and you need to try to understand what they want, and so that gives us the flexibility to say it doesn't work… that's another thing that happens with projects, especially projects with USAID funding is that it changes. It depends on that year what their PEPFAR goals and indicators are for that year. There's always politics, so the project might be five years but if PEPFAR changes every two or three years their goals then...

The above example describes the large Know Your Status testing campaign, the first and only in the world, that attempted to go door to door seeking to HIV test the entire population. The project temporarily employed many people and put in significant resources into getting to hard to reach areas in Lesotho. However as she points out little investment was put into what would happen after people were tested. For many people this meant knowing your status but being left without further counseling or access to treatment and services. She connects the lack of internal flexibility and the vulnerability to external mandated changes to the political goals and timetables of funding institutions like PEPFAR. She also describes how the dominance of quantitative indicators sometimes obscures the goals that programs are trying to achieve:

We love numbers and we love statistics and it’s like we are turning people into numbers. We fail to see the tree for the woods, the individual ceases to exist and we start looking only at numbers. For example, last year the National Strategy Policy for HIV the one that ended in 2011 had things [indicators] on there like 80% HIV comprehensive knowledge by such and such a date. You think…what is comprehensive? Because right now you go anywhere in Lesotho and people have heard about HIV, but does that mean they're conversant in it? Do they have a sense of their own risk perception? Do they understand that? Do they know really the signs of HIV?

The above excerpt highlights the challenge in trying to measure an ambiguous qualitative attribute, such as comprehensive, using a quantitative indicator. Furthermore, the danger in claiming to have achieved such a goal as 80% HIV comprehensive knowledge if it was in reality only a superficial
The participant went on to discuss how the donor community would talk about supporting NGOs in the behavior change strategies that they were already implementing and had seen success. Yet in practice, the type of projects that would get the funding were quick two or three day projects for mapping or testing, longer term projects were often deemed “too expensive” and were cut:

…somebody has decided that it’s too expensive [to run longer behavior change programs]. I think that is the thing for me where I can't reconcile our expectations for actual impact and the little that we do. I don't understand how, what do we base the decisions on. Expense, what does that mean it’s too expensive, it takes too long? Like how long is long?...That is why I was saying to you like I don't know what, who, what informs Sharon up there making the decisions but those decisions have a direct impact so for me that's where the disconnect is like we really will be under the same umbrella and we think we are speaking the same language, but it turns out we're not. And so far that's where I have a problem. Like I don’t know how they can keep doing this.

Highlighted above, decisions regarding project implementation and evaluation are oftentimes made by a management who are distant from the local reality and with strict attention to keeping “expenses” at the local level as low as possible. In the case of the NAC/UNAIDS/FHI(USAID) MCP research project, relatively more money and time was spent on building the capacity of research team members than what is typically spent. I asked the participant to consider her experience with the MCP project, the time and money invested and rate her capacity built in qualitative research from one to five:

For me it was a five. But I think it was because the way, like the way in which it was structured, like I appreciated a lot of the things that happened during that time. I have worked on government projects mostly with foreign funded projects. It [2008 MCP project] was the first time... the difference now is that there was no spoon feeding. It wasn't necessarily the study. It was the people involved like we had the team, we had Kate, and then we had people who were coming, who were saying we want you to think about this, we're not going to tell you how, let’s sit down and go work through it together. I appreciate that it wasn't necessarily the structure, it just so happened that the people who were pulled in to work on that, from the first were those kinds of people…. It can be replicated, if you're documenting what happened then you know, these are the steps we took, this is what we did, this was the preparation that went into it, this is what happened during, even the qual analysis going on at the same time, all the things that happened you can make those uniform. You can write them up and structure them so that you don't need the individual, you don't need the Sharons and the Kate MacQueens who ever is there, if this is how we do things. This is the curriculum and you will have those positive consequences. Because if you look at us, after, what happened to most of us after we left. Most of us went back to school, and we started working on our post-grads and we started working more, and being involved more. Like everybody has started on something...we might be going about it different ways, some might be permanent in school enrolled, and doing it full time some are doing it part time, some are working and you’re going at some point, like you wanted MORE. You wanted more skills, you wanted to develop your skills...I relate it to this experience. Because even the relationships that we formed. Like the support, the encouragement the motivation.
The MCP project had many of its own faults. However, one of the small messages for large development institutions working in HIV prevention that came out of this project was to pay attention and remember that it is not only what you do in HIV prevention, it’s how you do it and with whom. The key to change is also investing in change agents. The focus on ‘our money,’ ‘our way of working,’ and ‘our way of measuring’ may inadvertently scare off or burn-out the type of people who can potentially create the most change. The participant emphasizes the participatory, process-oriented way of developing and implementing the MCP research study that made the difference. Unlike most donor funded projects, with pre-packaged plans to be adapted to the local situation, this project did not spoon-feed but engaged the local team in revising, creating, implementing, analyzing, and disseminating activities. Furthermore, the MCP kept at the center the collective responsibility to transform the findings into tools that could help people prevent the spread of HIV in Lesotho.

10.2.3.. “People should not view HIV as governments’ business its everybody else’s business”

During conversations about money being wasted, professionalization of the response, and the lack of “buy in” in the HIV/AIDS response I asked about what could help the situation. Several participants highlighted the need to foster genuine grass roots responses, in addition to the professional approaches to the epidemic. One female respondent, permanently employed by the government explained how she felt using qualified volunteers, like the old MCP team, to perform outreach teaching/counseling on the weekends as an inexpensive efficacious way to build up community capacity in preventing and dealing with HIV:

I think we can do it, we can volunteer to do it, like I can work where I am working now but then I know that in this month I am going to Mohales Hoek for a weekend, if MAYBE I am catered for transport and accommodation then that’s fine. I think having a permanent position that would be expensive. I think when you volunteer to do something you do it with passion no one is forcing you, no incentives, nothing if you don't want to do it you don't do it, but then if you are employed to do it you can go and say you are going to do it and then you don't do it. So I think volunteering would be much better. Just get people motivated, I think the MCP group can do it, just meet us once in a while two people are going to this site, just to see, for a half a day or so, just like that.
The participant is suggesting to draw upon people who already have the capacity and training in talking about HIV and MCP but who have gone on to other permanent employment opportunities: to tap into these individuals as resources. An entity would need to cover the expenses for what would hinder volunteers from starting a volunteer outreach program on their own, the cost of transport and accommodation. She implies that ex research team members would not need to be paid, or given incentives but would be willing out of passion to volunteer and do outreach in communities. Another female participant independently talked about the difference in the quality of an interaction about HIV when it is not motivated by the fact that you are getting paid or have to record certain information:

When it’s not my job, when it’s just a conversation it’s interesting when you just talk about it. When you talk about it and you are not paid it is more interesting than when you know it’s a job…It’s different I think it’s more interesting when you are not paid because, you don't have the time limit you talk about everything as freely as you want to and you don't even have the recorder! As much as they do open up when you get paid and you record them but it becomes more original when you just talk about it...so it’s different.

Participants articulated well the problem of HIV being left to “professionals” where only getting monetary returns is the motivation. This way of thinking has led to a sort of paralysis or ‘pass the buck’ situation where it is someone else’s responsibility to deal with the problem. Like the above example, several participants highlighted the need to repatriate the response. The following male participant, still actively involved in HIV prevention, argues:

I think curbing the spread of HIV should not be left in the hands of government alone. It is everybody else’s responsibility it begins with me, it begins with my neighbor and it begins with everybody else the entire nation. It is the responsibility of everybody, it’s the responsibility of civil society and the responsibility of NGO's and a whole lot of parties involved in HIV and AIDS. What government needs to do is to try and come up with preventive policies that will try and inform the HIV and AIDS activities in Lesotho most importantly prevention. My line of argument in one line is that government should not, people should not view HIV as governments business, it’s everybody else’s business. Government needs to play a leading role but everybody else needs to have a role to play to try and prevent HIV and AIDS in Lesotho. It’s got to be a comprehensive approach and not look at each other, let us unite, unite and fight the enemy and kill the enemy.

It is important to remember that in the case of referring to the “government” that the “government” is supported by outside donor funding for HIV; that in fact, outside funding is the main source for
“government” HIV prevention projects. Thus, the respondent’s reference to the government and “everybody else” can be interpreted as a call for locals, more indigenous involvement, outside of those working for the government or government projects.

In the next example, this female participant, like other researchers makes the connection in the quality of work depending more upon an internal motivation than monetary retribution. In fact, she argues that the norm of having a monetary retribution in order to research or talk about HIV has fostered a situation where people working in HIV make their interactions with people at the community level impersonal and take lightly their responsibility to provide quality information. She discusses her experiences in a post MCP research employment as an outreach educator in a well-funded HIV prevention project. She explained that the project met its outreach numerical targets but did not educate community members with quality information for long-term change. The people leading and working on the projected wasted money and resources and did not use the opportunity well to generate change:

That is not a good experience at all [with the well-funded prevention project], I think to be a good researcher or educator, it’s a calling. It has to come from within you. Because if you do it for money, then you are not going to do it properly. That is what I learned from that experience...for Lesotho, we are not going anywhere if the country is full of people like that then we are not going anywhere, there will be money wasted, resources and everything else...people will be suffering, people will be dying if we have that attitude. (pause) I think we have to be taught how to love ourselves, how to love this country, how to love other people, so that we can share that love around us. So that we can see hope that there is still light you know. So much has happened there's babies are born from HIV positive mothers and they are HIV negative and we have to capitalize on such things all we have to do is just TALK TO PEOPLE give them what is correct and what is not correct. I think as educators and researchers people who are working in the community. It has to be a priority. The community has to be a priority. You have to love what you are doing, first of all. Then you can do it properly.

Her discussion points out that building capacity to educate about HIV in particular contexts is not solely about memorizing and teaching facts but about igniting hope. In her perspective about Lesotho, educating people about HIV entails helping people to reconnect to a reason to change social and individual behaviors; love for their country, for other people and a better future for the next generation. I probed the participant further asking why she believed there were so many people who do not love what they are doing, she responded:
I think, because a lack of employment in the country. That is why we end up going to anything that comes around, ok and then just doing it to get money. I think that is a big problem.

In focusing on these examples, I am not arguing for “volunteerism,” or even for less money for the response, rather I am arguing for a heightened awareness of the consequences of the way in which those involved in the AIDS response are currently working. More must be done to ensure that the money is used to maximize the potentiality to save lives and do no harm. There is a need to more thoughtfully create space for a process of critical consciousness building, a true education about the problem of HIV, and to rely on the capacity of those who have personally “awoken” to take responsibility and disseminate knowledge formally and informally. One such method may be in fostering and supporting “paid” employees to initiate their own outreach mechanisms.

10.3. Theorizing About the Money Making Machine

AIDS at one point was described as a disease of poverty but transitioned to be known as a disease which settles along the ever-deepening chasm between rich and poor, the collision between worlds (Farmer 1992; Epstein 2007). Thus, inequality as an element fostering the spread of HIV is often treated as having its roots in larger social economic factors within the country that split people between the “I haves” and the “I wants” where the “I wants” use sex to get what they want or need and the “I haves” redistribute their wealth through relationships with the “I wants”. The assumption is that inequalities are pre-existing. However, what is rarely brought to light is the fact that the AIDS industry itself exasperates inequalities and feeds corruption. The money brought into a country to “fight the epidemic” or “health systems strengthening” provides opportunities that otherwise would not be available—jobs, contracts, support, “incentives” to leaders, and copious amounts of research. This giving to some and not to others based on their association with AIDS has many consequences. One of these is the problem of the “haves” and the “wants”. The second, based on the examples given by participants about the multiple ways in which money or work jaded the delivery and receipt of the message, is related to a human aversion to
inequality. The apparent disgust for the inequalities associated with the AIDS industry creates a wall, or a mental rejection, to talking about the true problem definition, consciousness, and resolution.

Most people can relate to that dirty feeling of receiving an injustice. Anthropologists and Primatologist from Emory suggest that a sense of equality and fairness is deeply ingrained in human evolutionary history and is not just a culturally learned response (van Wolkenten, Brosnan et al. 2007). Studies on capuchin new world monkeys even reveal that Capuchins actually preferred receiving no prize in an exchange with researchers, than being rewarded inequitably in favor of a second monkey. Furthermore, they appeared to target their anger at the researchers responsible for the inequitable distribution of food. This gives further strength to arguments about the inequity response evolving in the context of more adaptive cooperative survival strategies than purely “competition” based survival (van Wolkenten, Brosnan et al. 2007).

In 1902 Peter Kropotkin, economist, philosopher, and geographer argued against popular social Darwinist arguments of animal and human survival based on competition and natural hierarchy (Kropotkin 1902,1955(reprinted 2005)). Instead, he argued that it was actually cooperation instead of competition that made for the success and survival of the species. While he acknowledged the presence of competitive urges in humans, he did not view competition as the driving force of history. Not all societies were based on competition and many societies actually defend against the accumulation of private property through bartering, distributing a person’s possession when they die, or not allowing a gift to be sold; even holding alternative values towards accumulation, prestige, social harmony, and collaboration (Mauss, Boas, Kroeber, Radin, Malinowski). Kropotkin also placed emphasis on the need for local organization and local production, including agriculture, industrial, and intellectual work, where small-scale communities strived for self-sufficiency.

In the case of Lesotho, it would seem that the pursuit of idealized democracy and market involvement is ever strengthening the government center at the direct cost of local organization, production, and cooperation. Coplan (1991) has argued that upward mobility and wealth building in Lesotho can only be sought through the control of the government. Furthermore, in the context of
economic and political modernization, the cultural identification of a homogenous Basotho remains an ideal, while the reality is that there are fractions not based on “traditional” divisions but rather modern ones associated with rapid and dynamic changes in categories of class (Turkon 2009a). Turkon (1996, 2003, and 2008) has documented the local and national dynamics in Lesotho in how political, economic, and symbolic manipulation by colonists (both in the old and new sense) and politicians has divided citizens into factions as a means to pursue economic and political advantages in the globalized neo-liberal capitalist market. Turkon (2009:101) further argues that government agents promote state building and international capital interests over local inclusion, capacity building, and work, with “few opportunities for survival let alone success”. Yet, within this context citizens do not blame the structural roots, but rather talk about “diminished reciprocity” (Turkon 2003) that intensifies distrust among neighbors. As Turkon argues:

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Very many of them see their problems as emanating not out of the abstract realm of transnational political and economic maneuvering, but out of the actions of neighbors who have abandoned behaviors that once defined what it meant to be Basotho and supported community life. There is not escape from insecurity, and it is partially out of this situation that jealousy, resentment, and feelings of unfairness on one side of the asymmetrical social system emanate (Turkon 2009a: 101).
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The infusion of resources dedicated to HIV initiatives in the high epidemic zones is fueling social change, not behavioral sexual practices or social cohesion, but rather socio-economic changes that promote competition and undermine cooperation. In a globalized reality where the hidden lines of interests are not clear the best interests of small-scale communities are suddenly in no one’s interest. Basotho are simultaneously living with real social and health consequences of industrial agriculture, a free-market economy, dependence on the global financial market and aid wrapped in strings. The problem of the influx of money only for HIV/AIDS or “health systems strengthening” in Lesotho is related to the neglect in dealing with problems of inequality and the mismatch between global donor resource prioritization and local needs. Add to this the internal mechanisms in Lesotho of skewed profit distributions which come from government tenders, border taxes, casinos, hydroelectric income, and diamonds, that go into the pockets of a few rather than create work for the masses (BTI 2016; CIA 2016).
Humans want livelihoods and freedom to live as they believe. The value of work is somehow detached from the problem of HIV/AIDS; yet, people on the ground continue to link the lack of work, the misappropriation of work, or “working” for HIV as an obstacle to ending HIV. We might appropriate a few principles taken from Pope John Paul II’s (1981) *Laborem Exercens* to use here: 1) the priority of work over capital, 2) the primacy of humans over things and, 3) the primacy of the *subjective* value of work over its *objective* value. If we are serious about dealing with the individual and structural aspects of the epidemic in Lesotho, we must take into consideration non-conventional visions of solutions, especially the dynamics of inequality and the notion of “work.” Arturo Escobar describes the increasingly delicate balance in many parts of the Third World between conventional development strategies and popular groups rising up and rejecting older development assumptions:

> Popular groups in many parts of the Third World seem to be increasingly aware of these dilemmas. Caught between conventional development strategies that refuse to die and the opening of spaces in the wake of ecological capital and discourses on cultural plurality, biodiversity, and ethnicity some of these groups respond by attempting to craft unprecedented visions of themselves and the world around them. Urged by the need to come up with alternatives—lest they be swept away by another round of conventional development, capitalist greed and violence—the organizing strategies of these groups begin to revolve more and more around two principles: the defense of cultural difference, not as a static but as a transformed and transformative force; and the valorization of economic needs and opportunities in terms that are not strictly those of profit and the market (Escobar 1995: 226).

The next chapter looks back at the results presented in this dissertation with the aim of bringing to light the lessons learned about this nexus of cultural difference and the valorization of economic opportunities associated with HIV prevention in Lesotho. It looks specifically back at these differences in order to highlight ways that communicating about sex and MCP can become a transformative force through the qualitative research experience. The discussion also reiterates the evidence documenting the mismatch between funding allocations towards clinical and technological solutions and the local prioritization for more behavioral, social and economic approaches.
CHAPTER 11. LOOKING BACK AND MOVING TOWARDS SOLUTIONS

National and international funding agencies recognize the need to close the gap between research findings and the real world to justify the investments of citizens and stakeholders (EC 2007; NIH 2010; WTO 2010; dos Remedios 2013). In the field of HIV, more than 30 years into the epidemic, the need to ensure that what researchers learn makes its way into tangible actions in the real world is especially poignant. This dissertation addressed the critical divide between research production and its translation into practice. The purpose of the dissertation was to advance ways to measure the investments of citizens and stakeholders in qualitative studies and offer new perspectives on the losses inadvertently caused by particular investments in health research and services.

This study drew upon Everett Rogers’ Diffusion of Innovations theory, which defines diffusion as “the process in which an innovation is communicated through certain channels over time among the members of a social system” (Rogers 2003: 5). An innovation is defined as “an idea, practice, or object that is perceived as new by an individual or other unit of adoption” (Rogers 2003: 12). A communication channel is "the means by which messages get from one individual to another" (Rogers 2003: 18). For the project, and basis for this dissertation, the new ideas and knowledge or information to be studied were the actual 2008 Multiple and Concurrent Partnerships research findings and the local researchers’ experience (knowledge gained, lessons learned) while participating in the research process.

The study was also anchored within Wandersman and colleagues’ (2008) Interactive Systems Framework for Dissemination and Implementation (ISF) which draws upon aspects of research to practice models as well as community-centered models (see Figure 8). The model was developed and utilized to bridge the gap between research and practice and to support evidence-based practices. The ISF describes an innovation as new knowledge or information that could be useful to prevention efforts in the field
In this framework, prevention innovations can be categorized as programs, policies, processes, and principles. What is particularly useful about this model, for this dissertation, is that it looks specifically at the systems and processes involved in the development and testing of innovations. Other translation models tend to describe the functions (e.g., exposure, selection, adoption), whereas this model takes into account the systems and infrastructure necessary to carry out these functions. Since the focus is on the infrastructure needed to carry out various activities in the implementation and dissemination process, a key component of this model is the notion of capacity.

Another major difference of the ISF model from other dissemination models is that it does not take the primary perspective of the researcher, practitioner, or community. Rather, it lays out the relationships between all of them, looking at all perspectives and leaving space for the user to decide where to begin and end in the framework. As a result, the emphasis of the framework is on collaboration and communication among all stakeholders, and not on a unidirectional flow of an innovation. This research addressed the lack of research examining the connections among systems identified by the authors of the framework (Wandersman, Duffy et al. 2008: 179). The findings of this dissertation illuminate these different systems and contribute to fill this lacuna by providing evidence on what promotes and what stifles the interactions among systems. Wandersman and colleagues (2012) note that literature on the support system, those who support an individual or organization to implement an innovation, is under-researched and underdeveloped. They emphasize the importance of strengthening the science and practice of support in order to enhance the capacity within the delivery system to implement with quality and achieve outcomes (Wandersman, Chien et al. 2012). Fundamental to this logic model of evidence-based system of innovation support are tools, training, technical assistance, and quality assurance/quality improvement. A central aspect of the research used for this dissertation study was the tool—qualitative research and the training, technical assistance and quality assurance provided by FHI360 and UNAIDS. By tracing the diffusion of the innovations, this research brought to light some of the ways the new knowledge moved (or not) through members of a social system and into practical use for prevention efforts in the field, focusing on two specific areas:
1. Local Researchers’ Participation in Qualitative Research as a Form of Prevention Delivery

Objective 1: To describe how the results and experience of the research process affected local researchers’ ability to incorporate health knowledge in their life.

- In what ways can stakeholders evaluate the medium/long-term investment in training local researchers in qualitative methods to investigate a health problem?
- How does the experience and process of involving indigenous researchers in an HIV study further local “capacity” for disseminating disease prevention knowledge?
- How does such participation affect local researchers?
- What were the unanticipated consequences of local involvement?

2. Organizational Uptake of Qualitative Research Findings

Objective 2: To identify how research results are integrated or rejected by local change agents.

- To what extent were the results of the research study integrated into local agent initiatives?
- What were the factors that affected (either facilitating or preventing) such adoption?

Despite having a small population size for this study, the results provide in-depth quality insights into the general utility of qualitative research and researchers in improving the translation of research into practice. This research clearly has no statistical significance but offers patterns and lines of connections that can be further tested with larger population sets or in comparative settings. While providing general lessons that improve our understanding of the type of interactions within the synthesis, support, and delivery systems, the dissertation also provides context specific applications that can improve HIV prevention in Lesotho. In answering the above questions, each chapter of the dissertation illuminates different points of interaction within the framework and illustrates how the larger level context, macro-policy, funding, and existing research and theory coalesce. This dissertation is an ambitious attempt to offer a snapshot of the real level of complexity and layers in translating research into action using a social science perspective. A perspective that looks at behavior “to understand how it simultaneously emerges from and influences the dynamics of human relationships at multiple levels” and as a “dynamic set of interlocking systems” (MacQueen 2011:4).
11.1. Organizations: Where Did the MCP Knowledge Go?

The results presented in Chapter 5 address objective two identifying how research results were integrated or rejected by local change agents by looking specifically at the extent of the integration of the study findings into local agent initiatives. The chapter also describes the factors that affected (either facilitating or preventing) such adoption.

11.1.1. Organizational learning about research in HIV prevention

An important finding indicating the lack of ease in which HIV research or evidence is translated into practice in Lesotho is that there is no central organization providing “evidence” or a resource center of information for those working in HIV. Furthermore, as the Prevention Revitalization Roadmap budgets $50,000 for a mapping of HIV prevention interventions and programs at the community and district council level (Team 2011: 7) indicates, not only is there no central research/information database, there is also no clear registry documenting which organizations are working in prevention, what they are working on and where they are working. Thus, neither prevention information nor activities are coordinated or well monitored. This means that in order to receive information, like the MCP research results, organizations and individuals had to rely on non-centralized modes of diffusion such as live presentations of results, sharing the research report on small list serves and referral to the results or to the report by a colleague or a friend.

11.1.2. Organizational Uptake of 2008 MCP Research Findings

A large majority (70%) of the organizational representatives interviewed (n=10 individuals with 15 organizations represented) connected their knowledge of the MCP research to a first-hand encounter with members of the original research team—whether from attending one of the original dissemination meetings or through a personal relationship. All expatriates interviewed knew or read about the MCP research, even if they were not in the country at the time of the original study dissemination. However, two indigenous organizational representatives in key positions dealing with HIV in the Ministry of Health
claimed no knowledge of any of the MCP studies. While all organizational representatives from NGO’s or affiliated with the National AIDS Commission knew about the MCP study. This seems to reflect some kind of disjuncture between the type of information and research that circulates in the Ministry of Health and that of the research which makes its way into the NGO community.

This disjuncture could be a product of the preceding fissure between NAC and Ministry of Health and Social Welfare (MOHSW) or a consequence of the MOHSW’s predominant focus on clinical rather than social and behavioral research. Working in collaboration with the NAC, outside funders motivated and financially supported the MCP research. One likely explanation for all of the NGO’s interviewed knowing about the research could be that the research diffusion followed a particular network of organizations that were more closely associated and dependent on outside funding sources. Whereas the MOHSW, receives funding from outside sources its management is predominantly Basotho and does not have to directly report to or seek funding from outside funders. Turning back to Roger’s concept of homophilious and heterophilous interactions, those Basotho working for and with outsiders were more likely to accept the innovation than Basotho’s with less dependence on outsiders who were more likely to dismiss the innovation. Participants described a type of refusal by Basotho’s to research or talk about MCP. Thus without the outside funding the MCP research would not have happened. It is likely that the internal rejection by the majority of Basotho working in the MOHSW as well as the lack of outsiders within the MOHSW infrastructure pushing the MCP agenda, closed the door to the diffusion and acceptance of this type of research. Thus, individuals working in NGOs having more heterophilous interactions within and between organizations were more likely to diffuse MCP information.

The findings did make their way into high-level policy documents (GoL/MoHSW/NAC 2009: 6). The National Strategic Plan for HIV and AIDS 2008-2011 and 2011-2016 (NAC 2011), 2009 Lesotho HIV Prevention Response, Modes of Transmission Analysis (Study) (Motlalepula, Tsehlo et al. 2009), Know Your Epidemic exercise, Lesotho Demographic Health Survey (2004 and 2009) (LDHS 2004; Lesotho Ministry of Health and Social Welfare (MOHSW) 2009) all state that the first objective is to reduce the sexual transmission of HIV and identified multiple and concurrent partnerships as a main
driver. The problem was well articulated as the most important problem to be addressed in preventing further transmissions. Policy makers outlined clear and aggressive action steps (see Table 6), however the translation of these declarations fell well short. All of the research assistants and a majority of the organizational representatives interviewed argued that they believed more should be done with not only the MCP research results but for the problem of MCP. Research participants noted that currently only one organization PHELA Health and Development Communications had the primary objective of addressing MCP. In verifying this information, a review of 250 organizations identified as working in HIV prevention found that 33 described themselves as working with Behavior Change and Communications, and only eight mentioned one of the key words MCP, dialogues, life skills, community mobilization, education or sex/STI. Moreover, confirming what the participants indicated, only one organization associated its work with MCP.

This one organization inherited a MCP project from 2007 and in 2011 was still implementing an eleven-week community dialogue program developed directly from the 2008 MCP research results, *Relationships: Intimacy Without Risk* dialogue kit including a facilitator’s guide, a training manual and communications materials (C-Change 2010). Program evaluations indicated the program was indeed successful especially in improving risk reduction behaviors, communication between partners, diffusion of information, health seeking behaviors, individuals’ acceptance of their own HIV status, and sense of community empowerment. The program had relatively little funding and was short-staffed, limiting the areas in Lesotho in which it could cover. The issues and lessons noted through this social and behavioral project, the only one that translated the MCP research results into programming, are similar to the structural prevention interventions discussed in Chapter 4. The issue of compensation and travel “reimbursement,” for instance, is a consistent problem and research and programming stakeholders continue to treat it as a minimal issue. Age and gender mixing in intervention groups often creates problems, which is also documented in the Stepping Stones evaluation and is well established in qualitative focus group dynamics. Thus, attempts at providing social structural or participatory intervention need to create space, and allow different ages and genders to separately and simultaneously
go through the dialogue process but come together for discussion at different intervals, rather than focusing only on “youth” or “women”. As discussed in detail section 4.3.5., the measurement of “success” in HIV participatory approaches is often undermined by researchers applying myopic eligibility criteria within communities where the problem and solutions cut across multiple categories of persons. The approach of selecting only one group (i.e. women 17-24) weakens the entire efficacy of a participatory approach based on the foundations of social empowerment as opposed to solely individual change. Not that all community members must participate in all aspects of every intervention but project planners must balance research or intervention budgets where different aspects of a community are provided with something that builds the enabling environment for measurable social and individual outcomes.

The Relationships: Intimacy Without Risk is a great program, but like other similar social and behavioral outreach programs, had no baseline data nor collected any biomarkers to provide more biomedical evidence. Other similar programs have demonstrated outcomes in lowering multiple partners, drinking, intergenerational sex, and economic vulnerability, and in increasing communications, condom negotiation, and testing (Pronyk, Hargreaves et al. 2006; Wallace 2006; Jewkes, Nduna et al. 2008; Jewkes, Gibbs et al. 2014) but according to large level policy makers like the Fast-Track they lack the “hard” evidence demonstrating their efficacy in lowering HIV incidence (ONAP 2015) (UNAIDS 2015). Thus, these programs will not be funded on their own but will have to run in combination with other biomedical initiatives (UNAIDS 2015). The literature reviewed for this dissertation and the results of this study highlight the importance of preserving these “combined” interventions in their integrity, rather than in abbreviated forms where the central components of social cohesion are undermined by eligibility criteria and incentives. Care must be sought that researchers implement and evaluate “combined” social and clinical approaches with equally valid markers for measuring individual (biomarkers and behavior) and social changes. Rather than the current norm of assessing social interventions, using the same short-term individual outcomes measured for clinical studies.
Closer attention should also be paid to the changes in higher-level partnerships, funding, and staff turnover, which had an immense impact on translating the MCP research into programming. This research found three separate initiatives attempting to translate MCP research into programmatic tools, two completely failed due to higher level partnerships and conflicts around funding while the "Relationships Without Risk," nearly collapsed several times. In fact the "Relationship Without Risk" program would have failed if it were not for the individuals working on the project providing their own funding or going without pay in order to sustain the project through vulnerable months. This lack of sustainability also creates problems with promoting indigenous professional talent and growth through continuity. Most research assistants went on to wherever they could find stable work. Only two researchers were involved with MCP from the research stage to formal translation and synthesis, program delivery, and support of that program delivery. The issues of funding, staff turnover, and fissures in higher-level partnerships noted here are common in and across structural prevention interventions. This repeated pattern suggests a generalizable trend in the types of problems experienced, and by addressing these problems far-reaching benefits could be had by researchers and practitioners. For example, organizations with a long-term vision for change, like USAID, UNAIDS, NIH, CDC could set aside funding to identify and retain high potential individuals to transition from the research stage, to translation, program delivery and program delivery support as a career development program specializing in dissemination and translation.

11.1.3. Prevention Resources Dictate Prevention Programming

This research made clear that the research surrounding MCP in Lesotho is well-documented quantitatively and qualitatively. The research made its way into policy documents and into programmatic intentions. A significant amount of energy and funding went into this initial stage of research implementation and synthesis; however, relatively very little human and financial resources were dedicated to sustaining the application of the MCP problem into program delivery. I argue that the main reason for this disjuncture is that prevention financial resources dictate prevention programming. Funding for the National HIV and AIDS response in Lesotho has increased 140% between 2007 and
2011, but only 12% of the national budget is allocated for HIV prevention. HIV prevention is in 4th place in terms of funding by thematic area. The consistently highest funding going towards treatment, care and support, second to orphaned and vulnerable children and third program management receives higher funding than the entire prevention budget (NAC 2011; MoHSW 2012: 74). Prevention funding is predominantly covered by foreign donors. Given that the top problem identified for prevention is the sexual transmission of HIV related to extremely high rates of multiple and concurrent partnerships, one might assume that the government is paying the bill for medicine and that the international community is supporting the messy work of social and behavior change related to the sexual transmission of HIV. But this is not the case, instead, policy documents and funding records demonstrate that the bulk of funding for “prevention” goes towards, testing, PMTCT, condom provision and promotion, male circumcision, and health systems strengthening (MoHSW 2012: 75). The 2006/2007 NASA reports only 2% of prevention funding going towards communication for social and behavioral change (NAC/MoHSW/UNAIDS 2009). Between 2011 and 2015, $112.9 million US dollars were spent for the provision of condoms, by far the highest prevention line item and nearly half of the entire $241 million prevention strategy (see Table 4 pg 203) (NAC 2011: 98). Funding mechanisms continue to require “priority populations” targeted for prevention activities. In the case of Lesotho, a generalized epidemic, where inter-generational sex is a research evidenced based problem, “youth”, “prisoners”, “people with disabilities”, “herd boys”, “sex workers”, “women and girls” are considered priority populations but not men (NAC 2011: 98). In fact, the “women and girls” category received $29.69 million while community mobilization received $3.87 million. Similarly, despite high unemployment and a large number of people working in the informal sector, formal workplace programs receive almost seven times as much funding as community mobilization (NAC 2011). Furthermore, increases in the prevention budget were seen only after post-exposure prophylaxis were added in 2009/10 (MoHSW 2012: 76), thus in the period after 2009 the prevention budget includes medicines (PMTCT and PrEP) that traditionally may be conceived as “treatment”. Appendix F documents how out of eight significant donors only Irish AID mentions the word sex. Other donors focus on medicines or clinical facilities for example, the UN allocating 25% of its
$85 million predominantly towards ARVs. The US Millennium Challenge Account provided $362 million in 2007 for the construction of a reference lab, blood bank and medical university. PEPFAR provided $29.2 million per year 2010-2015 for testing, counseling, ARVs and TB treatment. And the World Bank providing a second $5 million technical assistance project in expenditure tracking and compliance to PMTCT protocols at the community level. While the Clinton Health Access Initiative (CHAI) is also listed as one of the eight significant development partners, the actual amount of funding is not stated, but can be assumed comparable to the other high donors. CHAI focused on HIV treatment, laboratory systems and increasing operational research capacity in the country (MoHSW 2012: 77).

Despite the fact that national stakeholders identify a highly specific cultural nuance, the solutions and funding proposed by the international community continue to focus on a highly uniform approach where condom use, testing, and PMTCT are the desired “behavior change”. Today in the era of the Fast-Track approach, treatment as prevention and PREP are additional prevention expenditures and “behaviors” to adopt. By highlighting the emphasis on technical and pharmaceutical solutions I am not arguing against them and “for” non-technical and non-pharma solutions. More than the false dichotomy, I argue that approaches that claim to be doing behavior and social change without supporting programming, providing individuals the opportunity to critically think, understand their reality, and change their lives and relationships, are not “preventing” anything. The international community is responsible for funding prevention in Lesotho. Funded prevention programs state that they have “behavior change” programming, but when one looks closer, there is little invested in initiatives facilitating a critical understanding of HIV, beyond “awareness”. In fact, the little that has been done is heavily linked and secondary to the primary objective of getting people to use condoms, get tested, and taking medications for prevention. This is despite the fact that in Lesotho condom use continues to be low and testing does not necessitate behavior changes that stop transmission. The argument is not a “rather than” but in “addition to” to make sure people understand what it takes to prevent transmission. A forty-minute pre-test and post-test counseling session with a counselor taught to regurgitate information is not the same as learning, discussing, questioning, or having context specific knowledge building education.
11.1.4. Resistance to Change

At the root of why so little has been done programmatically about MCP is not just the diffusion of research on the topic, nor funding prioritization. Another important factor is the ideology surrounding what people “believe” about the science of concurrency and the transmission of HIV as well as, perhaps, their own current practices. Results of this study demonstrate that this mix of ideology and a type of denial about one’s own MCP practices or those of important figures (as shown in the example provided by the nun or those of people working in health services, family members, famous politicians) in their life creates a type of “resistance” to the diffusion of information about MCP. Oftentimes, hard scientific evidence is seen as something that speaks for itself. However, in the case of the science connected to MCP, the acceptance of this scientific knowledge cannot be taken as an assumed agreed-upon reality for a specific context. In fact, some health authorities may accept the evidence as shown in another setting but deny its reality in Lesotho because the research was not done in Lesotho with Basotho. This puts into question the “generalizability” of positivistic research—not to deny that there are objective scientific truths but even the most clinical controlled, sterile research can no longer be assumed to be the gold standard for everyone. After all, what good is the gold if it is only believed to be gold in the lab and as soon as you step out into ministries of health, communities, or government offices it is disputed as only being imitation gold, maybe gold-plated but not truly gold? Data, information, research being accessible and even available without being understood, accepted and backed by the “will” to commit to change, are rendered worthless.

It is the government’s responsibility to not only ensure access to sexual education, services, and technology, but also to ensure the most appropriate way to disseminate and relay information so that people can make informed decisions and have the resources to protect themselves. Unfortunately, the Relationships Without Risk dialogue series has been greatly abbreviated and squeezed into a larger social marketing campaign for the “brand” PushaLove. PushaLove is supported by large foreign donors and promotes the priorities set out in the Fast-Track of the “good life” being associated with sex, condoms,
testing and treatment. It is important to keep in mind that this approach is promoted for all sexually active individuals and is supported by the recently approved Test and Treat protocol where every person who tests can then get on treatment—one regiment for prevention and another for treatment. If the PushaLove campaign is indeed a process facilitating critical consciousness where people are given information not for “awareness” or “demand generation” but for education, where they learn communication skills and have all the tools they need to decide the best strategies for their life and relationships—then this campaign will save lives and bring down incidence. Furthermore, if the campaign reinforces social fabrics through open discussions on HIV, stigma, and people actively discussing which cultural practices to keep, re-invent or throw-out—then the approach to prevention in Lesotho will be revolutionary. Yet, recent history shows that despite the success, or lack of evidence of success, stakeholders do not prioritize individual and social change programming for MCP. This, despite the fact that the perceived positive effects demonstrated in the evaluation of the one project attempting participatory education reflected changes in the exact drivers identified from the SADC 2006 meeting and the Lesotho based MCP formative studies (Meyanathan and Rogers 2012). It is unlikely that all of the positive outcomes were present or sustained in every individual; however, the fact that some of the participants walked away from the experience with these tools is extremely important. Using a condom, testing and counseling, receiving PMTCT or PrEP on their own do not provide a lifelong tool to navigate sexual relationships and social communications. However, more money and investments go towards continuing testing campaigns of thousands and condom demonstrations rather than to adapting, building upon the strengths and weaknesses of the dialogues, and maintaining an experienced team for outreach and support.

11.2 The Climate: Lesotho 2012 Middle Class Talk About HIV and MCP

Results presented in Chapter 6 illustrated the local context in Lesotho, especially how people in general talk about sex, HIV and MCP. Without this background, neither the challenge of diffusion of this type of information nor the difference in research participants’ lives could be understood.
11.2.1. Normalcy of Not Talking, Condoms and Rape

Across all participant groups—original research team members, comparison group, and organizational representatives—participants noted that talking about sex and HIV is awkward, uncomfortable, a discourse that is not “Basotho” or “African” to discuss. When participants were probed specifically by asking ‘If someone that you knew had passed away and their funeral is coming on Saturday, would you be able to talk about what they died of?’ a majority of participants said that the cause of death would not be stated and it is actually rare to specify a death as being related to HIV. According to these middle class participants, there is still a strong perception that the main contributing factors for high rates of HIV are ignorance, poverty, and/or “rural” thinking. Yet, statistics from the onset of tracking the epidemic in 1988 to the present consistently show rural populations with lower HIV prevalence than urban ones, as reported in the National Modes of Transmission study conducted in 2009 (See Figure 18). Thus, how people talk about and perceive the problem do not necessarily match with the science tracking and monitoring the epidemic in Lesotho.

One unexpected finding from participant discussions about how people in Lesotho talk about HIV was the common reference to events of rape. Rape is often associated with violence against women and not with the HIV response in Lesotho. The re-occurring theme of rape by participants in this study provoked the question of why is the high frequency of rape within a small network not considered as a compounding factor in sexual networks and the transmission of HIV. The “normalcy” of rape in early sexual encounters may be more of a vector than suspected. The likelihood of negotiating condom use in these cases is obviously lower, and there is seemingly nothing the victim could have done to avoid contracting HIV. Bringing the social reality of rape past and present to the front line could have many potential untapped benefits. Primarily, building awareness empowers victims to know they are not alone, and strengthens them to heal and act towards helping others prevent this violence. Leclerc-Madlala quotes a letter to The Natal Witness where an organization promoting virginity testing in South Africa started testing girls at age 12 but found that over half of the girls had already lost their virginity because most of them had been abused by their relatives—brothers, fathers, uncles, and cousins (Leclerc-Madlala
2001). A secondary, indirect, benefit of bringing to light the social reality of rape in Lesotho is that it allows another context for the contraction of HIV that gives less culpability. The recognition of the social reality of rape and incest may take away from the way in which many people automatically associate HIV with sexual promiscuity or a lack of condom use. This does not imply that a person needs to personally identify and say “I was a rape victim,” but the social connotation of the disease is expanded rendering it easier to live positively. In other words, talking about the local nuances and prevalence of rape and incest is tapping into the social trigger of rape and HIV to evoke anger, sympathy, and a sense of injustice. Use of the social trigger to protect those who cannot or could not protect themselves, opens the door to HIV positive people being more open about their status, after all, no one knows how a person contracted HIV. This may also open doors for continued dialogue about the sexual transmission of HIV to motivate individuals and communities to go beyond “awareness” towards sexual and HIV education—be that from the schools, religious or traditional institutions, and informal conversations.

The results presented a powerful story from a participant who recounted a woman being raped who begged the assailant to at least use a condom. The assailant was so disturbed by her request and the fact that she was a condom carrying woman, that he left her without raping her. This example has many layers but one important element is that it illuminates the fact that after 20 years of Population Services International working in Lesotho, condoms are still not socially acceptable. Participant responses indicated that condoms are currently in fashion for urban educated young people. PSI and Lesotho Demographic Health surveys report an increase in condom uptake, however PSI’s own five country comparison study found low consistent condom use, especially within long-term relationships (PSI 2008). Thus, despite 20 years of campaigns and condom promotion, condoms are still not widely socially acceptable and people who do use them report inconsistent usage. The unrelenting (financial) focus on condoms in behavior change prevention strategies in Lesotho is both an example of research evidence not making its way into policy and practice at the ground level as well as an integral part of understanding why MCP and other social and behavioral approaches have been neglected.
In 2004, 150 experts signed a Comment in the Lancet calling for an evidence-based approach to preventing the sexual transmission of HIV/AIDS in generalized epidemics that placed behavior change first rather than promoting condoms (Halperin 2004). Prevention programming disproportionally focusing on condoms ignores scientific evidence. Studies demonstrate that risk-compensation occurs where individuals switch from inherently safer strategies (partner selection, fewer partners, non-penetrative sex) to having a higher number of partners and higher number of sexual acts resulting in an increased probability for inconsistent condom use and condom failure (Richens, Imrie et al. 2000; Green 2003; Cassell, Halperin et al. 2006). As the results of this study indicated, having young women conduct outreach all over Lesotho with rural men giving live fake penis demonstrations, playing “up the edge” as the PSI representative noted, may be facilitating more arousal than prevention. Several studies have showed the unintended consequence of vigorous condom promotion (without behavior change or STD/HIV/AIDS education) increasing sexually activity (Kajubi, Kamya et al. 2005). This is especially poignant in conservative or traditional settings where studies indicate conservative men being more susceptible to sexual prompts and imagery (Roberts, Gibbons et al. 2014). Furthermore, when considering that an intervention that is 99.8 percent effective for a single sexual act can yield an 18 percent cumulative failure rate with 100 exposures (Fitch, Stine et al. 2002), promoting condoms and sex as part of the “good life” as the latest PushaLove campaign in Lesotho advertises, may be inadvertently increasing sexual acts, sexual partners, and condom cumulative failure rates. Despite MCP being identified as the primary behavior change target, more resources continue to go towards condom promotion rather than targeting social and behavior issues aggravating the epidemic in Lesotho. Condoms are indeed important, but can no longer dominate the sexual transmission prevention landscape in Lesotho. It is beyond time for change. Not only does future prevention work need to expand to include integral social and economic aspects of the epidemic, but it may also have to include damage control for the ways in which particular methods of condom promotion may have inadvertently increased risky behaviors in Lesotho.
11.2.2. An Eye-Opening Experience

A fundamental argument of this dissertation is that prevention initiatives in Lesotho do not need to further document MCP practice, but rather to change the focus to understanding what this knowledge means to people. As evidenced in the data from individual interviews, in 2012, MCP was still normal and socially accepted even if people were aware that it increases HIV transmission risk. Participants described the concept of MCP portrayed by the media as normalizing the behavior as if everyone in the world is the same but by some oddity Lesotho gets more HIV. For example, despite television portrayals, the U.S. 2004 General Social Survey found that 3.9% of married American men and 3.1% of married women reported having more than one partner in the previous year (Smith 2006: 54). Similarly, a 2004 French national survey found 3.8% of married men and 2% of married women reporting more than one sex partner in the previous year (Druckerman 2007). This is in comparison to various surveys in Lesotho where the rates for multiple partners was 40% for sexually active men, including married men, and between 11 and 30% for sexually active women (Caraël 1995). More needs to be done to point out the statistical difference in types of relationships and sexual practices that make Lesotho’s ongoing practice of MCP dangerous for HIV transmission in comparison with other contexts.

Participants repeatedly noted how talk about the sexual transmission of HIV and AIDS had often been pushed out of the personal sphere and relegated to structural settings—hospital/clinic, work, or school. Despite growing up in an environment lush with HIV campaigns such as Kick for Life, Know Your Status, OneLove, and other institutional messaging (as opposed to educational dialogues), young people were not seeming to take grassroots ownership of the problem or the solution for HIV and AIDS. Instead, engagement took the lead from outside donors, the providers of resources and opportunities. As noted earlier, the participants’ engagement as researchers investigating sexual transmission and multiple concurrent partnerships was predominantly for employment, not because they were driven to work on this specific issue and aspect of HIV. Several participants confirmed the common perception that if someone talks or reads about HIV, they must be either conducting research for study or are paid to talk about the topic—not for personal edification. Another surprising finding was that some people in Lesotho describe
HIV as something “for the people”. This begs the question: how is it possible that HIV is seen as a “good thing?” Probing about this “it is for the people” catch phrase revealed that for some people HIV has a conundrum of associations between disease that kills and disease that gives advantages, disease that is inevitable, that brings inequalities, but a disease that one may benefit from through jobs, food packages, and support. Foreign institutions have been driving the HIV/AIDS response in Lesotho for over twenty years. There is clearly a need to understand, with greater depth, some of the unintentional consequences of this “lucrative” outsider presence on how locals perceive the problem and solutions to HIV.

In contrast to the respondents’ descriptions of the general population’s impersonal, indifferent, and sometimes opportunistic reactions to the problem of HIV are the research team’s accounts of how the act of qualitative research changed their response to the problem. Helping them to see responding to the epidemic as personal, vital, “something that comes from inside” and not for the money. One of the dominant findings in this dissertation is how qualitative research, the practice of conducting interviews, transcribing, the first hand relationship with evidence that qualitative researchers have is a valuable resource in the diffusion of prevention information and more importantly as an awakening, or raising of consciousness, that can lead to personal and social change. The term “eye-opener” was used by six of the nine original research team members to describe the difference in what they learned about sex and HIV during the MCP study experience. However, it is not a matter of HIV and AIDS information ignorance. These respondents are middle class, young adults, and university educated. They have a certain type of information and knowledge on the topic but either the information or the way it is taught does not translate into a personal working knowledge that converts into prevention. Participants highlighted how their experience as part of the MCP study changed their personal outlook on HIV and also their perspectives on the need for the broader population to change their attitudes towards sex. Participants noted how the act of conducting and transcribing other people’s interviews—the act of listening to people’s stories—made the reality of their own risk come to surface in such a way as to provoke change in attitudes and behaviors in addition to taking preventive measures (e.g., using condoms). Coming face to face with real life examples helped research team members break down barriers of communication
about sex and HIV within their personal networks. This is not to imply that only research team members who conduct qualitative research are able to open up, talk more, and become open to behavior change strategies. Rather, it can be demonstrated that mechanisms and programs that create space for people to talk, ask questions, and understand how their own local epidemic is touching their lives and what they can do personally and communally to prevent the sexual transmission of HIV are fundamental to creating the type of consciousness that results in behavioral and social change. This may be costly and difficult to measure but is worth investing in.

11.3 Capacity Building Consequences in Employing Local Researchers

Chapter 7 addresses objective one on the description of how the results and experience of the research process affected local researcher’s ability to incorporate health knowledge in their life. The chapter brought to light how the process of involving indigenous researchers furthers local capacity in terms of qualitative research, ethical practices, and HIV prevention.

11.3.1. Increasing Local Capacity Through the Inclusion of Local Researchers

The results of this study indicate that the research team’s motivations for applying to the MCP research project were overall economic in nature. But even if the initial motivation was money, the opportunity to work in HIV served as a hook for an eye opening or awakening experience about HIV. Participants rated their post-MCP level in understanding and implementing qualitative research quite high. Some participants noted that the missing link was more participation in the analysis process. This is despite the fact that the research assistants were part of a collaborative analysis helping to define and verify codes, but they wanted a chance to learn how to conduct the coding and analysis using qualitative software. Many times in “north-south” collaborations, the north does not budget for this type of capacity building for “data collectors.” In moving towards long-term investments, empowering young researchers and helping them gain access to expensive software will contribute to better means of creating “evidence” on questions and priorities that are locally motivated. Capacity building in analysis will require funding
for the actual on-site training/mentoring of researchers by an analyst. And in consideration of the necessary learning curve, funders will need to accept a “doubling up” on budgeting for analysts with experience to run a parallel or shadow analysis to ensure quality and validity of the findings.

The researchers’ perceived level of capacity in understanding, implementing, and conducting ethical research was viewed quite highly. Particularly important was the way in which they contrasted the local norms of coercion, pressuring, and not respecting participants with their new post-MCP perspective. Ethical research training, even behavioral for clinical research workers helps change immediate interactions for the job at hand, and changes perspectives about respect for persons, harm, and benefit that are applicable in future work situations. Another unexpected finding was the discussion about the importance of explaining to research participants the “randomness” of their selection and their “stranger” status to the researcher during recruitment and the informed consent process. According to the research assistants, this direct way of distancing themselves from the research participants, helped participants to trust, open up, and reflect more deeply about their sexual lives and relationships. The explanation of the randomness also reinforced the importance of absolute confidentiality by the research team members in relation to their participants—not being related or knowing each other—a dynamic that for many researchers is hard to comprehend when working in smaller communities, where everyone “knows” everyone else. This is a key concept that may be underestimated in clinical trials and other translational research settings.

The importance of “who” conducts the research is not only relevant to the specific capacity and single research job, but to the future lives and experiences of each individual researcher. Most team members went on to apply what they learned about communications, ethics, research implementation, leadership, and HIV in future capacities of networking, other work opportunities, and HIV activism. These middle class individuals were exposed to another world within their own country. Unlike recruiting lower educated, “peer” or rural data collectors for rural sites, the employment of educated middle class individuals, in this setting, opened a unique space for exchange. The knowledge gained through the experience cut across social classes, and then travelled with the middle class who flowed between urban
and rural settings and took up future positions of power. These findings reaffirm the findings of Pisani (2008) on the efficacy of employing middle class civil servants as local researchers to do sensitive research while tapping into the strengths of “peers” for mapping, questionnaire design, and field supervision.

11.3.2. General Capacity Consequences

The MCP project initially faced much resistance from local leaders who argued that asking a Basotho about their sex lives would be offensive and upsetting to individuals and local leaders. In fact, the initial training of convincing the research team that they could indeed implement the research was difficult. With this in mind, revisiting the research team years later, they were probed about unanticipated negative consequences from family, friends, or in future job opportunities. The former researchers all indicated that there were no negative consequences; respondents highlighted instead positive consequences in their life in regards to the experience opening up future career opportunities and helping them to improve their relationships with friends, family, and partners. Furthermore, participants noted their genuine surprise against their own preconceptions that culturally, Basotho do not talk about sex and especially do not talk about sex with elders and instead finding that people were willing and wanting to talk.

One surprising finding was that many on the team had never connected before with the issues of HIV/AIDS, and the opportunity of working in this sector provided them with the motivation to continue to work against the spread of HIV in Lesotho. Based on participant responses, the study had a life changing, long-term impact on their futures. It is clear that the project management including social and behavioral scientists and especially anthropologists made a difference in how training and project implementing were approached. Efforts were made by project management to engage research assistants in question construction, translating yet maintaining nuanced linguistic phrases, codebook creation and theme identification as well as synthesizing and presenting final results. In fact, the anthropologists involved did not take on their role as “cultural experts” but rather facilitators for exploring cultural
dynamics, helping research assistants to understand their own culture and HIV within their specific context. Learning to think about cultural and social aspects of the HIV problem typically does not occur when trained for biomedical and public health research or interventions. Considering the predominance of biomedical and public health approaches, inclusion of general capacity training in cultural and social aspects, regardless of their seeming irrelevance to the specific capacity for implementing a project, can have long lasting rippling effects for curbing the epidemic.

11.3.3. Qualitative Research Makes an HIV Prevention Difference

As discussed in Chapter 4, the act of discussing, like the STOP AIDS program in California, naturally evolved from research focus group discussions into prevention interventions because it was a rare opportunity for people living through the same problem to be led through a process of reflection. A process that consequentially leads to problem identification and a realization, that HIV is a “social problem” that can only be resolved through collective action. Because qualitative inquiry is seen as “research” and not an “intervention” no entities, research organizations, or NGO’s evaluate the effect of interviews and focus group discussions on participants. Obviously, this is not important in every setting. But like the unique situation in Uganda with Maxine Ankrah’s (discussed in Chapter 4 section 4.3.2.2.) research team that “spanned across the country,” the act of getting people to talk and think about a socially sensitive topic such as HIV and AIDS may have had an effect that thus far prevention researchers are not measuring.

In seeking to determine if research assistants perceived this type of prevention difference, it was found that most participants were confident that the individual in-depth interviews had this type of prevention consequence. Research assistants described how the act of talking, having someone listen without judgement, and then listening to yourself provoked a type of reflection for research participants (and themselves) that may have led to behavior changes. Interestingly, female respondents argued that individual interviews made more of a prevention difference. In contrast, all the male research assistants noted that they felt the focus group discussions made more of a difference because they presented a
unique opportunity for a group of men with the same age-set to open up and talk about sex, MCP, and HIV. Further, participants noted that within this group context, not having the information directly pertaining to the focus group participants made them more likely to ask questions and discuss. In fact, the male research assistants noted that they were relieved because there was typically one person in the discussion, or different people with different knowledge, who were well informed and could address the questions and misconceptions that came up from other group members. Both male and female research assistants noted the difficulty in closing FGD discussions, participants would ask “when is the next meeting?” and oftentimes research assistants left meetings with groups of people still talking. These findings further support arguments that the use of qualitative methods itself becomes a trust-promoting activity that is useful throughout the translation and dissemination process (Scharff and Mathews 2008). Others have noted the almost therapeutic value in the process of talking, not only to be heard, but to be listened to with genuine interest (Butterfield, Borgen et al. 2009; Clark 2010).

Research assistants were asked about the value of the MCP project based on the amount of money and time invested. The reasons given for the study “worthiness” were linked to the capacity built in qualitative research, the quality of the overall research results, and the changes they personally experienced in their ability to communicate in general and about HIV and sex. None of the participants stated feeling satisfied that the research fulfilled its potential. The participant who gave the lowest value on the worth of the project explained that it was due to her perception of the report and results not making it into programs and her suspicions about the larger level of mismanagement of funds causing the failure of translating results into programming. Another researcher emphasized the good that came out for each of the individuals on the study team, but noted the limitations of the study design which did not gather systematic information about the social economic backgrounds of the participants. She believes that presenting sexual behavior results tied to participants’ economic status would have helped stakeholders in Lesotho understand the dynamics of the epidemic. This points to a larger problem in getting evidence into action as well. There is much rhetoric around combination prevention approaches that bring together clinical, social, economic, and behavioral approaches, yet researchers working from these perspectives
rarely include indicators and measures of other paradigms. For example, social and behavioral studies rarely have the clinical expertise to include biomarkers in their analysis, whereas clinical studies with biomarkers rarely collect in depth quality social and economic data. There is still a need to invest in either creating better funding opportunities for interdisciplinary research, where the different paradigms are given equal power and voice in the study design, or creating support systems where a particular paradigm can seek out help in integrating components that are not in their specialty area.

In several of the hyperendemic zones, there is a reliance on mass-media campaigns, the distribution of condoms and other commodities, and hospital-based services. These services undoubtedly benefit many individuals. However, without the chance to interact, ask questions, or talk to someone, the ownership, the individual consciousness, and social responsibility for prevention are not triggered. As demonstrated in the results in this dissertation, the opportunity to talk is not only that of the participants but also the researchers who go on to have conversations in their personal and professional networks. Because qualitative research fosters conversations at both the primary point of researcher participant interaction as well as secondary conversations, it is important to re-conceptualize the purpose of research. For example, maybe we “already know” information based on previous research or surveillance, but the action of letting people do science and discover for themselves what is known may have more long-term success in creating change than in “programs” using what is already known.

11.4. Prevention Support System: Human Researchers, Building or Diminishing the Capacity to Cope?

Chapter 8 addressed objective one describing how the results and experience of the research process affected local researcher’s ability to incorporate health knowledge in their life, including their capacity for disseminating HIV prevention knowledge. The way in which the use of an ethnographic reflexive approach helped to pinpoint and understand the ethical implications for research members (not just participants) themselves in conducting research on sensitive and emotionally laden topics was
examined. The findings highlighted the importance of dealing with investigators’ emotions and their capacity to cope, and how these influence the conduct and output of research as well as its dissemination. The chapter explored critical questions of what is was like for researchers to interview people whom could easily be neighbors, friends, or family members and asked about cases which stood out in particular, or had lasting impressions on investigators. Finally, the subject of crossing over the line between researcher and educator/interventionist was addressed. Several research members felt that while they understood the need to conduct research according to certain guidelines and ethics, their ‘humanity’ often intervened, and they were left feeling that the research had not done enough for follow-up communication of information for the participants involved.

11.4.1. Transforming Statistics into Stories

Several studies have shown how systematically listening to and documenting people’s stories of trauma, struggles, and injustice impact researchers (Gilbert 2000; Goldenberg 2002; Rager 2005; Blackman 2007; Wray, Markovic et al. 2007; Dickson-Swift, James et al. 2008; Watts 2008). This interaction between and among researcher and participants is especially heightened in the context of work with HIV/AIDS, sexual behavior, and social change. In this research project, participants were asked what it was like for them as Basotho to interview people that could easily have been their friends, family, and even lovers, and listening to these stories of love, betrayal, risk, vulnerability, etc. Five out of nine research assistants independently responded using the term “eye opener” to the above question. All participants described how the process of listening to people’s sexual history changed how they looked at HIV in general and how they saw themselves within the larger story of HIV and AIDS in Lesotho. The act of listening transformed statistics into stories. While administering the series of questions on study participants, researchers inadvertently asked themselves the same questions. They ended up turning the lens back upon themselves.

Professional AIDS response narratives often recount stories of HIV stigma and discrimination or the sacrifices and support made by or for children. However, stories of forgiveness, undeserved love, and
support among adults seem to be a neglected narrative. These stories and experiences deeply touched research participants. For example participants discussed the experiences that affected them most including a young bride whose husband impregnated her right before dying of HIV, wives who forgave their partners infidelity and despite their discordant HIV status cared for them as they were suffering and dying, and researchers who gave life changing advice to seek testing, treatment or to get out of a dangerous relationship.

11.4.2. Research Encounters That Leave a Lasting Impact

While recalling the difficulty in listening and transcribing such sensitive accounts, researchers paused several times, reflecting the challenge in facing again these memories, even after four years. One male researcher acknowledged that the experience could have been traumatizing but because he was young and the research was so exciting, he surpassed the difficulties. Interestingly, the research participants described their version of “shared confidentiality” where they actually shared their research experiences and used each other to vent and deal with difficult field encounters. Principal investigators and research managers should take this informal practice into account, often management stresses the need to uphold confidentiality. However when dealing with sensitive subjects, it is likely that this practice of sharing experiences will happen, and –as in this case-- may actually be therapeutic, even if unethical. Perhaps it is more appropriate that certain projects institutionalize “shared confidentiality” and provide a safe space and time for it to happen, rather than at lunch breaks, car rides, and off hours where non-team members can hear. The team leaders provided each of the research assistants a reference number and a list of counselors and resources specific to each of the fieldwork districts in the case of coming across participants in interviews or focus group discussions who seemed to be in need of help. Yet the team leaders did not provide a counselor or psychologist for the research team members. In light of the high prevalence context and the way that the stories inevitably affected research team members, I would suggest that principal investigators and study managers, structurally provide a reference point—a counselor who trains the research team in how to deal with work related stress or budgeting for the
potential need for researchers to seek help if needed. While the research project may have only lasted six months, the damage of a strong story could last a lifetime. This is a work-related harm, and we, as researchers, should think not only of the harm to study participants but also to our staff and ourselves. Yet, we must be careful not to fall into the trap of “harm” being conceptualized as an IRB check in the box to avoid legal ramifications. This type of “harm” is part of the job, part of our practice, and thereby needs attention not because it is “required” but because protecting researchers against it is the humane thing to do.

11.4.3. Research Experience Effect on Personal Sexual Relationships

Researchers described several important ways in which the research experience affected their personal sexual relationships (see Figure 28). The most common response revolved around having better communications with sexual partners. Researchers also connected the experience to improving their test-seeking behaviors individually and within partnerships. The three male researchers mentioned how the study helped them to go against the MCP trend and be a “one woman man.” While there was no direct message of fear, participants brought up how the experience motivated them to change by forcing them to reflect on their own situation and invoking a bit of “fear”. Participants, especially the women, explained how the research experience improved their ability to carry, discuss, and use condoms. Female participants articulated how the experience helped them to take ownership of their negative status and established a new found assertiveness for HIV testing in relationships, empowering them to bridge conversations about sex, past relationships, HIV testing, and condoms. Several participants made it clear that testing and condoms were not only about protecting their own negative status but it was about realistically facing their high HIV prevalence reality and taking the needed steps to create a healthy future, even within an HIV discordant relationship. Participants emphasized that it was not only the field experiences but also the training and team discussions that helped them to be “free” to talk about personal issues. One male participant explained how a specific conversation during training changed his long-term relationship, giving him the impetus to talk frankly, receive couples counseling and get tested strengthening their relationship and moving forward together with more openness and trust.
11.4.4. Keeping or Crossing Over the “Researcher” Line

During the original MCP study, training, and piloting of instruments, team members had many discussions about their roles as “researchers” and NOT as educators or interventionists. In the four-year follow-up, each researcher was asked if they were able to always maintain the researcher line or if they ever crossed over it during research implementation. Only three of the nine participants stated that they did not ever cross the line beyond their researcher role. A fourth researcher acknowledged crossing the line once. However all nine admitted to the desire to cross the line and the frustration in not providing more information, but understood the rationale of the principal investigators.

Those that did not cross the line did so out of responsibility to their employers, as well as not feeling adequate in their HIV knowledge. Thus, the ever-changing information seemed to make HIV education something for “professionals” out of the capacity of even college degree researchers working for the National AIDS Commission and UNAIDS. Researchers who did not cross the line made the connection between their silence during the research process, and their belief that the research would go on to practice application, returning to provide an intervention for the people they left in ignorance. Interestingly, all three of those who maintained the line were still working professionally in the HIV response. In contrast, only one of the six individuals who crossed the line was still working in the field of HIV/AIDS. The former groups’ continued work in the professional HIV response may be a product of their natural inclination to follow what is dictated by outside project management or of a genuine dynamic between their frustration and dedication to ensuring the results went into programmatic change.

The questions asked on the original MCP study guide were designed to gain information about risk perceptions and norms surrounding MCP to inform prevention efforts, not to be a prevention effort. While it may not have been the intent of the principal investigators, it is clear from the interviews in this case study that the act of asking these types of questions is a form of intervention. The questions provoked reflection and interactions by and between researcher and participant about their individual risks and behaviors creating a type of prevention moment. In a context with lower HIV prevalence or where information and prevention services are easily
accessible, the opportunity for this discussion would not be as significant. However, in Lesotho where people tend not to talk about HIV and where many people do not know their risk, these one-on-one intense moments were an opportunity for researchers to potentially affect major change on the study participants. Research team members who crossed the line brought up the sense of responsibility they felt to say something that would help the participants they encountered. They described how they perceived a unique space for the participant having a professional outsider present to listen, answer questions and gain guidance. Research assistants described occasions where they would intervene and provide information or advice either by turning off the recorder or waiting to the end of an interview or focus group. Research assistants contrasted their presence with that of peer educators from the community, noting the comfort participants seemed to feel in talking to a “stranger” or a person that “you'll know you'll never need stuff from”. There is indeed a unique difference between a researcher and a typical counselor. First, the individual does not seek out the researcher, it is the researcher who recruits and opens the space for dialogue. Therefore, many people who may never have sought out a counselor or physically go to an HIV resource center found themselves with a young educated professional who seemed to know more about HIV than themselves. Secondly, community outreach workers and HIV peer educators are often immediately associated with testing, or delivering medicines to the HIV positive, a community members’ association with them can lead to later problems of stigma. In contrast, these research assistants were perceived as neutral, the interaction was completely random, which opened doors to people that may have otherwise remain closed.

11.4.5. “A difficult battle between ethics and humanity”

After collecting so much information, research assistants wanted to know what was next—how the research they were collecting would translate into programs and initiatives that would help people. At follow-up research assistants explained that while they were conducting the research they were dissatisfied with keeping quiet and not exchanging anything, no information or knowledge with the people who were actually giving freely of their time and life story. Several of the respondents used the same words to express how they felt about the researcher vs intervention dichotomy. Ironically, they often
put in juxtaposition their humanity with upholding ethics. Respondents said they felt “bad”, “guilty”, “frustrated” one participant described feeling like an “instrument” or “tool” used to get stories.

Participants described the literal pain in hearing misconceptions about HIV/AIDS and not being able to convey information. As stated above, a majority of the researchers, even those who started the project maintaining well their researcher role, ended up crossing the line. Research assistants intervened directly into the lives of those they interviewed giving serious life changing advice such as encouraging them to seek testing, initiating treatment, and leaving dangerous relationships. These middle class researchers were forced to enter into the homes and stories of the poor. One participant described how she “couldn’t just disassociate” and after conducting an interview with a poor woman, instead of providing chips and juice box that were part of the standard courteous procedure in the “no compensation” for participation, she gave her own money to the woman to buy food for her children.

These experiences speak to the complexity of long-term expectations at the personal level and false expectations about direct benefits. Despite informed consent documents explicitly saying “you will receive no direct benefit” these in-depth intense human interactions begged for something more. In cases where there is no direct benefit to the participant, common IRB practice asks researchers to simply state that the research may go on to inform future interventions. An individual participating cannot help but to hope that the future intervention will be near them, and research assistants who repeatedly build rapport and see the expectations of participants often cannot resist feeling responsible in ensuring some kind of benefit. For a few of the research team members this meant giving their phone numbers and providing ongoing information and advice and for others this meant continuing to work in the HIV prevention sector. The MCP project actually went above the normal level of diffusion by returning to the research districts and conducting a dissemination meeting. However, in efforts to protect privacy, the study protocol required research assistants to destroy participants’ contact information so there was no official means for inviting individual participants to the dissemination meetings. The MCP dissemination meetings ended up being with a general audience of stakeholders and not necessarily with research participants. One participant during the 2012 follow-up suggested that research team conducting a rapid follow-up inviting research participants and community members to a general informational meeting a few days following
data collection while the team was still in the research district could have improved the old MCP project. While it is too late to adopt this approach for the MCP research, the suggestion is valid for future similar projects.

Unfortunately, getting solid education opportunities back out to every study district did not happen. It is clear, today that in most cases, the encounter with participants during field work was a missed prevention opportunity. The fact that principal investigators require research assistants not to intervene or provide immediate informational sessions, but to have faith in the integration of results into broader interventions provokes a theoretical and methodological question. If the local researchers had more of a say and power in how the research was conducted, would the design have been different to address the need for people to exchange information about HIV and MCP rather than only extract information?

Ethical quandaries exist because there is often no black and white clear solution to the problem presented. No one can definitively say whether or not the participants who crossed the line between research and intervention did the right thing. From a technical, maintenance of research standards perspective these line crossers are in the wrong. From a human perspective, one can question if this is a just standard in high prevalence settings where future opportunities for intervening are not guaranteed. Perhaps it is time to tap into the benefit of having middle class civil servants and University graduates conducting research as “strangers” to provide an opportunity for participants to not only divulge sensitive information in the security of a “non-relationship” but also to receive relevant information. In this case, principal investigators would have to take on the responsibility of training research assistants to answer questions and correct misconceptions, thereby making it possible that the interview interaction can also serve as a prevention interaction.

11.5. Prevention Delivery System: Tracing HIV and MCP Communication Diffusion

Chapter 9 presented data from the communication diffusion activity and contributed to both objective one, describing how the results and experience of the research process affected local researchers’ ability to incorporate health knowledge in their life, and two identifying how research results are integrated or rejected by local change agents. For objective one the results demonstrates an additional tool to help stakeholders evaluate the medium to long-term investment in training local researchers in
qualitative methods to investigate issues around HIV. The chapter also speaks to the importance of involving indigenous researchers for the dissemination of disease prevention information in formal and informal settings. The activity compared quality conversations about sex, HIV, and MCP by the nine original research team members with a small comparison group of four individuals. Interestingly, one comparison male could not recall any conversations about HIV and MCP but everyone else who reported, even if just one, could recall with whom and where the conversation took place as well as the content of the conversation. This may confirm the methodological assumption that these conversations are an exceptional event and that if a quality conversation had taken place, an impression remained so that, when an interviewer probed, an individual could recall the details.

11.5.1. Triggers of Quality Conversation About Sex, HIV, and MCP

Triggers for conversations about sex, HIV, and MCP fell into five main categories. 1. An immediate crisis that makes initiating an HIV prevention conversation imperative. 2. A health professional, friend, or relative who brings up the conversation based on an experience they had. 3. Constructive gossip a conversation during lunch break with colleagues, at the gym or bar with friends, or office gossip about a celebrity or another person. 4. A significant life transition, experienced by the researchers or by study participants in their personal network like getting a new job, starting back at University, new relationships, new pregnancy, a death. For example, respondents cited compulsory testing during pregnancy and the suggested policy of women to stop breast-feeding as a conversation motivator for all of the participants, both male and female, who had children after 2007. Other time and life transition sensitive conversations within the researchers’ network were stimulated by family and friends asking questions, (that they otherwise would not) because they knew that the individual was part of a team working on issues about sex and HIV. And 5. work-place HIV orientations and HIV trainings with people who had not participated on the 2008 MCP.
11.5.2. With whom did they have conversations?

All of the original male team members reported conversations with partners, family members, and friends, whereas only one comparison male reported a conversation within people in these categories. Numerically speaking, participants had more conversations with non-HIV sector work colleagues than they did with partners, friends, and family members. None of the original male team member reported conversations with acquaintances or discussions initiated during non-HIV teaching/training opportunities, and only one comparison group male reported a conversation with one acquaintance. In contrast, six out of the seven female researchers reported these types of encounters and their approximate outreach was with over 1,355 people. These findings may reflect a gender trend of discourse, where men are less likely than women to seek out opportunities to teach or train about HIV and sex or to recognize the occasion to discuss this type of topic with mere acquaintances. These results seem to imply that men, when trained about how to talk about HIV and Sex in a professional context, go on to diffuse their knowledge mostly with close friends and work colleagues rather than with family members and acquaintances. All of the male high diffusers noted how they do not hold back if the subject of HIV or the danger of MCP "comes up," however, if it does not come up, they will not initiate conversation. Further, studies should be done on understanding what constitutes “the topic coming up” and opening the way for sharing sexual health information. Three men said they talked repeatedly to their male core group of friends explaining and bringing to light the risks in multiple concurrent partnerships, supporting each other in decisions to avoid risky behavior, and providing a place for alternative practices. All of the former research assistants explained that they would bring in their MCP and HIV knowledge into conversations during different life situations that their friends were facing. These repeated encounters over time with family, friends and co-workers are the type of outcome that if only quantitatively measured by persons contacted would not be measured. Nor would a simple quantitative indicator measure the depth and the type of relationships that allow the information to be tailored to the life need of the recipient. In other words, 25 acquaintances contacted may not have the same long-term value in raising consciousness or behavior change as the repeated and higher quality encounters with five friends or work colleagues.
None of the participants report initiating conversations with older siblings (especially older sisters). They reported initiating conversations with younger siblings, nieces and nephews, and the friends of younger siblings. There is also a pattern of having had very few conversations with broader extended family members. All of the comparison group, including # 10 who had the most populated communication diagram in this group, maintained that talking to elders or parents about sex and HIV was something they did not and could not do since it goes against cultural norms. This is in contrast to the original research team members who reported that their role on the research team had changed their cultural expectations; thus, they were now able to have conversations with elders and their parents, thereby opening up a space for intergenerational knowledge transfer. Respondent noted how talking to older people during study implementation helped them to open up and talk to their own elders. This ability to bridge the gap allowed them to receive and divulge a wealth of information that otherwise they would not have transmitted. Three participants mentioned how they were able to share what they learned from the MCP project experience with their parents and how their parents went on to share the knowledge in their spheres of influence. Thus, an especially important finding of this research was that participation opened up lines of communication within and across generations.

11.5.3. Opening Channels of Communication About HIV Through Social Networks

As discussed in Chapter 4, teaching and training opportunities are unique spaces for engaging in critical thought about HIV, sexuality, and social realities. Several respondents described how they brought in stories, statistics, ethical examples, and ways of talking about HIV and MCP that they gained from the original MCP project, into their teaching and training employment.

Diffusion activity conversations revealed how HIV prevention information, disseminated by participants, is not formulated in a unilinear pathway from “target” potentially sexually active persons and their direct exchanges to their partners. Instead, the quality conversations discussed by participants built up a social awareness, a cultural translation of information that creates an enabling environment. These conversations repeatedly show the special dynamic of kinship relationships. People hear the same
information differently because it is coming from a person in the family that is respected and that is socially sanctioned to call on when in need of help in fulfilling social obligations for marriage, inheritance, death and respect to the ancestors. People in key kinship roles can facilitate this type of conversation. However, study results also revealed the consistent trend of not talking to family members of certain kinship relationships. Most of the time, for instance, younger siblings did not initiate conversations with the oldest sister in the family. Participants also drew an invisible line of who was “close” enough in the family to have conversations about sex and HIV. Participants seemed to open up and share information about HIV more with friends, work colleagues, acquaintances and strangers than they did with extended family members.

Epstein describes a similar experience during her research gathering sexual histories in seven countries she underlines, “I was surprised at how open people were with a stranger and how willing they were to share their experience” (Epstein 2007: 67). Epstein (ibid) makes the contrast between young people in Botswana, South Africa, and Swaziland who avoided direct discourse on AIDS and people in Uganda, who talked about the disease as it relates to family members and friends. Several researchers have highlighted the stark difference in the way that people talk about HIV and AIDS in high prevalence countries versus in countries that have had a decrease in transmission rates.

Epidemiologists Rand Stoneburner and Daniel Low Beer conducted a comparative analysis of demographic and HIV behavioral data from DHS III in Uganda, Kenya, Tanzania, Malawi, Zambia, and Zimbabwe (Low-Beer and Stoneburner 2004). They also carried out Knowledge, Attitudes, Beliefs, and Practices (KABP) surveys, and modeled from which point in the progression of an HIV epidemic people will know someone with AIDS. The authors also compared this modeling information to trends in Voluntary Counseling and Testing (VCT) with the main goal of understanding AIDS behaviors, social communications, and channels for communication about AIDS. They found that during the period of 1989-1995, Uganda differed greatly from the other countries in the method of communications. The other countries had communications that were dominated by large mass media, institutional, and clinical channels, whereas Uganda uniquely showed a shift from these methods to more personal channels of
communicating through social networks. The researchers also pointed to an association between people knowing someone with AIDS and behavior change such as reducing casual sex and increasing condom usage. They also identified patterns of disclosure and AIDS diagnosis as being influential in changing communications (Low-Beer and Stoneburner 2004). They highlight the significant influence of ordinary, candid, conversations people had with family, friends, and neighbors, not just about sex but about the painful reality of AIDS itself in helping Ugandans to decrease stigma, seek out and give care, and change their own sexual behaviors (Low-Beer and Stoneburner 2004) influencing the decline in prevalence and incidence in Uganda during the 1980s and 1990s.

When asked about how they felt following HIV, sex, and MCP conversations, participants provided responses that seemed mixed between feeling content that they said something to make a change and feeling frustration and resignation that their words could not make a difference. Yet regardless, of this frustration they continue to initiate these prevention conversations.

11.6. HIV Response and the dynamics of social, economic and political change

Part of looking at the complexities of social systems requires that the lens be placed on the social changes caused by HIV research and interventions themselves. Chapter 10 looks at HIV as part of economic, social and health development in Lesotho supported by the aid industry, presenting data on how the investments of money influence the ways in which local leaders and everyday citizens define, communicate, and conceive solutions to the problem of HIV. Findings make clear that, in trying to understand the diffusion process of the MCP research findings and the way in which the experience affected the research team, the full story cannot be told without consideration of the larger institutional forces at play. By pointing out inconsistencies and problems caused by the HIV response itself, the chapter stresses the importance of taking a praxis approach to reflect on how everyday normal research and intervention practices may aggravate or help communities cope and resolve the epidemic.

Participants explained how the way in which funding and project timetables are structured erodes long-term local visioning and the diffusion of MCP information. Researchers noted how the need for
regional uniformity, according to directives given from abroad, actually undermines efforts to look back at, use what is known, or even think beyond what is to follow the project, campaign, or initiative. In a system where funding success is measured only by short-term quantitative outreach numbers rather than by measuring how the integration of short and long-term quantitative and qualitative indicators has benefited communities, things will stay the same.

The chapter provided evidence on how the infusion of resources dedicated to HIV initiatives in the high epidemic zones is fueling social change, not behavioral sexual practices or social cohesion, but rather socio-economic changes that promote competition and undermine cooperation. Respondents explained how the norm of having a monetary retribution in order to research or talk about HIV has fostered a situation where people working in HIV make their interactions with people at the community level impersonal and take lightly their responsibility to provide quality information. Participants discussed the connection in the quality of work depending more upon an internal motivation than upon monetary retribution, yet the lucrative nature of HIV work quenches and distorts this inspiration. The “money making machine” of the HIV response formalizes the energy and work of its subjects as a profitable pursuit; individuals pursue money and/or benefits rather than a critical consciousness of what the disease is, how transmission occurs, and what the best sustainable solutions for curbing the epidemic in specific communities are. The examples provided in Chapter 10 demonstrate the reality of outsiders and insiders getting increasingly richer from working in the HIV response while at the same time, no sustainable change or programming visible at the community level. Thereby creating a ripe recipe for accusations of corruption and scapegoating. Thus, there are many people going into the “business” not because they believe or understand the disease or problem, but because it is lucrative.

Even the best thought-out evidence based interventions, if not implemented by people who understand the point and the message, become a waste of money. Instead of fostering interactions within the dissemination system, this type of social, economic, and political context creates black holes where system inputs vanish, taking with them the opportunities to diffuse quality HIV prevention information and programming.
11.7. The Way Forward

It is a seductive argument to accept that social and behavioral forms of prevention do not work, and perhaps it is indeed time to treat HIV as any other chronic non-communicable disease. In this case, populations in high HIV prevalence settings like Lesotho will shift to a norm where taking a pill, shot, or gel every day is what all sexually active people do regardless of whether they are positive or negative. Following this line of reason, stigma against HIV would erode because everyone is treated (emotionally and medically) as if they had HIV. However, HIV is not just another chronic disease: it is preventable. There is an advantage to learning about HIV. Drugs have side effects, the regimes are hard to follow, and they are expensive (between $280 and $4,097 a month, per person (NIH 2016)). While first generation drugs are now much more affordable, second and third generation medications still protected under patents will cost much more. Hu Yuanqiong, legal and policy advisor for MSF Access Campaign, notes that the price of third-line regimens is 14 times higher than the recommended first line (Saez and New 2015). Keeping in mind that there are already people in Lesotho being treated with second and third line regimens at the “Centers of Excellence” (BIPAI 2016). It is to the advantage of both those who have and those who do not have the disease to understand how the virus and medicines “work” in their body and what they mean for society. Perpetuating a system that depends on drugs, biotechnology, and a particular type of health system means that investments are not going to other social, technical, and occupational developments.

As humans looking out for other humans, we must seize every opportunity to educate holistically about this disease. Considering the weight of the trajectory, most researchers and health professionals in developing countries will be hired into the biomedical dominant paradigm for employment. In the mid-term, translating biomedical findings into real world realities requires qualitative research. Ethically sound and well-trained qualitative researchers are fundamental in the creation and diffusion of knowledge. The findings from organizations representatives interviewed in this study reveal that the creation of research and diffusion of information will follow the funding. If a particular perspective is not
a priority for donors or decision makers, the message will stop. As the findings in this study indicate, if given a chance to understand the epidemic, people will change their own behaviors, influence those around them, and have the desire to facilitate conversations to provoke social action and change. However, this study also demonstrates how people can go years talking, studying, and working in HIV without ever having an “awakening” or deeper understanding of HIV in their local reality. Once, and if, that “awakening” takes place, there is a window of opportunity with a flurry of conversations and actions for change. But without ongoing informational or conversational inputs about HIV, the flurry of outward interactions deflates and the knowledge gained reverts to the personal domain. Currently, comprehensive correct knowledge about HIV is measured by the percent of participants who correctly identify the two major ways of preventing the sexual transmission of HIV (using condoms and limiting sex to one faithful, uninfected partner), those who reject the two most common local misconceptions about HIV transmission, and those who know that a healthy-looking person can have HIV (DHS 2015). But are these indicators an accurate measure of true education about HIV that translates to social and behavioral change? The act of “educating” if often judged to be complete when an evaluator can check off the boxes on these indicators. Based on this research, I argue that true education about HIV is not ascertained by a person being able check off a box education done; education is a dialogical perpetual process of interrogating what we know, imagining what should be done and trying: Praxis. By praxis, I mean reflection and action. This heightened awareness of how our daily research practices link to larger systems will help us not to allow our do-gooder attempts to blind us to the harm we may inadvertently do, or to the lost opportunities we squander. Instead, we must capture and maximize our investments in research and people as agents of change and not only as patients or employees.

11.8. Anthropology and the Qualitative Research Contribution

Brook Schoepf, an anthropologist who has worked on various prevention projects in Africa since the 1980’s, provides with other anthropologists the following recommendations about what works to reduce HIV transmission:
• Involve the communities in program development and implementation
• Know the local sexual norms and behaviors and develop programs that consider them.
• Provide safer sex options that not only reflect community norms but also are available without discrimination, stigma, and judgmental attitudes.
• Create programs that are holistic and address other pressing economic issues as well
• Provide viable alternatives to breast-feeding and drugs that are accessible and affordable.
• Work with kin groups and communities to foster tolerance and accurate HIV information.
• Use traditional values and beliefs that support safer sex practices, value women and men, and emphasize kin group and community cooperation
• Provide educational and economic opportunities for women (Whelehan 2009: 230)

With the Fast-Track Approach, it is clear that we are moving into the next, and hopefully last, era of AIDS. The present phase is characterized by a stress on improving health systems, creating demand for HIV technologies and services, and improving accessibility to these technologies through youth- and women-friendly clinics and circumcision services for men. All of these are good for prevention. What is troubling is the seeming absence in supporting what we know works in non-biomedical approaches to prevention, such as those listed by Schoepf. She is one of many professionals working in the field of HIV prevention who for years have struggled to convey the message that biomedical and technical solutions alone will not end the epidemic nor are these solutions possible without taking into account social and behavioral dynamics.

Green and Herling Ruark authors of *AIDS Behavior and Culture Understanding Evidence-Based Prevention* describe what they see as the most pertinent role for anthropologist working in prevention:

Successful HIV prevention will require a fundamentally different approach than what has, for most of the epidemic, been accepted as best practice. Ideology, inertia, and the financial self-interest that has grown up around a robust and ever-expanding AIDS-related industry have largely set the HIV prevention agenda, causing even experts (including anthropologists) to miss clear evidence. In our view, anthropologists ought to be more aligned with advocates for simple, low-cost, sustainable, and culturally tailored solutions and less aligned with the multi-billion dollar industry of biomedical research and pharmaceutical companies, hospitals, and clinics. We ought to be more willing to “speak truth to power” (an old Quaker call to action) and more ready to challenge Western-driven approaches to AIDS. It is time to put financial, political, and ideological interests aside and adopt approaches to AIDS prevention that make public health and anthropological sense—and that work. (Green and Herling Ruark 2011: 17)

While I agree that anthropologists should be more aligned with locally, driven, low cost, sustainable, culturally tailored responses, and I do not know many anthropologists who would publicly
disagree, I would like to point out that there would be lost opportunities to affect change for the better or to prevent further damages done if anthropologists decided only to apply their skills and expertise outside of the AIDS-industry. Biomedical research, pharmaceutical companies, hospitals, and clinics are not “bad” in and of themselves. Many social and health benefits come from these institutions. What is bad are the tentacles of power and the “gross” investment into these entities at the neglect and strangulation of more culturally tailored and indigenous perspectives. Being an anthropologist working within the biomedical context does not preclude being aligned with advocates for simple solutions. Given the “investments” that have already been made and will be implemented, anthropologists can play a key role to enter into the agendas of these institutions in order to “speak truth to power” from within, exploit the opportunity to reinvest from their own financial benefit into local initiatives, and create space for social, cultural, and behavioral reflection and discussion within these institutions. More importantly, they can support local professionals and intellectuals to counteract the negative consequences of a purely biomedical technological approach.

The contribution made by the “anthropologist” as the “cultural expert” is often perceived as the most important way in which anthropologists can influence current issues and problems. I would argue that “expert” should be accompanied well with humility and perhaps, even more, the charge of mediating perspectives and power differences. Supporting local critical-minded leaders is not as easy as it is often portrayed to be. The “low-hanging fruit” usually selected to serve as community representatives or “leaders” tend to be individuals seeking personal gain and not critical minded leaders. Furthermore, we are three generations in on the “Western-driven approaches,” that some local professionals, educated and building their careers under this paradigm, see as natural progress. Other individuals see themselves as critical and wanting to promote indigenous solutions, but trapped under the economic need for the presence of “western-driven approaches,” either biomedical, religious, or ideological (Epstein 2007, Pisano 2008, Green and Herling Ruark 2011). It is in this context that I would argue for the importance of anthropologists collaborating with professionals and intellectuals to interrogate each other’s assumptions, through conversations figuring out the best ways to navigate how to extract the best out of what we know
about HIV/AIDS (biomedical, best practices, evidence) while acknowledging that many homegrown solutions have never been measured. This dialogue and exchange of ideas between what is “known” by different parties has the potential to facilitate sustainable prevention approaches.

In order for this to happen, we would have to recognize that not all (many, but not all) anthropologists who work for well-funded agencies or even pharmaceutical companies are necessarily “handmaidens.” As Laura Nader pointed out generations ago, anthropologists find themselves much more comfortable studying the underdog, but it is beyond time to study up, down, and across. As Nader states:

> It is appropriate that a reinvented anthropology study powerful institutions and bureaucratic organizations such as food chains in the United States, for such institutions and their network systems affect our lives and also affect the lives of people that anthropologists have traditionally studied all around the world. It is particularly appropriate that anthropologists should lead the way in this work by virtue of a number of characteristics of our discipline. The study of man has had to be eclectic in its methods, broad in its vision of what it takes to understand man—his past, his present, his culture, his biology. We have specialized in understanding whole cultures in a cross-cultural context. We should, for example, be at home in studying the law firms as a secret society, in finding and analyzing the networks of power—which on paper may not be there, in describing those unwritten customary behaviors that are completely indispensable for understanding, for example, what makes congress tick. (Nader 1972: 9)

In all reality, the only way that a Western anthropologist can work in sub-Saharan Africa is because some entity outside of sub-Saharan Africa has the money and “interest” to fund them. It is sometimes implied that by studying the underdog, or going to the villages, an anthropologist’s “handmaidenship” is lessened. However, if the field anthropologists (insider or outsider) working in HIV/AIDS in Africa do not become equally comfortable with arguments and conversations with educated colleagues in hyper-endemic zones, and with the even more challenging global institutions and elites, the work of the “cultural expert” will be irrelevant and ineffective. The sub-Saharan hyper-endemic zones will only change when local professionals, intellectuals, indigenous leaders, and elites are given space as colleagues and as cultural experts whose ideas, even if fundamentally in opposition to outsiders, may make sense and have the flame to heighten local sensibilities about prevention. Good qualitative research forces all parties to listen to what people are saying, thinking, and doing. Both the questions asked and the
results attained, if interrogated well, can serve as points of illumination personally and socially for insider and outsider experts.

Unfortunately, in recent years rather than engaging in conversations, compromise, or dialogue, “experts” are digging trenches and fortifying defenses. Experts, including anthropologists, are putting each other in boxes. We form intellectual silos, where if you take the side of one of the debates previously discussed, you are automatically aligned and packaged to promote a particular stance on key debates. While there is perceived security in knowing who shares your ideologies and scientific convictions, the lack of exchange and respect for diverse ways of knowing and thinking stifles the potential fruits of compromise and synergy. We know the human need for categorization and for creating dichotomies; yet, we ignore the way this need limits the topics and ways that we do research. Risk reduction or elimination, limiting partners or using condoms, biomedical or indigenous, experts or community, scientific or participatory, we take stances on one side or the other, and all the positive changes that can happen for the good if we met in between are neglected. While we should not give up what we believe in, we can at least absorb those aspects that can fortify our research and work together more harmoniously. As critical thinking and dynamic social scientists, we are allowed to change ideas and perspectives along the way, based on evidence and experience, even if they do not correspond with perceived “packages.” Key to ongoing dialogue is to not only surround ourselves with like-minded ideas, but to inform ourselves of alternative ideas that may not nicely correspond with our “expertise.” The ultimate goal, whether it be as ‘handmaiden’, collaborator, or defender of the underdog, is that people be educated very clearly about HIV transmission, culturally contextualized senses of risk, the incurable nature of the disease, treatment that is available, the implications of being on medicines for treatment or prevention, and the ways of preventing transmission within their daily reality.

By providing expert solutions, we side-step the messy work of collaborative problem definition. This is not applicable to clinical research alone, but also to behavioral studies; we increase understanding of the social and cultural contributing factors but rarely is the public brought in to identify the right angle or action step to use what we have learned. For example, multiple studies were conducted in Lesotho to
confirm the reality and uncover the nuances surrounding the practice of having multiple and concurrent partners, but little was done to ask people the right angle to change behavior regarding MCP, involve traditional healers, ask how the behavior agrees or conflicts with religious and cultural teachings, identify if partner reduction education is needed, strengthen the message of using condoms with all partners all the time, or simply explain how MCP increases transmission.

In conclusion, nowhere in translation and dissemination research descriptions are the research team members discussed (NIH 2010; NIH 2004; Woolf 2008; Arrington, Kimmey et al. 2008; Callard, Rose et al. 2012; Wandersman, Duffy et al. 2008; IOM 1994; Mercy, Rosenberg et al. 1993), as if research is produced by robots and not by humans who along the way have their own observations and experience with the problem and the proposed solution. After conducting a thorough review of translation research and medicine, Callard, Rose, and colleagues (2012) call for a change in the way knowledge is created and advocate for greater involvement of the public and stakeholders in the knowledge creation loop. Based on this research, I would argue that, in addition to greater involvement of the public and stakeholders in translation research, there is also a need to include the “implementers” of research beyond that of the principal investigators: the research staff. There is a need to further conceptualize the role of the “research team” in the translation of research to practice paradigm. As evidenced in this study, team members are part of the larger social system. They have the potential to influence the formal dissemination of HIV prevention information into policy and programming as well as the informal diffusion into their own life and in the lives of those they encounter in their social network.
CHAPTER 12: CONCLUSION AND RECOMMENDATIONS

Anthropologist Sol Tax, founder of action anthropology, argued in the fifties that the generation of theoretical knowledge and the generation of solutions to practical problems should share equal status (Tax 1958; Tax 1975). This chapter of conclusions and recommendations seeks to give justice to the value of the interplay between anthropological practice and theory. The chapter begins by linking the dissertation to larger literature within anthropology as well as to other anthropologists working in Lesotho. The next section re-emphasizes key recommendations from this study and revisits propositions provided by other anthropologists specific to HIV sexual transmission prevention. The last section attempts to apply larger level theoretical perspectives to this specific project creating a grounded practice based theory of the problem in MCP information diffusion in Lesotho, and more importantly a vision on how to change.

12.1. Anthropology: Remaking the World

“If we make the world through social practice, we can unmake and remake the world through social practice” (Sherry Ortner 2016: 63)

This dissertation is an explicitly applied anthropological endeavor. While it may draw on interdisciplinary aspects of public health, clinical science, psychology, political economy, and communications the methodology and theoretical perspective are anthropological. For example, taking the same set of questions of understanding what happened to the MCP research findings and team members, a public health lens may focus predominantly on population-based outcomes, policy aspects or the researchers as a “work-force” impacting health sector productivity or absenteeism. A clinical lens may
try to associate the research experience with researcher’s individual biomarkers or follow up solely on how the findings relate to specific HIV biomedical, clinical settings or interventions. Similarly, psychological perspective would lean towards fixed individual measures. Communications may have looked at the diffusion of information focusing on the means and the sending and receiving messages but not the interrelationships between the individual, society and economy.

In this anthropological dissertation I take a holistic perspective of the human experience of how the findings weave their way (or not) into the individual and social fabrics of Lesotho within a specific, historical, social and economic context. In anthropology, unlike many other disciplines the problem determines one’s sub-disciplinary orientation. Specialist expertise and methodology are problem-solving tools, not ends in themselves (Bodley 2001). Thus, I have placed together different aspects of the problem that when left in disciplinary compartments do not convey the total social phenomenon. I have systematically focused on qualitative research both as a way of working in prevention or practice, as well as in its application as a traditional anthropological methodology using open semi-structured key informant and in-depth interviews. This qualitative method and elicitation of the type of honest and critical reflections are fruits of a rapport built over time, in the real world and not in a lab—key aspects distinguishing the anthropological application of qualitative methods as opposed to other disciplines. Furthermore, the lines of study and interaction with participant concerns developed after repeated and long-term work in the same country across different topical, geographical, social and economic contexts, yet another important feature of anthropological work.

My anthropological lens framing this study was highly influenced by theoretical work combining structural violence and political economy (Farmer 1992; Schepere-Hughes 1992), and anthropology of development (Ferguson 1990; Escobar 1995; Gardner and Lewis 2015) looking at how institutions and colonial legacies influence the every-day realities of the poor and oppressed. These anthropological theories uniting structural, political and economic perspectives on human biological and behavioral outcomes provided fruitful detailed links between negative structural aspects and the effects on individuals and populations, in particular the consequences of neoliberalism. This genre of work Ortner
describes as “dark anthropology” focusing on the harsh dimensions of social life (power, domination, inequality, and oppression) as well as the subjective experience of these dimensions. However, during my academic career, studies on “resiliency” were often criticized for inadvertently supporting structural injustices. And as a general impression, the concept of “positivity” and even “love” seemed to be treated with skepticism and cynicism in anthropology. While at the same time studies from psychology and medicine were demonstrating the role of positivity on individual and organizational outcomes. This study, much like other recent work in Anthropology is no longer satisfied with the documentation and recounting of the damage inflicted by health, economic and governmental neoliberalism, but is interested in showing how structures and institutions influence our daily reality while keeping a tune to the resilience, glimmers of hope and seeds of social action for transformative change. Sherry Ortner’s (2016) article reviewing trends in anthropology since the 1980s describes well a new type of anthropology of critique, resistance, and activism. She defines this as including both “cultural critique”—the critical study of the existing order—and studies that accentuate thinking about alternative political and economic futures (both “rethinking capitalism” and social movements) (Ortner 2016: 66). After a thorough review of both “dark anthropology” and new studies of the “anthropologies of the good” Ortner concludes by provoking a call for new directions in anthropology:

I would agree with scholars of the good life that the study of power and inequality, and the damage they do, cannot be the whole of anthropology. I would also agree with scholars of morality and ethics that it is important to look at the caring and ethical dimensions of human life, for what is the point of opposing neoliberalism if we cannot imagine better ways of living and better futures? How can we be both realistic about the ugly realities of the world today and hopeful about the possibilities of changing them (Ortner 2016: 60)?

It is within this new direction of anthropology that this dissertation finds its home in a balance of critique and hope by showing how domination by neoliberal biomedical and development aid paradigms within a context of unemployment, inequality and political instability has and is influencing the Basotho HIV response, while presenting lessons and visions for simple and transformative social changes.
12.1.1. Anthropological Contributions on action, work, aid and inequality in Lesotho and beyond

In discussing the success of Uganda’s initial response to the spread of HIV during the late 1990s, Epstein (2007) critically contrasts the public health model of international stakeholders leading the HIV response at the time with that of the local theory. The public health model focused on changing the behaviors of “high-risk” categories of sex workers and their clients, truck drivers, and soldiers. Meanwhile, the local, grassroots response in Uganda did not stress “target” groups but rather emphasized the shared social reality of HIV affecting everyone. Epstein argues:

Public health programs were supposed to be “rational” “budgeted,” and targeted at those groups thought to be most at risk. They were not supposed to be a free-for-all. But what WHO officials did not understand at the time was that there was a theory. It just wasn’t their theory. The intimate, personalized nature of Uganda’s early AIDS campaigns—the open discussions led by government field workers and in small groups of women and church goers, the compassionate work of the home-based care volunteers, the courage and strength of the women’s rights activists—helped people see AIDS not as a disease spread by disreputable high-risk groups or “others” but as shared calamity affecting everyone. This made discussion of sexual behavior possible without seeming preachy or prurient. Behavior change then became a matter of common sense. Maybe foreign public health officials missed this at the time because such “social mobilization” is actually quite hard to program. It is a spirit that flourishes when people come together to face a common threat. It is not something that can be packaged and paid for and then shipped around the world. (Epstein 2007: 167)

There is a vagueness to Epstein’s call for action, and in the case of Lesotho the “spirit” flourishing is not so simple or straightforward. Thirty years into the epidemic in Lesotho, when it comes to prevention, the active interests of outsiders leading the response, insider elite financial interests, and lack of general interest by most to change an embedded cultural norm complicate matters. As Fox argues when discussing the AIDS response in Southern Africa:

the success of these "grassroots" strategies hinges on spontaneous popular mobilization, especially at the local level, which has not so far manifested in Southern Africa where HIV continues to be viewed with extreme suspicion fueled by skepticism towards the intentions of Western donors. Ironically, Western donor attention to HIV, including in trying to mimic or recreate the Uganda experience, could inadvertently be stifling an indigenous response (Fox 2009: 160)

This results in a predicament: it appears that the scale is too heavy on the part of biomedical-technical outsider prevention programming, yet, there seems to be little hope in activating a genuine indigenous response. Western aid, for the immediate future, will and needs to continue. However in
working towards sustainable change, and freedom from “assistance,” more attention must be paid not only to “teaching how to fish rather than giving fish,” as one respondent stated, but also to giving space for “fishermen” to learn, try new things, make mistakes, supporting, and sustaining the change environment while learning how to “fish by themselves”. Having invested quite heavily in one approach, Western donors cannot simply walk out and say “ok, go fish, we’re out of here”. If stakeholders truly want to invigorate an indigenous response they have to navigate a middle ground of creating balanced economic, social, behavioral, and biomedical responses to the epidemic. In fact, anthropologists have long problematized the simplistic assumptions and paternalistic practices of training seminars and capacity building associated with “teaching how to fish” (Englund 2006). While Marxian scholars point out that despite the poor knowing how to fish the elite still control the means of production. Thus, change will not happen until the proletariat take over the productive centers (Wig 2016). Development anthropologist James Ferguson in his book Giving a Man Fish makes another argument that the problem is not that there are too few trained workers who “know how to fish” but rather there are too many workers for the economy to absorb(Ferguson 2015). Within the context of this study, the analogy runs in two parallel lines. In one stream for many working in HIV in Lesotho they are academically and skills qualified to fulfill a place in the wage labor market but there is no work. They go to whatever they can find to make a livelihood, the large influx of earmarked funding for HIV, including jobs like the MCP research project, play an integral role in occupying the excess work force and enticing the educated employed into higher waged HIV projects. Here in this context, training is typically project specific and based on promoting the paradigm dictated by biomedical and global donors and not local initiative and critical thinking. The subjective reality and relationship with HIV in Lesotho is undoubtedly linked to the role HIV plays in the economy both for work and as a point of receiving economic and social assistance (chapters 5, 6, and 10). This dissertation brings to light the consequences of a system of aid that is exasperating problems of inequality and fostering a subjective resistance to dealing with social and cultural dimensions of transmission in need of change. Thus provoking deeper questions of the value of work, the consequences of aid and the redistribution of in country wealth.
Several recent anthropologists studying HIV in Lesotho have documented the problem of inequalities, unsustainable development, the stifling of local participation, problems in “democracy”, corruption, and a perverse globalized presence (Kenworthy 2014a; Kenworthy 2014b; Bulled 2012; Workman 2012; Block 2012; Wig: 2016). Kenworthy (2014) studied a decentralization participatory HIV project funded by an outside agency, that attempted to provide a structure where communities could select from a list of HIV-related priorities what they wanted to focus on and then receive technical support in implementing different essential service packages (Kenworthy 2014a; Kenworthy 2014b). On paper, this was a seemingly participatory and decentralized approach. However, the program was created by significant foreign donor momentum and implemented by using local employees to piggyback on internal state mechanisms. The role of the “state” in a national wide program was “consultative”; that is, external stakeholders considered the National AIDS Commission’s knowledge and interest, but outsiders defined the problem and solution, Kenworthy points out:

Yet for many of my informants in Lesotho, the problem with HIV programming is not that it reaches too far into their lives, but that HIV represents a retreat of the state, its eclipse by NGOs and donors and its absence from public discourse with citizens – even as it became more and more accountable to external partners (Kenworthy 2014a).

There is a need to “study up” to go beyond “the politics of HIV at the level of biological intrusions and interventions” (Kenworthy 2014a: 6) by looking at the influence this outsider-driven HIV scale-up had on the agency, subjectivity, and forms of public life. While there were genuine good intentions to mobilize and build a democracy, this push from “HIV’s global activist legacies” struggled to align with Lesotho’s domestic realities, and “in particular, the predominant logics of good governance and the lack of vibrant public mobilizations for HIV services” (Kenworthy 2014a: 28). Similar to what happened with my own research, Kenworthy set out to evaluate the participatory project but ended by a call to action to “study up” the undemocratic global health practices in Lesotho dictating what is important and how to respond:

Rather than speak about democracy, we must speak about power: the fix will arise not from changes or clarifications of procedural rules or technical mandates, but out of the recognition of truly undemocratic inequities in global health practice. To continue to use the language of
democratization in initiatives that fail to address fundamental inequities between communities and institutions is to conceal the undemocratic tendencies in largely well-meaning global health approaches (Kenworthy 2014a: 17).

Likewise, problems of inequality, ideas of corruption, and some people getting rich created a reluctance to engage and participate (ibid). Even in cases where there was truly no one getting money or becoming rich, the precedence of HIV mobilization associated with employment or getting something in return tended to undermine attempts by program implementers to stimulate a “community” based response. Bulled (2012) also discussed the negative impact of modernity and consumerism on risk perception and behaviors. Like Kenworthy and I, Bulled provides several examples of the repulsion people demonstrated at perceived inequality concluding that “individuals are intimately connected with their social networks and equality is the established norm” (Bulled 2012: 322).

Workman’s (2012) study on food security, water, and HIV also comes to the same conclusion of the compounded problem of years of outsider “development” in Lesotho. Workman writes:

Considering all these conflicting accounts and assertions about programs suddenly ending without notice, there seems to be an obvious and problematic lack of sustainability of development programs in Lesotho. This lack of sustainability explains, in part, why people seemed disinterested in development programs and could not describe specific programs in their communities. The findings suggest that people are experiencing “development fatigue,” that is, there is little incentive for them to participate in programs, as the program’s long-term goals are unclear and they are unlikely to remain in place. This is perfectly captured in the following respondent’s assessment: “At the moment the agriculture center isn’t functioning, I never participated but I heard they were doing well. I’m not interested in farming…Maybe it would interest me if it were sustainable. Things come and shut down.” (Workman 2012: 328).

All of these recent studies by “outsider” anthropologists examining different aspects of the epidemic point to the need to pay particular attention to the role of outsider intervention in the local reality of Lesotho. Block (2012) writes about a holistic study on kinship and care taking in rural Lesotho. Like my research in 2007 (Watson Lai, Mpemi et al. 2008), and the participants in this study, she recommends further attention to the ways aid is distributed in Lesotho:

Future comparative research projects should focus on the ways in which local populations are divided and often stigmatized because of the assistance of CBOs, the unequal and exclusionary provision of services and the ways that people present and identify themselves to make claims about their eligibility for services. (Block 2012: 356)
She also points out the need to pay attention to power dynamics within country as well as those brought in by outside researchers. Quoting Razack, Block discusses the unintended consequences of work in the developing world, “Many social workers share the ideals of global justice and human rights…Some are more conscious of the limitations of their subject positions in local and global space. The power and privilege of whiteness in Southern space can interfere with their original intent to practice global justice and human rights” (Razack 2009) quoted in (Block 2012: 51). Block’s recommendations for intervention included self-reflexivity, awareness of position and of the impact that “whiteness” has on the Other, a theme also repeated by participants in this study (see Chapter 10). Block considers this type of power difference reduction pertinent not only during fieldwork but also while writing and providing intervention recommendations.

As shown in Chapter 10 people in Lesotho have become quite savvy in using the influx of development aid, not necessarily agreeing or having power to invest the aid as they may see fit, but to make the best out of funds that are often not sufficient. Sometimes this takes the form of corruption, getting what you can for yourself, and in others a type of Robin Hooding. Anthropologist Ståle Wig, in his work studying development in Lesotho describes this alternative use of aid money for a “training” in Lesotho:

Contradicting the proverb, the participants seemed to care little about being taught ‘how to fish’. What mattered was the fish: the meals served during breaks, and the ‘transport reimbursements’ which ought to cover costs of getting to the workshop. Ought to, that is. In reality, such ‘reimbursements’ functioned as a cash grant. At the end of each workshop, participants would line up to receive bus and taxi money – only to proceed to walk long journeys on foot back to their homes in neighboring villages. The local NGO professionals celebrated how they could distribute money to the poor in this way, under the radar. They complained, however, that the amounts they were able to extract were insufficient. ‘We need to give them something more. Something they can touch!’(Wig 2016: 512)

Example, after example from Lesotho indicates that there is not enough work, people need money and they will, as one participant described the problem, “end up going to anything that comes around, ok and then just doing it to get money” or packages and services. The problem in Lesotho is part of a
regional problem, Ferguson quotes a South African social researcher who suggests that 10 million citizens can drop dead without making a ripple on the Johannesburg stock exchange. Large populations in Southern Africa, as well as in much of the world, are ‘simply left out of the global production regime’ (Ferguson 2015: 90). According to some measures it is estimated that in Africa only every fourth able-bodied has steady paid jobs (Fine, van Wamelen et al. 2012)(in Wig 2016). Ferguson describes the development goal of total employment as a ‘vanishing dream’(Ferguson 2015: 51). As seen in this dissertation, money given in the form of traditional aid is either through temporary projects, targeted at specific groups and often tied to some action or offered for a limited period. Cash transfers, HIV projects linked to economic empowerment, and entrepreneurship may be good in the short run BUT an indigenous vision for sustainable changes in creating work in various sectors must be a priority. Furthermore, there must be space for local leaders and activists to envision the quality and form of “the good life” that may not align with globalized Western interests or conventional thinking. There are current debates about the massive quantity of money invested for HIV and Health Service Strengthening that are provoking new ways of envisioning the future. For example, young leaders from all over the world are mobilizing to create an international research division for people not for profit (UAEM 2016) challenging norms of patent protections and the high costs of medicines. Anti-corruption movements and popular demands for transparency and accountability are increasing (ACI 2015; AFP 2015).

Facing the vast growing inequities between the rich and the poor and the steadily increasing lack of employment opportunities worldwide discussions on the investment in “citizen checks” or a basic income for all citizens is gaining momentum (Lowrey 2013; Boffey 2015; Coelho 2016; O'Farrell 2016). As participants in this study suggested rather than social support based on sero-status perhaps an implementation of a basic income or a social dividend of the wealth from in country resources could eliminate poverty, promote entrepreneurship and increase employment (BIG 2004; Lechesa 2011).

Development anthropologist Ferguson’s book, *Give a Man Fish*, brings together arguments and examples from all over the world about what he describes as a new “politics of distribution”. Ferguson draws on examples from countries as diverse as Alaska, Norway, Iran, Brazil, Switzerland and South Africa
documenting the different ways that wealth from mineral extraction, oil, environmental payments based on climate justice are being distributed back to populations in non-conventional ways that are based not on welfare, or labor but as a right attached to membership in a society. A region-wide campaign across the entire Southern African Development Community sums up the argument well with the slogan ‘Our Right – Our Wealth – Our Share’ (Ferguson 2015:183). Wheels are turning, incremental steps are being taken in various countries moving closer to new rights or “share” based mechanisms of distribution and social protection. Ferguson points out that something new and different is on the horizon:

Such a development, if it occurs, will not be led by a new vanguard class (whether “precariat,” “multitude,” or any other) that might take over the role of mystical protagonist long played by the proletariat in Leftist imaginings, nor will it be founded on the centrality or universality of wage labor. But neither will it have much to do with the “welfare” of old, with its breadwinners and dependents, its safety nets and insurance mechanisms. What it will look like is up for grabs (208).

Todd Moss writing for the Washington DC think tank Center for Global Development argues that profits from natural resources extracted should be given back directly to the population through a check, rather than going through government channels which have proven to be inefficient and often corrupt (Moss 2012), as has been documented in Lesotho. For the case of Lesotho the “rightful share” argument could be extended to the diamonds, casinos, hydro-electricity and water but not only, a perspective that Ferguson does not present in his book, what about the bodies, the pharmaceutical and health technology research that was done in Lesotho that later was translated into profits on international markets—do Basotho have an unclaimed “right” to these profits? What about the interest raised in international AID funds and accounts? Furthermore, based on the nature of profits arising from foreign international entities and not states perhaps more direct –share based redistribution straight to individuals regardless of “participation” or “sero-status” may boost the development of the local economy.

Ideas supporting bringing an end to stifling inequality and redistribution are coming from the global North and South as well as across very different sectors of power. Pope Francis has strongly argued that, “just as the commandment "Thou shalt not kill" sets a clear limit in order to safeguard the value of human life, today we also have to say "thou shalt not" to an economy of exclusion and
inequality. Such an economy kills” (Bergoglio 2013: 53) and furthermore that, “the private ownership of goods is justified by the need to protect and increase them, so that they can better serve the common good; for this reason, solidarity must be lived as the decision to restore to the poor what belongs to them” (ibid: 189). He makes the plea that we should be “scandalized because we know that there is enough food for everyone and that hunger is the result of a poor distribution of goods and income” (ibid: 191). With this lens, it is not about charity but returning what is due amidst a global economy continually increasing profits without generating “work” in the traditional sense. Ferguson describes this, as “a vision of direct distribution not as a charity but as liberation, and of the daily lives of the “unemployed” and grant-supported poor not as some lamentable warren of idleness, lack, and incapacity but as a domain of deeply knowledgeable, sometimes joyous, and socially and economically valuable (Ferguson 2015: 203). From being able to re-invest what is given into pursuing entrepreneur dreams, artistic ventures to compensating activities in society that are undervalued and frequently performed by women. In taking off certain limits of eligibility and distributing to a wider constituency you can include, and thereby give economic value, to what feminist literature describes as “practices of care” (care for children, those with special needs, the sick and elderly) as an integral part of societal membership and “among the most important ways that citizens in fact contribute to society” (ibid: 205). Thus expanding contribution to society beyond terms of paid labor but to acknowledge the universal societal importance of “care” work, not confined to the family but in its contribution to the larger social and economic system (Sevenhuijsen 1998; Spiegel 2005; Ferguson 2015).

Arguments for new forms of distribution are not dreamy ideals but are already experimental facts playing out all over the world in rich and poor contexts. Important for Lesotho, is that it’s all encompassing neighbor, South Africa has been moving steadily, under the radar, towards the elimination of “income insufficiency”, regardless of the cause while increasing income support, thereby moving closer toward a type of universalistic citizenship-based entitlement (Ferguson 2015: 204). Ferguson’s ethnographic work with The South African Department of Social Development discusses the gradual transitions in the past decade from removing the “means test” from established child support, disables and
pensions, the inclusion of “job seeking” men between the ages 18-24, as well as pre-retirement grant for unemployed adults 45-59. Ferguson points out that the only category remaining would be non-disabled adults aged 25-44 yet there was a grant proposed targeting those not covered by unemployment. While not officially claiming a new form of entitlement distribution, South African Social Policies are taking steady and incremental steps in that direction. Applying new forms of distribution in Lesotho is not a radical delusion, as seen in the way it is already being explored in neighboring countries and other parts of the world, but a sensible alternative to the current practices aggravating inequality in the country.

12.1.1.1. Investing in Change: Resilience the Bridge Between Humanitarian and Development Aid

As mentioned previously, the concept of “resilience” is gaining momentum across academic disciplines as well as in the world of practice. With this momentum, there is growing discussion around how to define and empirically measure the phenomenon of resilience. In the world of “practice”, over the last twenty years, the concept of resilience, or resilience building by humanitarian and development efforts is steadily growing. It is a widely used term that has the institutional support of the Hyogo Framework for Action (2005-2015) and the Sendai Framework for Disaster Risk Reduction (2015-2030) which are international documents adopted by UN member states to address disaster risk and climate change adaptation (UNISDR 2017a; UNISDR 2017b). The UN International Strategy for Disaster Reduction defines resilience as “the ability of a system, community or society exposed to hazards to resist, absorb, accommodate to and recover from the effects of a hazard in a timely and efficient manner” (UNISDR 2017). While, the Intergovernmental Panel on Climate Change, more simply describes resilience as “the amount of change a system can undergo without changing state” (IPCC 2017). The UK Department for International Development defines it as “the ability of countries, communities and households to manage change, by maintaining or transforming living standards in the face of shocks or stresses… without compromising their long-term prospects” (DFID 2011). Similarly the UNDP is defining resistance as a “transformative process of strengthening the capacity of people, communities and countries to anticipate, manage, recover and transform from shocks” (UNDP 2016). The insertion of the
concept of transforming and process, in these latter two definitions differ from the other definitions in that they imply the idea of “building back better” and an ongoing process. This expansion of the definition subtly blurs the lines between reacting to a humanitarian crisis and the longer-term work of development visions and programs.

Simon Levine, a researcher with the Overseas Development Institute (ODI), believes that the discussions and workshops on resilience among humanitarian aid groups is focusing more and more in “building back better” and attempting to prevent crisis from recurring. Levine argues that this “puts the accent in the wrong place… the real driver behind the resilience agenda ought to be the realization that the job of ‘development aid’ is to prevent people falling into crisis” (Jaspreet 2013). Unfortunately, across problems be that flood, famine or HIV, there is a great divide between the humanitarian and development response. There are different languages of measurement and standards for evidence about resilience between the humanitarian and development response and it would take a significant change by big donors to put into implementable steps the bridge between immediate crisis reaction and sustainable/transformative change.

Within academia, there are interdisciplinary discussions on the definitions, theory and challenges surrounding the concept of resilience (Southwick, Bonanno et al. 2014). Neuroscientist Dr. Rachel Yehuda, who specializes in epigenetics and the study of PTSD, describes a transition based on empirical evidence of resilience not being a dichotic category of something a trauma survivor has or does not have. For example, one of her studies first divided trauma survivors in two groups, those who had PTSD and those who did not. However, as they gathered data they found, there were those non-PTSD survivors who had actually had PTSD or other symptoms but who no longer had symptoms and had bounced back (Yehuda and Flory 2007; Yehuda, Bierer et al. 2010; Yehuda, Daskalakis et al. 2013). Thus, a resilient person was not necessarily someone who inherently was resistant to the primary shock but also included those that may at first response not have been “resilient”, but later lost symptoms and appeared “resilient”. Drawing on her experiences with people who had experienced catastrophic events such as the holocaust, famine, war and 9/11, she attributes the best definition of resilience to a Timex commercial:
The watch was described as having the ability to “take a licking and keep on ticking” ... but for a person, perhaps it is better to conceptualize resilience as a process of moving forward and not returning back... a reintegration of self that includes a conscious effort to move forward in an insightful integrated positive manner as a result of lessons learned from an adverse experience... this notion recognizes that some of the most resilient people may have had or still have very severe PTSD that they struggle with every day. But they don’t succumb to its negative effects... resilience involves an active decision, like sobriety, that must be frequently reconfirmed. That decision is to keep moving forward (Southwick, Bonanno et al. 2014).

Anthropologist, Catherine Panter-Brick studies risk, resilience and health in settings of violence and poverty (Panter-Brick 2014a) in various contexts including people experiencing famine in Niger, homeless street-children in Nepal, and citizens of post war Afghanistan (Panter-Brick, Goodman et al. 2011; Panter-Brick, Grimon et al. 2014b). Having worked with many humanitarian organizations, she understands their frustration in supporting the rhetoric of resilience but having a rather weak toolkit to measure and evaluate it. Panter-Brick notes how some researchers in attempts to find a cross cultural and disciplinary definition of resilience argue to keep it simple. She however warns of the three deadly sins of resilience research as being conceptually hazy, empirically light, and methodologically lame (Panter-Brick and Leckman 2013). Her definition of resilience is a process to harness resources to sustain well-being. “Process” because it is not an attribute or a capacity, “resources” because it implies that researchers identify what are the most relevant resources for people in each specific context and “sustained well-being” because it encompasses a broad notion rather than a narrow definition of health or the absence of pathology (Panter-Brick and Leckman 2013). Based on her work interviewing over a thousand families in Afghanistan, including youth and adults, she synthesizes the concept of resilience down to one word, hope. For these Afghan families she found that:

The future matters much more than the past in determining their present well-being: being able to get up each day and go harness resources toward securing a better future matters more than the turmoil and traumas of the past... what makes some families more resilient than others is their ability to hang on to a sense of hope that gives meaning and order to suffering in life and helps to articulate a coherent narrative to link the future to the past and present... a sense of hope that life does indeed make sense, despite chaos, brutality, stress, worry, or despair (Southwick, Bonanno et al. 2014).
With this lens, Panter-Brick argues, that in designing interventions the “arrow of change” can be pointed from the social to behavioral or development outcomes, so rather than tinkering with individual capacities to cope, the level of change needed is at the societal-level blocking the individuals opportunities to seek out a better life (Eggerman and Panter-Brick 2010; Panter-Brick and Eggerman 2012; Reed, Fazel et al. 2012). She describes this as turning towards thinking about “structural resilience” where the focus is on “building robust structures in society that provide people with the wherewithal to make a living, secure housing, access good education and health care and realize their human potential” (Ager, Annan et al. 2013).

Psychologist George Bonanno in his twenty years of work leading research teams studying how humans cope with extreme life events, loss, and potential trauma, has determined that there are five basic categories of factors that predict a minimal-impact trajectory or a stable trajectory of healthy functioning (Bonanno and Diminich 2013). This trajectory showing consistently low levels of distress and symptoms or consistently positive adjustment, both before and after the occurrence of a potentially traumatic event (PTE) point to five important factors including social resources, personality, genetic factors, demographics and economic resources (Bonanno, Westphal et al. 2011). Bonanno’s empirical modelling shows that no single one of these factors has been shown to predict or enhance resilience by more than a small degree (Southwick, Bonanno et al. 2014). However, Bonanno notes that economic resources have been highlighted as key in resilience for a number of years (Hobfoll, Watson et al. 2007), yet despite their importance they are often neglected, “they’re basic, not quite as sexy, and building resources costs a lot of money” (Southwick, Bonanno et al. 2014). In my review of the literature research tends to target personality, genes, social capital, and in the case of HIV dealing with the immediate medical and care-taking response (treatment, biomedical prevention such as PMTCT and PrEP, orphans/vulnerable children).

IRIN news reporter, Tawanda Majoni, exploring the impact of climate change on the food security and livelihoods of small-scale farmers in Kenya, Nigeria, Senegal and Zimbabwe, points out that while “the goals of addressing the underlying vulnerabilities that lead to humanitarian crisis are laudable,
it has proved difficult to fully harness as an organizing principle” (Majoni 2017). She clarifies that putting these goals into action means focusing on the grassroots level and necessitates the slow, often tedious and resource intensive investment in local consultation, in order to understand why people are at risk. And furthermore, taking this knowledge gained and facilitating the necessary inter-agency collaboration to deliver interventions that address holistically the local needs identified (Majoni 2017).

Top-down, regional, “cookie-cutter” responses cannot do this. Research fellow Christophe Béné, with the Institute of Development Studies, working on vulnerability and poverty reduction, argues that the current expansion and over-emphasis on resilience is unintentionally pushing policy makers in the wrong direction. He points out that:

Resilience is a very technical, neutral, apolitical term. It was initially designed to characterize systems, and it doesn’t address power, equity or agency… also, strengthening resilience is not free - you can have some winners and some losers…The question becomes ‘do you want to strengthen the resilience of a community or improve its well-being’? It’s not necessarily the same thing (IRIN 2012).

The lack of taking into account issues of power, equity and agency results in development experts focusing on the effects of shocks while overlooking root causes which are often closely linked to unequal power dynamics. Another researcher at the Institute of Development Studies, Terry Cannon, argues that this omission makes the concept of resilience seductive for institutions and donors who do not want to engage in controversial and often political issues of inequity (IRIN 2012). Oxfam humanitarian advisor Debbie Hillier posits that debates about the definition of resilience are irrelevant on the ground but she too advocates for greater linkages between the humanitarian response and development schemes:

When we are talking about the Horn of Africa or the Sahel, we all know what resilience means. It’s about not having to do repeated humanitarian interventions. It’s about bringing the humanitarian and development sides much closer, and making people much less vulnerable…Most poor people have an incredible drive to get out of poverty, but they keep getting knocked back by shocks. We have to act on the root causes of their vulnerability, and not just make people better able to bear their effects. If our work doesn’t do that, it’s not useful. That’s what real resilience is about (IRIN 2012).

In this dissertation research, I see these changes in conceptualizing resilience as closely linked to both the theoretical and practical way of shifting from what Ortner describes the Anthropology of the dark
towards the anthropology of the good. Resilience as previously criticized as supporting the status quo, these scientists are actually offering new perspectives based on empirical evidence, that help in moving from (dark anthropology) cultural critique, or the critical study of the existing order, towards documenting and engaging in alternative political and economic possibilities (good anthropology) (Ortner 2016). These scientists and practitioners do this by bringing into light resilience as a process, with multiple trajectories that can be measured, and are influenced by access to resources (emotive and physical). Rather than resilience as seeing how far an organism, individual, group, state, economy can resist collapse in the midst of crisis or shocks these new definitions are challenging what is considered healthy, adaptive or a state of equilibrium. Pantor-Brick, Tehuda, Hillier, and Béné, in their definitions of resilience all underline that academics and practitioners cannot use abstract conceptions of resilience to mask root causes, that resilience is not about accepting the status quo but dealing with the root obstacles, building the resources to move forward, and creating a better life (IRIN 2012; Southwick, Bonanno et al. 2014; Majoni 2017). Thereby pointing to both the need for a critical study of the existing order of power and economy but also to practical steps in measuring and envisioning new possibilities for how people may respond to crisis.

This of course sounds complicated, and perhaps makes it easy for both humanitarian and development institutions and experts to step back and say that is not part of our mandate. However, there are several recent examples of innovative responses that are indeed challenging controversial root causes, experimenting with alternative funding mechanisms and putting under scrutiny the very relevance of large international organizations in (Maclean 2014; Parker 2017). For example, in flood prone Jakarta, the NGO Mercy Corps started by seeking to understand what were the main problems of the lived experience of these repeated floods (Maclean 2014). They found that illnesses related to the feces people waded through in densely populated flood areas as a significant issue. They launched a holistic response that included working in communities to raise awareness about septic tanks at the individual home level and then campaigned the municipal government to install larger tanks so the household tanks could be deposited regularly. Rather than leaving the community to depend on the NGO or the government to
maintain the new system, Mercy Corps provided microcredit loans to create work through small entrepreneurs opening private waste control services to transport waste from the small tanks to the big central tank. In this case the initial stimulus was supported by outsider funding but the success of the project was in local ownership and the creation of a resource generating opportunity for the community—resources such as not dealing with the risk of feces borne illnesses as well as the generation of work and income for some community members (Maclean 2014). Obviously, NGO’s work on limited budgets and oftentimes communities lack the initial funding and support to deal with root problems. In the case of this project, scaling up of the approach was supported by the Swedish retailer, IKEA which pledged to fund the installation of additional septic tanks over several years. The NGO served as a bridge between locals who needed access to resources with that of a large international company. Whether IKEA sources some of its wood from Indonesia, or just needed good public relations to promote their trademark in the consumer market of 240 million people (Esler 2012; Koenig 2016), the relationship between local communities and this global giant served to redistribute some of the IKEA profits made from Indonesia. This all demonstrating the inter-agency private, public, global and local collaboration needed to achieve an end that neither could have done on its own.

In fact, the concept of “resilience” like the problem of HIV, is generating new attention towards private-public partnerships and new funding mechanisms. The notion of “investing” in resilience is similar to “investing” in the HIV response because they are both utilizing private funds to be pooled into investment funds to build money for the cause and the donor. For example in 2006 US $583 million of emergency aid was channeled through pooled funds by 2011 this was $900 million during this period it was not only the amount given that increased but more importantly the number of smaller donors joining the pooled fund (Parker 2017). Again, similar to the HIV response, resilience and humanitarian work making “good investment sense”. Within this context the significance of banks and investment groups is gaining in importance for large donors while the traditional role of international organizations and NGO’s is being challenged. For example, the EU and Britain recently proposed a new system for an $85 million project to simplify cash allowances for Syrian refugees in Lebanon (Parker 2017). The proposal is to have
only one contractor who will handle the payments and another that will monitor the project thereby replacing systems involving nine aid agencies. The project transitions to the use of direct cash rather than the traditional e-voucher system. Simply put, the ECHO-DFID partnership proposes to increase the “fund base” while cutting out intermediary IGO’s and NGO’s to provide cash directly to affected people. The below image taken from the ECHO-DFID presentation demonstrates this streamlining (Figure 34).

![Cost Efficiency and Cost-Effectiveness](image)

*Figure 34: Slide from DFID-ECHO presentation “If not now, when?” describing the need for a single contractor and independent operational, monitoring and evaluation mechanisms (Parker 2017). Copyright ©DFID / EU_ECHO reprinted with permission.*

A recent evaluation of the EU/ Britain Lebanon project found that refugees preferred pure cash and ate a better and more varied diet than those using the preferred World Food Program food e-vouchers redeemable at approved shops. Nick van Praag from the organization Ground Truth Solutions argues that there is an “enormous amount at stake” that cash is enabling a broader change in the aid system that will “winnow out” aid agencies and their roles. In his opinion aid agencies must “stop haggling about modalities” and instead focus on the needs and opinions of the people on the ground about the aid packages they receive (Parker 2017). Proponents of the plan argue that resistance to this new approach stems from “aid agencies’ self-interested fear of reduced turnover, influence and relevance. Big UN agencies specialize be it on children, food, health or refugees. Multipurpose cash undermines their
operational models and cuts across their mandates. These silos of the current system make for political barriers to change” (Parker 2017).

Opponents of the system argue that the move to implement the approach is going ahead too fast without enough evidence supporting the benefits of the approach. And furthermore, that the diversity and the fruits of comprehensive coordinated efforts by several agencies collaborating will be lost by the single agency provider modality (Parker 2017). Other critics claim that there will be a drop in the overall quality and sophistication of services provided to people in need and that the new system concentrates power in the agencies big enough to bid and will by default create a monopoly. The EU’s ECHO and Britain’s DFID, deny that the project is a model or a blueprint for wider changes across different settings. However, some sources interviewed by IRIN Head of Enterprise journalist Ben Parker, close to the process noted how this project can have a potential “global effect” and may be the beginning of “a new humanitarian order” (Parker 2017).

It is clear that “investing in change” in the humanitarian and development sector is becoming increasingly complex. Arturo Escobar is sometimes hailed and criticized for his strong position on imagining the end of development or a post-development world (Escobar 1995; Gardner and Lewis 2015). I lean more towards Escobar that we are indeed at a crossroads where humanitarian aid and development of the past no longer suffices and will be transformed. Looking around at the current political climate state to state, and even large international organization aid and development are decreasing funding allocations (Quinn 2017). There is also a large movement by some traditional donors towards retreating looking out for one’s national interest and keeping others out—be it countries or markets (Hughes 2016; Cameron 2017; Quinn 2017; Wintour 2017). At the same time, there is a frustration by aid recipients to have more autonomy and flexibility in the way foreign controlled help is implemented. In this dissertation, this frustration is seen in research team members describing the power of donors who dictate what should happen, when, and how to measure change. They articulated how foreign entities in Lesotho fostered a cycle of dependency rather than local innovation to the HIV response. One participant when asked what she would tell the donor community responded in frustration
by saying, I'm really tempted to say “go away.” Others remarked how the “professionalization” and the attachment of HIV to benefits has fostered a tune out “not my problem” attitude and a resentment of the message about HIV itself when it comes from artist and leaders paid to be champions. One participant noted how some people are coming to terms with HIV as something “for the people” because at least it provides benefits based on sero-status, while others described the disturbing trend of people seeking out HIV and TB so as to qualify for NGO benefits. Furthermore, the over emphasis on prophylactically preventing HIV through condoms and now PrEP may unintentionally be increasing less cautious behaviors, such as reporting an increase in condom usage, but with more partners and not necessarily all the time. These conflicting encounters with the HIV response is fostering a distancing from talking and dealing with the problem of HIV at a personal and social level. All of these things come together to undermine people’s natural resilience, as described by Bonanno & Burton 2013, to read the situation in their context, critically think about their repertoire of behaviors and putting into place corrective feedback to regroup and come up with their own solutions (Bonanno and Burton 2013).

These new definitions of resilience have stressed that humans are indeed “endowed with great potential to weather adversity and to change or adapt when necessary, but they need basic social and material resources to do so” (Southwick, Bonanno et al. 2014: 12). Which brings us to back to the current debates on cash transfers and streamlining aid mechanisms. What is the best way to invest in change? Based on this research there is a need for a “new humanitarian era” in Lesotho. I somewhat agree with streamlining aid mechanisms and implementing more direct transfers of economic assistance. However, doing this without dealing with the underlying issues of inequality and political instability is a recipe for disaster. Furthermore, cutting out different organizations and increasing the “fund base” may result in a greater return on investment for the donors, seemingly more money going to more people but less sustainable change. Giving out money without supporting the creation of work, helping people in finding work or expanding their current activities may exacerbate vulnerability and dependency in Lesotho. On account of previous development and support efforts, there is a large and growing level of educated professionals. The future of aid and development organizational collaboration in Lesotho must move from
a philosophy of top-down, we are here to save you because you cannot do it yourself to that of true collaboration as equals. This entails exchanging knowledge and technology on the nuances of HIV, agriculture, nutrition and climate change. However, there are still many people in the population who build flexibility and resistance to vulnerabilities through the assistance, exposure and experiences provided by non-profit organizations. Furthermore, the long-term shift in “aid” and financing must encompass an intentional sharing of access to economic opportunities on the global market such as; preferential trade agreements, opening access to shares and investment funds, repatriating profits of research conducted in Lesotho, supporting transparency and anti-corruption efforts, ensuring corporate and especially government responsibility in the redistribution of profits made from natural resources (water, diamonds, bodies) and industries (textile industry, casinos, cell phones, border tax) in Lesotho.

12.1.2. Listen and Act

People keep saying we need work. Social scientist study, document the problems of poverty and inequality and then keep asking about AIDS. It is time for serious engagement in larger questions and debates, like this, about the value of work in society. If we can spend $112 million on condoms and support billions in Health Systems Strengthening and Health infrastructure in Lesotho—we need to face the reality and see in what ways this foreign aid is helping and in what ways this foreign aid is “helping” the American economy and the pharmaceutical industry and may be at the harm of the local reality. Fingers are not only pointing to outsiders, if individuals in the country are accumulating wealth from national resources (development projects, border tax, diamonds, water, and bodies) it is past time to investigate where that money is invested and spent. Investing in the invisible market may create profit, but it is also important that a country that has the highest GINI indication of inequality, invests in generating the dignity of work or alternative forms of distribution so that people can provide for the “family” (not necessarily nuclear) and the community.

This dissertation has shown how the association of HIV with inequality, corruption, and a highly structured and Western dominated biomedical response confines local conceptions and the response to the
disease. Yet, some may still argue that these are peripheral issues to the study question of the diffusion of information about MCP and the utility of the qualitative research experience for prevention. I would argue that these are not tangential but fundamental issues for understanding why things are the way they are in Lesotho and what new ways of thinking and working are needed to change the situation. In his review of anthropological studies on corruption for the European Commission, Davide Torsello notes the difficulty in setting out to study corruption and larger level dynamics in real world environments and the reality that most anthropologists “happen upon” these dynamics while the primary study objective is something else (Torsello 2014). Whether it be light corruption of witnessing earmarked funding “redistributed” in another way, or gross corruption of money laundering, development aid siphoned to investment banking for dividends to the philanthropists, or “aid” invested in projects that profit the donor country and not the locals…anthropologists happen upon these things and face the choice to ignore or act. When posing the problem of the practice/theory divide, we often leave the divide between unintended results and the intended research proposition confined to the micro and meso levels. As Peter Little (Hill and Baba 2000: 126) has argued, Northern hemisphere scholars “comfortably distance themselves” from practice and policy focusing on intellectual concerns of their own interests. Little has repeatedly pointed out the difference between northern and southern scholars where for the latter, “selective distancing is not…an option for social scientists who are, with rare exceptions, immersed in the popular struggles of their countries whether they wish to be or not” (Little and Painter 1995: 606). Oftentimes, volatile situations at the macro level in “southern” research sites that may relate to the topic of study are conveniently deemed not directly related to the research question “of interest.” Northern researchers can then justify themselves in not dabbling into macro issues, while furthering their own micro level professional specialty areas “of interest”. Little quotes Appadurai: “Is there a principled way to close the gap between U.S. social scientists, who are suspicious of any form of applied or policy-driven research and social scientists from many other parts of the world who see themselves as profoundly involved in the social transformations sweeping their own societies?” (Appadurai 1997: 59). While Laura Nader (2000) in the NAPA bulletin preface provocatively asserts:
University professors in the United States are peculiar in the separation they make between theory and practice, between private and public careers, between their professional lives and their concerns as citizens. Pick any part of the world—Latin America, Europe, Asia, the Middle East—and the picture is different because intellectuals qua intellectuals are expected to participate in large questions, and they do so even if such activity lands them in prison (Nader 2000: 1).

The dominance of US and Western-funded practice and research within Lesotho may unfortunately stifle the voice and growth of intellectuals willing to participate critically in large questions and radical social transformations. There is a strange dynamic by training and providing jobs for experts, leaders, and intellectuals, which suppresses social consciousness against seeing the deeper harm being done by these structures. This is not just a theoretical problem but also a practical issue that leaves these individuals with less time to explore alternative pathways. Gramsci describes this tension:

The active man-in-the-mass has a practical activity, but has no clear theoretical consciousness of his practical activity, which nonetheless involves understanding the world in so far as it transforms it. His theoretical consciousness can indeed be historically in opposition to his activity. One might almost say that he has two theoretical consciousness, or one contradictory consciousness: one which is implicit in his activity and which in reality unites him with his fellow-workers in the practical transformation of the real world; and one, superficially explicit or verbal, which he has inherited from the past and uncritically absorbed. But this verbal conception influences conduct and the direction of will, often powerfully enough to produce a condition of moral and political passivity. (Knauft 1996: 201)

As we take on board the recommendations discussed here and truly begin to reflect upon the current reality in Lesotho, future topics of study must be all encompassing, holistic, and locally led. Ways of working should be sensitive to local perceptions and problems with collaborative efforts. In order to promote positivity and equality, scholars should consider the following manifesto inspired by the findings of this dissertation in Table 6.
Table 6. Topics of study and ways of working, scholars should consider for future study in Lesotho.

<table>
<thead>
<tr>
<th>Listen and Act</th>
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<tbody>
<tr>
<td><strong>Listen and Act.</strong> Development and biomedical technical dominance in Lesotho is depleting the meaning out of words such as education, knowledge, participation, community engagement, mobilization, grassroots, empowerment, praxis—as outsiders working with insiders we can facilitate critical dialogue about these terms, methodologies, and theoretical positions in a social justice paradigm.</td>
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<tr>
<td><strong>Listen and Act.</strong> People are conveying fears about speaking up, political instability, and corruption, and we keep asking about AIDS. As an outsider listening, these concerns are not trivial themes to be placed aside for future research when and if there is time, but outsider researchers have the moral responsibility to find out and do more. Penalizing an entire country by suspending aid because of “undemocratic” practices does not provide a solution…examining what is making people live in fear and using our power to understand the situation seems like working closer to a solution. Politicians’ accusations of infringement on “sovereignty” are serious, especially because of Lesotho’s dependence on foreign aid. Do people in Lesotho accusing the United States want the US out? Are they willing to withstand the worst of that reality on their own? Or are there other political and economic alliances to break the fall?</td>
<td></td>
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<tr>
<td><strong>Listen and Act.</strong> Document and draw attention to power and corruption that an insider may not have the liberty to challenge. If there are problems of corruption of misuse of power facilitated or committed by an institution, trace the lines and speak up—even if it means the line ending at home with western tax dollars. Do not penalize corruption by taking away funding from people who need it. Figure out a way not to be draconian but to monitor and manage better. If we are supporting the growth of democracy—supporting healthy judicial systems that can carry case loads for investigation and prosecution. In Lesotho there is no disincentive for corruption. People ceremoniously lament about corruption but no real actions are taken against those who misuse money—they are allowed to continue working, shifting from one lucrative posting to the next (post corruption). Foreign agencies heavily involved in Lesotho should also invest in supporting the infrastructure to penalize people for corruption assisting in breaking the corruption chain by ensuring the return of money and goods stolen, seizing accounts of the guilty, and implementing due punishment for corruption. More research is needed into the “invisible market” of global funds and financial pooling of resources for HIV used to make a profit in the shadow banking system. Future research is needed to document the influence of funds for HIV and trace who is benefiting at the global level and what policies are promoted because of invisible market interests.</td>
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12.2. Translating Knowledge into Action

It is not that no one knows what to do to prevent the sexual transmission of HIV in Lesotho, it is really getting what we know into practice. The largest point of resistance to diffusion of information found in this study is the diversion of time, money, talent, and attention to what large donors, especially the US, prioritize at the neglect of acting on the simple things researchers have already demonstrated. MCP research is only one example of the many aspects of the epidemic that outsiders and insiders have studied and made well-founded recommendations, yet these have not made their way into broader changes. This section starts by revisiting specific recommendations on MCP and HIV prevention provided by anthropologists and social scientists and transitions to presenting recommendations from this dissertation study.

12.2.1. Revisiting Old Recommendations

The MCP findings did eventually make their way into an active education 11-week module and into policy documents. Table 6 provides an example of the 2008-2013 Behavior Change and Communications (BCC) strategy objective and activities (*GoL/MoHSW/NAC 2009; NAC 2011*). However, the scaling up, the actual implementation of these points, did not happen. Lack of political will, NAC’s demise, and a cultural behavior of MCP where few people are ready to change, contributed to the insufficient implementation of these points. Yet, pre-packaged solutions such as condom provision, PMTCT, and treatment from centers of excellence with “operational research” continue to be well-funded, spreading, and growing.

The rate of HIV is highest amongst the divorced and widowed, and MCP studies found dissatisfaction in relationships to be a significant factor in seeking out additional partners. If supporting social education and adult conversations can decrease divorce and increase sexual satisfaction, then such programs can impact the trajectory of the epidemic. Yet, initiatives like the Fast-Track approach are less supportive of the types of social-economic approaches prioritized in Table 7, despite these approaches showing positive outcomes on communications, depression, intimate partner violence,
Table 7. National activity steps for reducing reporting of multiple partners

<table>
<thead>
<tr>
<th>National HIV and AIDS Strategic Plan, the Health Sector Policy on Comprehensive HIV Prevention, and the National Behaviour Change Communications Strategy, 2008 – 2013</th>
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<tbody>
<tr>
<td><strong>1.1.1 Reduction of the number of youth and adults reporting multiple partners, with a focus on reducing levels of concurrency, intergenerational sex</strong></td>
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<tr>
<td>Review, implement, and assess SBCC addressing multiple and concurrent sexual partnering</td>
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<tr>
<td>Develop SBCC materials and tools with a focus for use by non-professionals at the community level among others</td>
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<tr>
<td>Conduct national and community level partner reduction and mutual fidelity campaigns</td>
</tr>
<tr>
<td>Build the capacity of traditional, religious, and other local opinion leaders to address multiple sexual partnering and concurrency through community mobilisation and interpersonal communications</td>
</tr>
<tr>
<td>Evaluate existing strategies and campaigns</td>
</tr>
<tr>
<td>Incorporate elements addressing multiple sexual partnering and concurrency into existing behavioural, biomedical, and structural HIV prevention programmes</td>
</tr>
<tr>
<td>Develop and implement HIV prevention and multiple sexual partnering communications modules with direction for referrals for incorporation into existing programmes</td>
</tr>
<tr>
<td>Increase the number of programmes providing training and income generation to females</td>
</tr>
<tr>
<td>Map life skills programmes/ income generation activities in each district</td>
</tr>
<tr>
<td>Link HIV prevention programmes with services that deliver life skills, vocational training, and income generation activities</td>
</tr>
<tr>
<td>Address the cultural and legislative barriers that prevent females from being economically empowered</td>
</tr>
<tr>
<td>Conduct advocacy initiatives with national and community leaders</td>
</tr>
<tr>
<td>Strengthen the dissemination of all relevant legal frameworks across the country with a focus on district and community levels</td>
</tr>
<tr>
<td>Incorporate elements addressing intergenerational sexual relationships and HIV prevention into existing HIV prevention programmes</td>
</tr>
<tr>
<td>Map intergenerational sexual relationship programming in each district</td>
</tr>
<tr>
<td>Design, implement, and assess intergenerational sexual relationship programmes</td>
</tr>
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</table>

Transactional sex, drinking and drug use, and Herpes Simplex Virus-2 (HSV-2) (Pronyk, Hargreaves et al. 2006; Wallace 2006) (Jewkes, Nduna et al. 2008) (see Chapter 4). Nonetheless, it is worthwhile to pursue the mapping and action steps listed in this table within programs, both formally and informally, in churches, and other groups that use what is known about MCP to get people talking and learning about relationships and communications.

Writing about the way in which labor migration and the forced separation of families fostered MCP, Romero-Daza wrote in 1993, “when compared to other African settings, Lesotho appears to be only
mildly affected by AIDS. However, it is very likely that in the near future the incidence of AIDS will acquire epidemic proportions. Recommendations are made to prevent such an epidemic” (Romero-Daza 1993: XV). Her work presents a tragic example of the consequence of not acting on what we know about MCP. One of the first recommendations was income generation activities. Citing Schoepf (1988 and 1991) Romero-Daza states, “of utmost importance is the provision of viable economic alternatives for women, in order to diminish their dependence on “Bonyatsi” [MCP] behavior” (Romero-Daza 1993: 310). Some of the further points outlined were the need to:

1. Address ecological and technological restrictions to improve agricultural production with the possibility of smaller scale communal gardens for domestic consumption and sale in local markets.
2. Prioritize the creation of a diverse set of income-generating activities for women of different economic backgrounds
3. Increase opportunities for women while simultaneously increasing women’s rights to own land, take out loans, and have “affordable (or if possible, free) child care services” to facilitate women’s involvement in the economy (Romero-Daza 1993: 310).
4. Provide education focusing upon the nature, causes, symptoms, prevention and consequences of STDs in general, and of AIDS in particular
5. Design education strategies targeting herdboys, initiation schools, clinic and health posts, and traditional healers
6. Find alternatives to communication to facilitate conversations and pay attention to fluid roles of family members
7. Overcome association of condoms with promiscuity and prostitution and increase their acceptance by both men and women and understand male views and attitudes as well (Caldwell, Orubuloye et al. 1992; De Bruyn 1992; Schoepf 1992; Romero-Daza 1993)

While many of these recommendations are over twenty years old, few have been implemented or taken into consideration in HIV interventions. The role and targeting of women, in particular, has not been fully appreciated. For instance, Romero-Daza (1993) noted that it would be essential to train influential women (especially those older than 50) in transmission knowledge and HIV, as they were more likely to be listened to, had experience with STDs, marriage, and relationships. This is also confirmed in the communications diagrams used in this dissertation; as researchers discussed how they passed on information to their influential mothers who went on to divulge the information in various settings. Particularly poignant are those conversations around pregnancy and preventing transmission to children and is a key impetus for conversations about HIV prevention. Romero-Daza noted that, since
most women were already aware about the potential for mother to child transmission, emphasizing the use of condoms as a way to protect offspring, could be especially important among pregnant or lactating women (Romero-Daza 1993: 341). This life moment of interaction between mothers, fathers, and extended family members and with clinical services for pregnancy and childbirth is a key outreach and interaction moment.

Other anthropologists working in Lesotho have come to the same conclusions about the importance of what is considered HIV prevention education and the best means to go about learning. Bulled’s (2012) 2011 research in an urban university environment concluded that internationally-generated HIV knowledge (as a form of biomedical technology), especially the type of information measured on standard indicators, are not adequate for generating prevention behavior changes. People can often regurgitate what they have heard, the ABC approach, misconceptions, etc. over and over again but it is “not only what but how knowledge is disseminated [that] is vital to guarantee its positive impact on risk behavior” (Bulled 2012: 316). Bulled recommends that the greatest impact in reducing HIV risk behaviors will only happen if youth have a chance to critically engage in the production and consumption of HIV information. There is a need for professional training and capacity building for adults working and researching in the AIDS response, and for educators to move towards Freire’s concepts of critical consciousness. In young people’s “education” of HIV, in particular, we need to go beyond the mere repetition of facts to have a critical understanding of HIV in their reality (Bulled 2012). Bulled recommends, “rather than teaching students the ABCs of HIV, students should be asked to critically consider news reports on HIV, or to critically evaluate fellow students as they try to educate mock students, thereby developing critical consciousness” (Bulled 2012: 321). Similarly, Sigamoney (2009), in her recommendations on BCC in Lesotho, also highlighted the need for content to be reworked and rethought because of several of her respondents emphasizing that “existing educational materials, messages, and efforts are not fully effective in promoting behavior change” (Sigamoney 2009: 11). She also concluded that participatory activity-based methods and interpersonal communications were considered to be most effective while print materials were seen as the least effective (Sigamoney 2009).
In light of the regrettable pertinency of the recommendations of earlier anthropological findings an important future step of analysis is to find out how these researchers disseminated their work. It is fundamental to understand the means used and whether they effectively reached the global HIV funders, policy makers and local actors. What were the barriers to communicating and being heard? Are there lessons learned for anthropologists with regard to how we can be more effective change agents at this level, with funders and policy makers?

12.2.2. Fast-Tracking the Response is Useless without Consciousness

If the response continues to be dominated by a focus on medicalized treatments and condoms, yet sexual networks and actual low condom usage remain the same, then the challenge for medical technology to keep up with the biological work of prevention is even harder. With the high level of ARTs being taken by the population and inevitable challenges to adherence over time, HIV has the serious potential for mutation. If a person is re-infected with a new strain of the virus, or if a mutated HIV type is introduced into the body through unsafe sex, treatment becomes much more complex and potentially ineffective. Assumptions about people properly taking their medicines and always using condoms are quite dangerous. Outsider interventions focusing on medicalization and condom promotion without the hard work of trying to EXPLAIN and educate about HIV and sexual transmission may seem effective in the short-term, but have the potential to create unintended long-term consequences. UNAIDS is emphasizing condoms, testing and treatment yet key in initiatives of “turning the tide,” “getting to zero,” and “fast-tracking” an end to the epidemic is the simple act of educating. Helping people in understanding how the virus works, how it spreads and having the tools and supportive environment to make well-informed decisions for behavior changes in their own life and for the preservation of others.

12.2.3 Recommendations and Applications from the Communication Diffusion Network Activity

The communication network activity and diagram does offer a starting point for an additional mid-term measuring tool. The tool is mid-term because it measures a process that requires some time to
pass, unlike short-term evaluations immediately after projects end but not a long-term tool because memory recall becomes more of a challenge. It warrants more research to determine its utility. However, even at this exploratory stage of development the communication diagram demonstrates usefulness in visualizing who is talking to whom and with what magnitude. Information that is not culturally grounded and practical does more harm than good (as described in Chapters 5 and 6). Culturally grounded and practical information pertains to the content itself and to the way in which this information is spread. Based on the research described in this dissertation, especially the communication activity, attempts to educate about HIV and MCP is not a matter of simply plastering and bombarding with posters and formal sex education, but it is the quality of education, the type, and who within a family or social network is best placed to convey the information to others. Thus, it is necessary to take sex education beyond teacher-student, health practitioner-patient, partner-partner dyads, and equip individuals with HIV education and communication skills that they can translate within their various personal and professional realms of influence. The lessons learned from the analysis of MCP and HIV conversations as well as the communication diffusion network activity are applicable for general research and evaluation practice as well as for Lesotho specifically.

12.2.3.1. General Practice

Health research assistants and professionals should be trained not only on clinical aspects of HIV, but also on how to explain, answer questions, and communicate (maybe even counsel) about HIV and the social, cultural, and behavioral risk environment in their community. The return on investment is not only pertinent for the clinical setting or specific research project but also in their off work social networks. This pilot methodology of using the diffusion activity to better understand how people go on to talk and with whom should be further explored to determine if this could be used as an evaluation tool for measuring long-term impact. For example, selecting different time points (six months, 1 year, 5 yrs, 10 yrs) to conduct the diffusion activity, after a particular project ends to measure if and how far the chain of sharing knowledge goes.
12.2.3.2. Lesotho-Specific Recommendations

As of 2011, the level of ignorance about HIV and MCP was still high in the educated middle class; more should be done about enhancing the quality of educational encounters rather than focusing only on counting the number of persons who have taken a KAPB and an HIV test. Current HIV communication focuses on partner-to-partner communication; more focus needs to be given on how to strengthen the social and cultural environment to help individuals make their own synthesis of information from various sources (traditional, biomedical, social media) for decision-making. For HIV interventions and research projects, this can be done by creating a work environment that facilitates ongoing points of open exchange and discussion.

**Intergenerational Knowledge Transfers:** More attention should be given to empowering individuals who have a high-level capacity in talking about HIV prevention and sex in the workplace to use their skills to open culturally appropriate HIV discussions with family members. Trainers should pay particular attention to kinship nuances, to take advantage of the role of an aunt, uncle, older sister/brother to talk to family members in which they have a special bond or social responsibility in raising. Special emphasis should also be placed on the fact that adult children could be instrumental in opening up space, breaking the ice, and communicating with parents and elders. Adult children can potentially serve as conduits if targeted as potential providers of learning materials and information for people who would not normally access the internet or health services.

**Time and Transition Sensitivity:** Opportunities for initiating and continuing quality conversations about HIV prevention and sex are time and life transition sensitive. Individuals working on short or longer-term HIV projects should be made aware of the types of times or life transitions when they may have more opportunities to initiate a prevention conversation or be prepared for the types of questions people may ask.

**Men Talk:** As seen in this research, men who had their capacity built in HIV and social, cultural, and behavioral aspects of the HIV epidemic in Lesotho, went on to use their HIV prevention and sex
knowledge in “man talk” with close family or friends in their inner circle, numerous times across several years. In Lesotho, projects target men for the promotion of condoms and HIV testing, but pay little attention to supporting “everyday” men in understanding the social, cultural, and behavioral aspects of the epidemic. Allowing “everyday” men to have more information enables them to discuss and come to their own conclusions about the best ways to prevent the spread of HIV. This is not an argument for the establishment of formal interventions for men or male-to-male groups (however in 2008 and 2012 this was still a lacuna) but also for people to operate knowing that any one man who has been given proper information will share it with his peers informally if he knows it is something that will help his friends’ life.

**Non-HIV Sector Work Environment:** Staff turnover and short-term contracts abound in the HIV and NGO private sector. Individuals often fluctuate from higher-paying NGO projects to lower-paying but stable government employment. People trained in HIV and on how to get others to talk about sex in one job will most likely transition into other HIV and non-HIV sector work. The findings in this study demonstrate that individuals who were trained with the specific capacity in explaining and discussing HIV and sex, go on to use this competency with colleagues in various non-HIV sector work environments is an important insight for project managers. This finding highlights the importance for project management to set aside time for building this type of capacity in talking about HIV and sex, regardless of the duration of a specific project, because it has the potential for impact long after project closure.

**Teaching and Training:** Short-term research projects that utilize highly educated young adults early in their career have the opportunity to invest in creating particularly effective change agents. These change agents will likely go on to apply their research knowledge and examples gained from the research experience in future teaching and training positions including university courses, HIV prevention, and general education programs in Lesotho. This means that their exposure to health information has the potential to diffuse to more people for a longer period of time.
12.3. Changing How We Work: Learning “how to love ourselves, how to love this country, how to love other people, so that we can share that love around us”

As discussed in the introduction to this chapter, this dissertation is part of a larger movement combining “dark anthropology” or the critical with that of anthropology that documents resilience, hope, action and resistance. This latter more positive streak is what Arjun Appadurai refers to as an “ethic of possibility,” which focuses on “those ways of thinking, feeling, and acting that increase the horizons of hope” (Appadurai 2013: 295). Appadurai calls on anthropologists to not be passive observers documenting the “possibilities” but rather “to be mediators, facilitators, and promoters of the ethics of possibility . . . which can offer a more inclusive platform for improving the planetary quality of life and can accommodate a plurality of visions of the good life” (ibid.: 299). With this perspective in mind, this section draws upon local lessons but applies larger level theoretical viewpoints to creating a grounded practice based theory of the problem in MCP information diffusion in Lesotho. Specifically, I take Don Clifton’s rationale for the theory of the “invisible dipper” and combine it with anthropological insights from this dissertation to form a new model of the critical, positive and possible for the HIV response in Lesotho and similar settings.

Don Clifton is cited as the “Father” of Strengths Psychology and highly respected for his contributions in research to improve quality outcomes for individuals, organizations, and businesses. Clifton is famous for his theory of the “invisible dipper,” which simply states that the more individuals dip out from others with negativity, the more they deplete their own bucket, but as a person fills the bucket of others with positive, but sincere, energy they fill their own bucket (Rath and Clifton 2009). Despite sounding fluffy, the theory, over the past 40 years, has been applied by millions of people and over 5000 organizations to improve individual and organization outcomes. Clifton’s interest in studying the effects of positive inputs in human relationships and productivity was sparked by a speech by the then Major William E. Mayer’s, who became the U.S. Army’s chief psychiatrist, on his study of 1000 American prisoners of war (POW) in North Korea (Mayer 1967) quoted in (Rath and Clifton 2009: 8).
Mayer described the paradox of having a 38% POW death rate, which was the highest rate in US military history, at the time, despite these soldiers having adequate food, water, shelter, and no physical torture. In fact, fewer cases of physical abuse were reported in North Korean POW camps than in other contemporary prison camps. The camp was not surrounded by barbed wire nor armed guards and yet, no soldier tried escaping, rather they broke rank and actually created close relationships with their captors.

Mayer argued that it was the most effective case of psychological warfare. The North Koreans’ objective was to “deny men the emotional support that comes from interpersonal relationships” (Rath and Clifton 2009: 9). They instituted incentives for informing about other soldiers, self-criticism, breaking loyalty to leadership and country, and withheld all positive emotional support. Over half of the soldiers died of marasmus, going off alone, pulling a blanket over their heads and dying within two days. To encourage informing North Korean captors would reward snitching without punishing the offender—the point being not to punish but to break relationships. To promote self-criticism, captors held group therapy sessions where men would stand up and have to tell all the bad things they had done as well as all the good things they could have done but failed to do, subtly eroding the caring, trust, respect, and social acceptance among soldiers. North Korean soldiers delivered negative mail from home immediately—overdue bills, notices of death, a wife’s departure, all the while withholding positive and uplifting news. Captors also undermined the worthiness of allegiance to the United States or military leadership. The North Koreans tried to create a reality where the U.S. soldiers had nothing to live for and lost basic belief in themselves, loved ones, God, and country. They were put, “into a kind of emotional and psychological isolation, the likes of which we had never seen” (Rath and Clifton 2009: 13).

On a theoretical level, revisiting the common themes in this dissertation, I propose that AIDS response is unintentionally fostering this kind of negative isolation when it comes to HIV prevention in Lesotho through:

1. **Professionalizing the problem**—talking about HIV as something for experts, negating an individual’s sense of empowerment to affect change while simultaneously providing much-needed services and employment. So, rather than trying to “escape” and form indigenous grassroots solutions, individuals in Lesotho form close relationships of dependency with the outsider led AIDS response who
have power and money. Examples of this dependency and stifling of empowerment are discussed in detail in Chapter 10.

2. **Presenting MCP behavior as feeding the epidemic without providing culturally appropriate opportunities to talk or to support change**—This fosters, as discussed in great detail in Chapters 5 and 6, continued silence, to not talk about sex or the current social acceptance in the continued practice of having multiple concurrent partners. Furthermore, the knowledge that MCP behaviors are fueling the epidemic without creating a supportive environment for change aggravates a subconscious sense of guilt and erodes trust and respect.

3. **Continuing the influx of money, amidst blatant mismanagement and corruption**—erodes even further belief in in-country leadership, allegiance to state or the good intentions of outsiders to help (Chapter 10).

4. **Completely ignoring cries for help in stopping the growth of inequalities, creating work and creating division** by investing in predetermined categories based on risk or need undermines social cohesion and sustainable development.

5. **Disproportionally promoting medicalizing/technologizing condoms and medicine** at the neglect of sustainable development and inter-human social solidarity through holistic and culturally appropriate education (Chapters 5, 6 and 10), like the North Korean camp, places people into a type of emotional and psychological isolation.

6. **Rewarding with money, projects and praise about prevention when it is evident that the fundamental changes have not happened**—of increased condom use, decreasing intergenerational partnerships, serial monogamy, partner reduction, delaying sexual onset, decrease in incidence, are not happening at a rate worthy of “reward”. This lacuna, amidst praise of progress from international organizations (such as PSI, EGPAF, JHU, BIPAI and UNAIDS), stimulates a type of disengagement by people employed in the Lesotho HIV response, which can be likened to the marasmus experienced by U.S. soldiers. In this situation, individuals can work, perform research on HIV but never have a personal awakening or spark of non-retribution based motivation to instigate change.
While not intentional, the AIDS response, through these mechanisms, has similarity to the North Korean war camp that denied individuals the emotional support that comes from facing the epidemic through interpersonal relationships and social solidarity. The next two sub-sections apply Rath and Clifton’s theory (2009) to specific ways in which those working in the HIV response, especially with research, can break the chains and allow an indigenous, grassroots spirit to flourish and change the trajectory of the epidemic in Lesotho and similar contexts.

12.3.1. False Optimism is Counterproductive But Produces Disengagement

Studies discussing HIV and the workforce tend to concentrate on how the workforce will meet the new and complex demands for HIV services or the turnover and absenteeism caused by HIV infected workers or their need to care for family members (Bollinger and Stover 1999; Rosen, Simon et al. 2000; Tawfik and Kinoti 2003; Fox, Rosen et al. 2004; Dovlo 2007). Published studies are predominantly clinical leaving a gap for the HIV non-clinical social services or NGO sector. Based on this research and the articles reviewed, I would argue that more consideration be given to indirect factors affecting the quality, efficacy and turnover of the HIV workforce in resource-constrained environments. Factors such as disengagement and turnover revisited with a non-conventional lens to consider the subjective influences of inverted brain drain—causing turnover as the talented and skills chase better paid or longer-term projects supplied by the international AIDS response (see Chapter 7). Furthermore the disengagement caused by false optimism and ignoring local perspectives for change.

Clifton and Rath argue that insincere recognition can do more harm than good (Rath and Clifton 2009). For example, an employee selected as “employee of the month” because everyone else has already had their turn does more damage than good to employee morale. Fredrickson (2003) and Losada (1999) found that workgroups with positive-to-negative interaction ratios greater than 3 to 1 are significantly more productive than teams that do not reach this ratio. However, their modeling also suggests an upper limit where things worsen if the ratio goes beyond 13 to 1 (Losada 1999; Frederickson and Losada 2003). Professionals working in the HIV response cannot ignore negativity and weaknesses with a deluge of
positivity. Positivity must be grounded in reality. False optimism is counterproductive. HIV prevalence and measures of incidence have remained relatively stable for fifteen years in Lesotho. The HIV response in Lesotho is failing when it comes to prevention, and it is time to face it. Applauding the do-gooder work of organizations like Population Services International, UNAIDS, Global Fund, Clinton Health Access Initiative, World Bank, PEPFAR, Elizabeth Glaser Pediatric AIDS Foundation (EGPAF), Kick 4 Life, the Baylor College of Medicine/Bristol-Myers Squibb Children's Clinical Center of Excellence, Columbia University's ICAP, John Hopkins Communication Change project, Partners in Health, Family Health International (to only name a few large donor initiatives) without turning an unpopular critical gaze is, in the end, counterproductive.

A study on recognition, which included more than 10,000 business units and more than 30 industries with 15 million employees worldwide, showed a direct link between regular recognition and praise and specific business outcomes (Harter, Schmidt et al. 2003) in (Rath and Clifton 2009). Their estimates suggest that there are more than 22 million workers, in the US, who are “actively disengaged,” costing the U.S. economy between $250-$300 billion every year in lost productivity. When workplace injury, illness, turnover, absences, and fraud are added, the cost could surpass 1 trillion per year or 10% of US GDP (Harter, Schmidt et al. 2003). When people reported that their manager did not focus on their strengths or their weaknesses (the manager ignored employees), there was a 40% chance of workers being actively disengaged on the job. If their manager focused primarily on weaknesses (and presumably was at least paying attention), things actually got better, and there was only a 22% chance of disengagement. But when the manager primarily focused on an employee’s strengths, there was just a 1% chance of that employee being very negative or actively disengaged on the job (Harter, Schmidt et al. 2003).

Considering the findings of this research, the reality of feeling “disengaged” is applicable to Lesotho’s AIDS prevention efforts on several levels. At the larger donor level, management is not attentive to know what the strengths and the weaknesses at the ground level for prevention efforts may be. Donor management measures and watches what it wants, but ignores what could be the unique cultural strengths that can bring about change. Even when local leaders say what they want and need, management
often acknowledges it, but then the financial and moral support (as documented in budgets and policy reports) does not match the verbal declarations. As the MCP researchers interviewed in this dissertation discussed in Chapters 7 and 10, there are individuals who want to do more for HIV prevention but are tied down by structures, indicators, pre-packaged plans, and mismanagement; many of these potential change makers become disengaged. Given that a majority of the MCP research team are no longer involved in any sort of formal HIV work or activism and the few that are recounted stories of frustration and disillusionment, it begs the question of how much of the funding for HIV is lost through the “actively disengaged” and their loss of productivity, turnover and fraud.

As pointed out in Chapters 5 and 10, the response to HIV in Lesotho has galvanized a significant amount of donor funding and activity, but where the resources are invested and in which type of activities seem to reflect the “interests” of those who bring the money. Participants repeatedly noted that more should have been and still needs to be done to address core adult HIV active learning about the virus, and the Lesotho nuances and behaviors promoting and preventing transmission. While these middle class individuals may perceive what needs to be done, they are constrained by the priority and packages brought in by outside funding and their own need to make a livelihood. Furthermore, the magnitude of wealth building by their own elites who do not place resources or importance on tackling the behavioral dynamics feeding the epidemic, nor supporting the non “expert” response, is frustrating and isolating. However, this research demonstrates that even within these constraints, individuals can and do rise up making changes in their own lives, within their family, community, and in governmental and organizational structures in which they continue to work and live.

12.3.2. Measuring Change: One person can make a difference

Nobel prize winning scientist Daniel Kahneman explains that we experience approximately 20,000 moments in every day (Kahneman 2002) (Rath and Clifton 2009). Usually people remember positive or negative moments, while the neutral moments are forgotten. As seen in this study, a single encounter can change a life forever. One person can make a difference, as documented in research
participants’ accounts of specific individual encounters during the research experience (Chapter 8) or within their personal social networks (Chapter 9). The change one individual could make was not contained to just these personal exchanges, but also located in organizations structures. As discussed in Chapters 5, 7, and 10, several research assistants, through their future employment, went on to ensure that the knowledge they gained in the MCP experience made its way into programs and policy documents. The nature of qualitative research uniquely fosters moments of encounter and change for the researcher and researched. The study results of this dissertation indicate that training well in the professional research realm about the art, science, and ethics of qualitative research in combination with HIV prevention education goes on to be applied in multiple other interactions. Empowering research assistants by talking with and educating about HIV and their local epidemic takes HIV out of professionalization, and even if not measured in a short time scale, builds the behavior change environment. Results also indicate that people forfeited opportunities to educate and talk about HIV because they are not “experts”. Furthermore, fostering ownership of the problem and research findings by research team members helped the researchers to move results out of the realm of theory into practice based applications and behavior change interventions.

The dissertation results also hint to the potential impact that empowering individuals through the use of qualitative research, education, and discussions could have on changing relationships and the epidemic in Lesotho. The post-study dissemination of research, where a small number of team members went out and presented findings using active learning techniques for feedback with national, district, and community stakeholders, was very effective in fostering critical conversations about HIV and the context specific social, economic, and behavioral factors with “non-experts”. There were three distinct challenges that the MCP project had to overcome in order to implement the outreach dissemination. First, funding for dissemination is usually part of the initial project proposal, a point at which research team members are often not involved, and what could be done with the findings is generally confined to the narrow perspective of those writing the proposal. Second, the findings themselves should inform the direction that needs to be taken, but narrowly prescribed dissemination plans at study initiation do not do this.
Third, studies are constrained by the need to re-apply for IRB approvals in order to “add” questions or a new “study group” for feedback or validating findings. Many times, if investigators have to submit, wait, and get approval they will not incorporate an interactive data gathering dissemination process. Thus, the research community should study and discuss the organic nature of creating a “dissemination plan,” and the funding and ethics constraints retarding dissemination beyond the experts.

Nine out of ten people say they are more productive when they are around positive people (Rath and Clifton 2009). Creating a positive work and research experience by acknowledging, responding, and creating collaborative space for local researchers increases productivity in what can be accomplished for the specific objective and in future formal and informal settings. A positive collaborative space for listening, exchange, and sometimes arguments will help both external and internal researchers interrogate what they “know”, help cope with ethical conundrums, and increase their future “productivity” in terms of prevention change. Part of creating this positive work environment is the need to face difficult questions about power, privilege, race, corruption, and aspects of culture to protect and others to set aside. Here is where the fruits of “dark anthropology” can be applied to create a transparent and sincere positive working environment by facing problems rather than glossing over them. Furthermore, the ethical aspects of studying highly sensitive and life threatening topics are important issues to confront. Leaving space to ask hard questions such as; what will happen next? who will use this data?, what is the researchers’ obligation to the people involved in the study and to the larger community?, and is education (active and critical) a debt we owe? All these questions are necessary to the conduct of good research.

In evaluating the utility of aid and outsider capacity building, such as done in qualitative research, donors and citizens must move towards measuring longer term effects as well as having “faith” in aspects of change that are not quantifiable or easily measured, and perhaps even acknowledging the limits to what “evidence” is available for making “evidence- based” decisions. Limiting the value of investments on change to only short-term easily quantifiable answers misses the value in the many individuals who pass on expertise, experience, and ways of working that live on and spread in numerous ways. I am critical of the negative aspects of outsider intervention and quite aware of the positioning of those involved (myself
included) in the collaboration: higher salaries, power, and privilege, not to mention the room to make mistakes. However, participants reported that the FHI-UN brought employment based on merit, broke pre-conceived cultural ideas showing that it is possible to talk about sex and that people can change, engaged in diverse and higher ethical practices and perspectives, and fostered an organizational culture based on collaboration, respect, shared decision making, high standards of quality, and attention to waste. These are concepts that many insider- and outsider-funded employment did not provide. As shown in Chapter 10, the participant who talked most and went on to work in policy and programming on MCP cited the way in which the project was implemented with a spirit of collaboration and facilitated a process, where the story was theirs to be told. While the project was not explicitly “participatory”, it nevertheless resulted in a wealth of experience, ideas, and ways of collaboratively working that make a difference. The importance of choosing the right kind of collaborators was also seen as influential by participants; expert scientists with years of experience and influential professors helped overall to change perceptions about HIV. My own outsider role was shaped by concepts and methodologies learned from applied anthropology theories on praxis and action research, community health courses, the book *Community Organizing & Community Building for Health* (Minkler 2002), and especially my participation in a collaborative multi-disciplinary project between the University of South Florida, the National University of Lesotho, Ithaca College, and a few villages in Lesotho which attempted to combine farming, food security, economic empowerment, and participatory learning about HIV and AIDS. The project was inspired by Drs. Himmelgreen, Romero-Daza, and Turkon, who conducted their dissertation research in Lesotho and never relinquished their responsibility to translate research into action (Himmelgreen, Romero-Daza et al. 2009). The team wrote and submitted proposals for several years, but never attained external funding (Watson Lai, Mpemi et al. 2008). The five-year collaborative experience on project conceptualization, project planning, community engagement, and grant writing -- including the disappointment of not getting funding -- was invaluable. Similarly, research participants in this MCP study explained how the cumulative experience exchanged influenced how they approached future positions and projects, including their contributions to helping formulate national policies,
educational curriculum, and behavior change community approaches/manuals. Formal project evaluations
do not often capture the investment from various U.S. funding sources supporting the training and
expertise of individuals like these, who give of their passion and experience, yet this is probably among
the most valuable long-term benefits of outside intervention.

In consideration of the continued need to build up capacity and support health systems
strengthening, the leadership by outsiders is still key in the epidemic response in Lesotho. Outsiders
should take it as a fundamental responsibility to educate about HIV in a holistic manner and create space
for locals to speak the truth and own the problem and the solution. In the process of implementing
biomedical, food security, or orphan interventions, it is important to take the time to let those who work,
the educated elite and middle class, to have accurate, up-to-date, and holistic knowledge about HIV
transmission and prevention. Literally, they need to practice how to answer questions and communicate
about HIV and MCP. It is thus necessary for donors to keep in mind both general and specific capacity of
the other settings these individuals will navigate.

Bad local leadership is also eroding the HIV/AIDS response. Participant discussions in Chapter
10 highlighted how “champions”, leaders, politicians and musicians that are perceived to have been paid
for their HIV activism tend to do more harm than expected. This shows how the diffusion of innovations’
concept of utilizing opinion leaders to accelerate the acceptance curve of an innovation by the majority
can sometimes be distorted and serve instead to slow even further the process of diffusion. Participants
described how the audience would almost turn off from listening because they felt these people were
insincere and paid to talk about HIV. Two expatriates and one indigenous participant in Chapter 5
explained one aspect of this dynamic noting that people working in the HIV industry, in hospitals, clinics,
outreach workers are paid to talk about MCP as a main driver in HIV epidemic in Lesotho but in their
personal lives still practice the MCP behaviors. Participants in Chapter 6 also confirmed this type of
dichotomy between the message of HIV transmission danger and MCP alongside an ongoing social
acceptance that the practice of having multiple partners is culturally acceptable and will continue.
Hypocrites breed hypocrites. Traditional healers, leaders, those working in HIV prevention, and churches
(like the nun example in Chapter 5) need to teach their specific teachings about sex, talk about behaviors and morality, but most importantly they need to practice what they preach being honest and sincere. This may at first sound ethnocentric, but the point is if you teach fidelity practice it. And if you practice having MCP you can teach fidelity but be real, practice and promote other means of preventing transmission such as through condoms and PrEP.

One of the pillars of anthropology is cultural relativism, the principle that the beliefs, values, and practices of a culture should be understood within the perspective of that culture itself. A common and typically good quality of anthropology is to cultivate understanding when ethnocentrism, the idea of one’s own culture as the ideal and lens for which to view the “other”, stifles comprehension and dialogue. However, this has also resulted in debates about the thin line on certain beliefs, values and practices that may appear to be harmful, or a part of the culture that not everyone within the culture sees as beneficial to hold on to, for example female genitalia modifications. Related to this idea are those who challenge the labeling of a culture with high rates of MCP as ‘wrong’ but see it as a neutral value free cultural reality. They question if MCP need be eliminated in order to end the HIV epidemic in contexts like Lesotho.

MacQueen has argued that there is an unwillingness to explore the possibility that MCP could “come out of the closet” so that HIV prevention could be discussed without the presumption that effective prevention requires an end to MCP. She argues that MCP does not “cause” HIV anymore than men having sex with men causes HIV. She points out how some people argue that eliminating male homosexuality is the most effective way to end the epidemic among MSM and asks is the argument against MCP different in any essential way (MacQueen 2017)?

I would argue that sex with men does not cause HIV. The virus becomes a problem, in terms of population transmission, when you add in multiple partners and a higher probability HIV transmission sexual act such as anal sex. Fewer partners reduces exposure to HIV risk. Yes, there may be those in both populations that will always seeks out multiple concurrent partners. And currently most prevention and condom promotion are marketed at those “misbehavers” as the PSI representative explained. However, addressing the root causes for why a person may seek out another partner or promoting the notion of sex,
love and a relationship as total self-giving, unconditional, and unique between two people—could only reduce risk. Instead, out of not wanting to offend, or treating the MCP practice as a static “it will never change” the prevention emphasis is on making the practice safer through condoms and PrEP. Which is right, good and necessary but an unproportioned focus on this approach may actually reaffirm the idea that MCP is unavoidable and the only solution are these types of harm reduction practices. This dissertation demonstrates that cultural change in regards to MCP is indeed possible.

As discussed in chapter 5, several of the MCP original team members were indifferent towards the plight of AIDS, they sought employment on the project for employment not necessarily as a point to make a change in HIV. They also described their own pre-project attitudes towards MCP, to not attempt to change cultural attitudes about the practice but to just minimize transmission possibilities through condoms while still keeping (or resigning that your partner has) multiple partners. However, the study changed this. All nine of the original research team members changed their own attitudes and behaviors in regards to MCP (chapters 6, 7, 8 and 9). It is important to note that the MCP project management never placed a right or wrong stamp on the MCP behavior nor tried to intervene with team member’s personal sexual behaviors or HIV status. After gaining an understanding of the science behind HIV transmission and concurrency and then coming face to face with peoples stories they shifted their perspectives. They placed a value on the behavior and decided to change the practice of having multiple partners (risk elimination) rather than continue having multiple partners but use more condoms (risk reduction). However, they did increase their ability to negotiate and use condoms as well as increased their communications about HIV with partners and sought out opportunities to know their own status. These changes were not contained to their own sexual relationships but flowed out in the conversations they went on to have with others about ending multiple and concurrent partner behaviors.

It appears that the question is not if the presumption that effective prevention requires an end to MCP, instead what if the presumption currently supported (and well-funded in condom and PrEP campaigns), to treat the entire population as MCP practitioners who will never change, is actually more problematic than the former. Under this paradigm, attempts for strengthening and understanding those
who do not practice MCP nor outreaching to support those who may be open to change or to prevent people from initiating the high risk to HIV transmission activity are grossly neglected, despite the clear links between HIV prevalence and coupling dynamics. The 2004 and 2014 DHS surveys consistently document that having more than one sexual partner in the past 12 months is positively associated with higher HIV prevalence, the association being stronger for women. According to the 2014 DHS survey 93% of the women interviewed reported having one sexual partner in the last year and 73% of men reported the same. In both the 2004 and 2014 DHS surveys approximately 60% of couples were HIV free, 20% both positive, and the remaining discordant. Divorced/separated women and men have higher HIV prevalence rates than those currently in unions 31.8% vs 48.6% for women and 29.6 vs 43.3 for men (MOH 2016: 246). With this in mind, I argue that yes MCP could “come out of the closet” so that HIV prevention could be discussed without the presumption that effective prevention requires an end to MCP. However, backing this perspective while neglecting to provide resources for those within the Basotho culture who do want to challenge MCP and create “new” norms or resurrect “old” ones that reduce the number of partners, support couples, reaffirm less concurrency and separation/divorce is equally problematic as the presumption that effective prevention does not require an engagement with the root causes and structures proliferating this high HIV risk of transmission behavior. I am not calling for an abstain and be faithful superficial campaign of posters, radio slots and TV commercials such as the OneLove campaign. This has been done in Lesotho but this type of media bombardment without the opportunity to reflect, talk, question the concept of risk behind the campaign turns it all into “white noise” as on participant described. However, media campaigns in conjunction with a deep engagement of getting people to talk and grapple with the economic, social and cultural aspects, from the emic perspective would help people to know the science and their own reality in such a way as to engender change. However, problem definition and discussion without the type of practical support to ameliorate economic and social root issues can only go so far. So what would this type of holistic investment in change look like?
12.3.2.1 Prospective Panel Study—No Boundaries 360

The ideal solution is not one I could describe but a ground up indigenous response informed by what we know so far about the epidemic. A small-scale example could be as simple as using the results of this dissertation to facilitate discussion with the original research team members and other pertinent stakeholders in the country to assess and brainstorm on what they think could be done. As I have already discussed, other solutions involve changing how the formal, highly outsider funded, AIDS Response works in Lesotho, by providing trainings to employees that not only role play, but equip those working in the HIV sector to have informal prevention conversations in their realm of influence. I also suggest the increased use of qualitative research about HIV, social triggers of the disease and on the ground solutions addressing problems not for “knowledge” accumulation sake, but rather as an explicit intervention. With this lens, the process of conducting, listening and participating in individual interviews and focus group discussions serves as a conscious awakening activity for change. Now given all that I have outlined about the call for “combined” biomedical, behavioral, structural and social prevention interventions and the tendency of the biomedical trumping (funding and human resources) attention toward the behavioral, cultural, social and economic. The question is based on the literature review, data of this dissertation as well as the experience on the MCP research and the previous experience on the food insecurity and community HIV project (Watson Lai, Mpemi et al. 2008; Himmelgreen, Romero-Daza et al. 2009; Turkon, Himmelgreen et al. 2009b) ---what would I do? What type of intervention for investing in change would I propose?

Turkon et al. (2009) describes the potential of longitudinal panel data as a sound monitoring and evaluation (ME) procedure and process for HIV and AIDS programming in Lesotho. They argue that this type of repeated standardized measurements at intervals across time with a cross section of individuals has the potential to generate culturally informed panel data capturing social, cultural, structural drivers that do not operate in uniform ways(Turkon, Himmelgreen et al. 2009b). These factors are often missed in the randomization and uniformity dictated in clinical trials. For this panel study I would select two catchment areas that overlap with current USAID or CDC projects (STAR, PUSH, UNITAID, AIDSFree,
SOAR) in order to ensure access to healthcare and especially HIV/TB testing and care. This would allow opportunities for potentially sharing overlapping data sets (with proper permissions) for study while ensuring a high level of access to testing and care to all participants.

The exact sample size would depend upon effect size and resources. One potential size could be a total of 4,000 people divided by intervention sites and rural vs urban. Each arm would have 1000 rural and 1000 urban participants. Recruitment would draw upon pre-existing groups within the sample area opening participation to all people in the zone. Investigators will choose an area estimating refusal to participate but ensuring the recruitment of 1000 individuals without dividing a community by eligibility criteria. In other words, being careful to choose an area where everyone who wants to participate can without going over the target number. At the intervention sites, if there are more individuals who want to participate they may participate but will not necessarily be part of the panel measurement and follow-up procedures.

Rather than an eligibility criteria pre-defined by age, socio-economic status, or HIV status—an entire catchment area will be recruited and then categorized by factors already collected by the DHS. These factors include, economic status and marital status (single, married, divorced/separated and widowed), and age. Families with children and declared couples will be analyzed as a unit. If a spouse or child is not physically present at the research site attempts will be made to include them. Recruitment will try to enroll the amount and diversity of participants necessary to mimic population level distributions in economic, marital, and age proportions at both intervention and comparison sites. This is an attempt to capture a “real” reflection of the population dynamics.

The foundation of the study will rest upon the initial baseline data collection between the intervention and comparison group. In order to determine which quantitative and qualititative indicators to collect, interviews and focus group discussions will be held with experts from the biomedical and social and behavioral sciences. The main objective being to collect the types of indicators that will show change and the difference (made or not made) by the intervention on HIV and the lives of individuals and social units. Paying particular attention to mix the correct methods to provide “evidence” that speaks to
biomedical, social, behavioral and economic indicators. In order to reap the full benefits of the interdisciplinary approach, project management and coordination will not be under a subdiscipline but rather each arm and expertise is treated with relatively equal funding and voice. In addition to traditional biomarkers of HIV sero-status, blood pressure, stress hormones, and immune function captured in blood, this project would also collaborate with researchers working on less invasive biomarkers such as hair, nails and baby teeth. These samples allow for long-term storage, and capture a wide range of information on short-term and long term exposures to environmental toxins, stressful life events, nutritional and dietary changes (Garban, Garban et al. 2006; Karlen, Ludvigsson et al. 2011; WHO 2011; Austin, Smith et al. 2013; Krol, Zabiegala et al. 2013; Panter-Brick 2014a; Hercules 2017; HumanExposome 2017).

Triangulating information from self-reported data with biomarkers will provide a holistic picture of both changes in the intervention group over time as well as comparisons to the non intervention panel. As Panter-Brick points out that as an evaluation tool biomarkers, help us to comprehend the mechanisms through which risk and resilience “leave epigenetic and physiological signatures on the body”, this pertains to both developmental consequences for children as well as long-term health implications for adults (Southwick, Bonanno et al. 2014). Other forms of evaluation proposed include not only sexual network analysis but also social network analysis. Given that this dissertation argues about the divisions and inequalities in Lesotho that are compounded by the AIDS Response, building community solidarity or at least understanding dynamics that may be undermining an indigenous response or the intervention itself is key. Turkon et al. argue that this type of analysis can “illuminate the types of social structures or relations they cluster around, such as political or religious affiliation, cooperative endeavours, class structures, lineage or clan membership” (Turkon, Himmelgreen et al. 2009b: 478). The communication diffusion used in this dissertation will also be explored to trace how information and knowledge given through the intervention is making its way (or not) through the study population and beyond. Follow-up and comparison of the intervention group and the comparison site will take place at 2yrs post baseline, 5yrs post baseline and 8yrs post baseline.
Rather than performing an intervention at each site where the control receives an adapted version of the intervention the control site will not receive any form of the actual intervention. However, they will already be in a service area with access to a HIV testing and care services. The point being to address the previous problem of diminishing the effect documented by providing a minimal intervention that actually may create more positive outcomes than realized. And furthermore, to compare a community that is receiving primarily biomedical outreach with that of a community receiving a “combined” preventative approach. The intervention group instead, will be part of a holistic life and community support system. The system will be led by a core team of 12 individuals whose goal is to facilitate understanding of the local HIV and socio-economic reality, prioritization of issues and local action. They will serve as mediators linking participants to the intervention components while conducting, training and facilitating research for action. Intervention components will include:

*Livelihoods:* In consideration that the main concern for people is usually work and money and not HIV, the intervention begins by addressing this concern. The core team acts as an intermediary helping individuals link up to mentors, funding, skill building and jobs. They will help participants by supporting what is already working in terms of providing work, identifying what is lacking and helping individuals to create and implement where they already have started or have an idea. In cases where participants are helped to link up with employment opportunities they will also be supported so that units can stay together and relocate and integrate as a group rather than an individual going and sending remittances. Cash-transfers and micro-credit loans will be made available. An important aspect is not the “giving away of money” but the support through mentorships and linkages to partners in the local and global economy to decrease unemployment and increase income or food generating activities for these individuals.

*Social and Behavioral:* Following the suggested groupings, of either pre-existing groups or age-mate groupings (Stepping Stones) adult participants will be asked to participate in the full Intimacy and Relationships without Risk modules—these modules will be “updated” and also will include the integration of “research” opportunities, such as conducting interviews and focus groups, for participants. During the same period that these programs are going on diverse media campaigns will be targeting the
participants. This may include the re-use of materials already piloted and used in Lesotho from various HIV campaigns such as OneLove, PushaLove, Know Your Status, AIDS Free Generation and the Fastrack. The point being to provide messaging from multiple coordinated channels with the opportunity to discuss with professionals and the space to interrogate what is heard amongst peers. Once again this approach differs from most social and behavioral interventions in Lesotho, in that the entire community is engaged in the process of reflection rather than a “target” group.

**Biomedical:** Community meetings and house visits to educate about the opportunities for testing, treatment and linkage to care. The fact that all participants are visited, regardless of status, should help eliminate any stigma related to having these visitors. Furthermore, additional health services identified as needed, such as diabetes, dental care, nutrition and weight management can be discussed. These less stigmatized grievances will also have services provided where the local HIV services are provided (fixed clinics or outreach mobile services). Once again this bundling of services will hopefully make it easier to access services (no one knows which service you are seeking) and once you make the link and build trust with the health provider community people who may traditionally not seek health services may start to seek services.

**Cultural:** The core team will conduct research specifically investigating unique cultural practices and institutions to support HIV prevention and overall well-being in the community. This will involve direct outreach and involvement of traditional healers, religious leaders, chiefs, and male and female initiation schools within the catchment area.

**Structural:** The core team will perform a participatory SWAT analysis of the specific structural dynamics for the community, once again with the focus on providing information to help participants better understand their reality, prioritize issues and take action.

The Core Support Mechanism will be in place for a minimum of five years. The specific activities and ongoing inputs will be determined in a participatory collaborative process with participants and project leaders. The intervention will be a cyclical Freirean cycle of understanding, reflection, action and evaluation. The project administration and funding will attempt to combine traditional structures of
competitive project funding (e.g. NIH, CDC, WB, foundations) as well as nontraditional private collaborations. Considering the livelihoods and importance placed on work the nontraditional project administration members will be recruited from private companies. These members will contribute economically but more importantly as mentors, brainstorming solutions and linking participants to local and global markets. A system of sustainability will be designed using a system of re-investment by participants back into the program. Other means of sustainability will be explored such as investing a certain percentage of the initial project funding into a “fund” for growth on the market.

12.3.3. Conclusion: The way towards change

The positivity of people in Lesotho facing the challenge together, breaking the silence, and fostering solidarity not isolation, may be more a key to fighting the epidemic than professionals responding to the epidemic realize. Empirical studies document the link between positivity and health outcomes, for example, a Mayo Clinic study following a cohort of 839 patients over a 30 year period found a link between optimism in how people explained life events and a lower risk of early death (Maruta, Colligan et al. 2000). A study of 180 elderly Catholic nuns whose journals had quantifiably more positive entries lived an average of 10 years longer than the “negative” nuns (Danner, Snowdon et al. 2001). A 35-year longitudinal study of Harvard graduates found that a pessimistic explanatory style was a risk factor for physical illness (Peterson, Seligman et al. 1988). Researchers have even analyzed blood counts and found optimists to have more T4 cells (Peterson and Bossio 1991). Dr. Barbara Fredrickson (2013) argues that positive emotions are not trivial luxuries, but instead may be critical necessities for optimal functioning protecting humans from, and undoing, negative emotions, fueling resilience, broadening thinking and creativity, and breaking down racial barriers, thus producing optimal functioning individuals and organizations, building reserves of physical, intellectual, social, and psychological resources and improving group performance (Frederickson 2013). In this study, all but one participant reported the research experience making them feel motivated to effect changes in Lesotho; none of them stated being “satisfied” that enough had been done to fulfill the potential change that the
findings could have made. Yet, eight of ten research team members stated having “hope” for change. Interestingly, the three individuals who did not cross the researcher line (and reported frustration in not doing and giving enough during the research) were among the few still actively involved in formal HIV prevention activities. Was this due to compliant characteristics in these individuals that helped them to follow the rules and continue working in the HIV sector? Or was there some mechanism in their frustration of not crossing the line that served as a motivation, or facilitator of dedication towards HIV prevention in the country? What is the dynamic balance between frustration, anger, hope, love, disengagement and social action? In consideration of the studies linking positivity with individual and organizational outcomes, a further point of study would be the effect of hope, positivity, and “love” in affecting social and cultural change.

In conclusion, these sub-sections applying Clifton’s bucket theory to specific aspects of the epidemic in Lesotho aid in understanding how organizational practices lead to disengagement and hamper the difference individuals can make in affecting positive change in Lesotho. Mechanisms of disengagement included the way in which foreign donor management in the response dictates measures and indicators that do not necessarily match the needs at the local level. Disengagement is also fostered by false optimism where the lack of change in culturally embedded norms such as MCP and intergenerational relationships are ignored and outsider driven initiatives such as condom distribution, testing and enrollment into treatment and treatment for prevention are praised. Clifton’s concept that each interaction has the potential to make a difference in the life and organization in which an individual works, be it positively or negatively, is another strong theme in these study results. The dissertation results demonstrate the importance in fostering the right conditions to allow individuals to make a difference in HIV prevention where and when they can. For example, acknowledging and tapping into the way that experience in learning and talking about sex, MCP and HIV flow into various formal and informal settings. There is also a need to change research practice norms surrounding the process of dissemination and creating a positive work environment where space is created for research assistants and study management to critically discuss difficult questions.
Looking back to the example of the North Korean War camp at the beginning of this section, what if the way out of the epidemic is through harnessing genuine positive emotions and engagement? Or as one participant said, “the love”? The following points invert the problems in Lesotho I listed previously that were compared to the mechanisms employed in the war camp. Here the previous points are converted into general recommendations for those working in the HIV response in Lesotho, or in similar settings on how to support creating HIV related work environments that foster long-term local engagement. Within the context of translating biomedical approaches into real world realities these recommendations will help researchers and interventionists to create a better context for the spread of innovation as well as the inclusion of social, behavioral and economic approaches.

1. **Deprofessionalize the problem**—Stakeholders often promoted the notion that talking about HIV is not something just for experts but everyone’s responsibility within their realm of influence. HIV research or programming employers should explain and teach about HIV and its cultural nuances rather than relying on an assumed knowledge based on info-bites and “messages” disseminated in the general population. Stakeholders should provide space for questions and answers throughout project duration oftentimes freshly hired employees do not want to reveal their ignorance about certain aspects of HIV, however as time passes, rapport is built, experience accumulates and a space for sincere exchange and learning opens. Employers should emphasize that even if employees are not an “expert” in all aspects of HIV that they should still share what they know, and provide a list of persons/resources where they can find out what they don’t know.

2. **Provide culturally appropriate opportunities** to talk or to train individuals so they are equipped for dialogue when the moment arises. Provide ongoing general capacity building to improve communications skills and knowledge about the local epidemic. Trainers can utilize role-play, video discussions, guest speakers, to help employees maintain a personal, local connection with the epidemic and improve their skills for communicating with others about HIV and MCP. Take the time in advance and throughout the life of the project to review the meaning and application of ethical practices and perspectives. For example, if there was more space during the life of the project to discuss and review the
implications of the researcher vs. interventionist line in the specific temporal and cultural context in Lesotho, perhaps there would have been different steps taken to provide support to the researchers (emotionally and informationally) as well as in meeting the expectations of participants. In the future, this means coming up with clear strategies on the distinctions between providing needed information, clearing up misconceptions with that of giving life-altering advice, “tainting” the research community by introducing bias into the way people respond, or inadvertently being judgmental and scaring/scaring participants. Further creativity and flexibility on the part of investigators, funders and IRB’s for experimenting with diverse mechanisms to provide needed feedback and information back to research participants and communities while the primary study is underway.

3. **Promote transparency, good management, and anti-corruption**—While these aspects may seem tangential, this research demonstrates that the lack of transparency, good management and witnessing corruption result in a deep disengagement for many individuals working within the AIDS response. By promoting transparency, good management, and anti-corruption practices organizations facilitate an environment where employees are motivated and engaged by being a part of an organization serving well the people of Lesotho. This environment helps to restore belief in in-country leadership, as well as the good intentions of outside funders.

4. **Respond to cries for help in stopping the growth of inequalities, creating work and creating division**—Oftentimes, research and project managers view these aspects as beyond the scope of their specific project. However, by responding, even if in a small way, to the way in which each project has the potential to either foster inequalities or help to build up social cohesion can make a difference. For example, thinking of creative ways and collaborations that allow projects and services to transform the notion of “eligibility” criteria to more sustainable social fabric supportive solutions. Solutions may also include collaborations that are more direct where project employees dedicate time, brain power or a certain percentage of their pay to supporting the growth of a local initiative.

5. **Promote keener attention to the proportionality of funding and support**—Currently, funding in Lesotho is significantly higher for medical, technical solutions such as condoms, health
equipment, and medicine. At the same time, it is difficult to determine how much money is coming in and going out for HIV initiatives. The last attempt to quantify HIV organizations and spending was in 2007. Institutions that have the power to illuminate the exact proportions of funding allocated will help inform future distributions of resources. For example, this research found that relatively little investment was given to implementing MCP and HIV community level interventions. By quantifying where money is going and for what there may be better justifications for targeting or sharing donor funding in other directions. One possible solution could be well-funded clinical projects like EGPAF and BIPAI, which currently focus on treatment of mothers and children, expanding to offering a combined outreach that includes a social and behavioral community component like the MCP dialogues. Clearly, assessing HIV spending and GDP contributions will strengthen arguments towards balancing the investment in biomedical approaches with other inter-human social solidarity and culturally appropriate education opportunities. As well as provide insights for more radical discussions about how “benefits” from research conducted on Basotho bodies is repatriated and distributed.

6. **Stop the undeserved praise chain**—Stakeholders working in HIV prevention in Lesotho must assess and admit to where things have gone wrong in prevention and seek out diverse local voices in envisioning alternative approaches to HIV risk reduction and elimination.

Great leaders seem to walk near the Drakensberg Mountains. Mandela, Gandhi, Tolkien and Moshoshoe I all walked in its shadows and changed history with their wisdom, mercy, and justice, leading and defying the thinking and oppressive powers of their time. Their influence is not confined to their lifetime, but still lives on today reminding humanity to fight and demand dignity for all peoples to live, work, and love in peace and freedom rather than accept the comfortable norm of exploitation, privilege, and oppression. May they inspire us to listen and act.
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APPENDICES
Appendix A: Article on racial, wealth and power dynamics of the 50’s and 60’s intertwining supernatural, biomedical and traditional justifications (Malieketseng 2012)

Appendix B: Article showing preferential treatment to foreign investors over locals
Appendix C: EGPAF and BIPAI Operational Research in Lesotho Similar to Clinical Trials

The types of research EGPAF has conducted include evaluating the effectiveness of the PMTCT programs post-implementation of Option B+ measuring HIV sero-incidence and HIV transmission and HIV-free survival rates among cohorts of HIV-negative and HIV-positive pregnant women and their infants; determining the population based 18-24 month HIV free survival among HIV exposed children, as well as factors associated with child HIV infection, death or HIV-free survival; field testing an innovative HIV test for rapid HIV detection in infants; and “a community focused intervention” to increase service uptake and retention among a cohort of HIV-positive and HIV-negative women in pregnancy through 18 months postpartum. They also have JAIDS published articles on preventing TB among HIV-infected pregnant women and the association between HIV status and antenatal care attendance in rural hospitals (EGPAF 2016).

(BIPAI 2016). Other examples of their research activity includes a retrospective study evaluating Isoniazid preventive therapy on anemia on HIV infected children, a prospective comparison of adherence to HAART between sites, and evaluating comparisons of the effectiveness of using single drug Zidovudine versus a 3-drug combination therapy for PMCT. In addition to the medical staff they employ a full-time treatment literacy, social work, nutritional, psychological staff and peer educators. The description of their patient home visits reads like trial follow-up standard procedures where “lost from care” substitutes “lost to follow-up”:

Patients who miss clinic appointments and fail to return for care are traced using a combination of phone calls and physical visits to their homes by a team of nurses, social workers, and trained volunteers. Over the last year, nearly 2,000 patients were called or visited to ensure retention in care. This resulted in dramatic reductions in patients who are lost from care and therefore receive inadequate treatment. The volunteers also visit households affected
Appendix D: 2011 Lesotho Pharmaceutical Country Profile

The 2011 Lesotho Pharmaceutical Country Profile report notes that there are no laws for authorizing import of medicines, legal provisions do not exist for controlling the pharma market, no independent lab for quality control testing, there are no legal or regulatory provisions affecting pricing of medicines, control the promotion and advertising of prescription meds legal provisions do not exist requiring authorization for Clinical Trials, no laws about ethics committee or IRB, for GMP compliance of investigational products, sponsor investigators are not legally required to comply with Good Clinical Practices, Legal provisions do not permit the inspection of facilities where clinical trials are performed (MoHSW and WHO 2011).

Appendix E: Part 1 Juxtaposing sources connecting employment, politics, inequalities, and pharmaceuticals larger more easily legible version of the texts (Editorial 2012; Lekhetho 2012)
Appendix E: Part 2 Juxtaposing sources connecting employment, politics, inequalities, and pharmaceuticals larger more easily legible version of the texts (Editorial 2012; Lekhetho 2012)

Excesses of a democracy

The quintessential American inventor of the light bulb amongst others and founder of General Electric, Thomas Edison, once revealed he did not understand Ohm’s law at the time he experimented on the incandescent lamp. On another occasion, he said: “I do not depend on the figures at all. I try an experiment and reason out the result, somehow, by methods I could not explain.”

Edison’s lack of understanding of Ohm’s law and figures is understandable as he lacked formal education. What is not clear is whether it was his deafness that strongly influenced his behaviour and career, providing the motivation for many of his inventions.

Yet, watching clueless politicians on Lesotho Television in the evenings baffles me as you would expect some of them to know basic principles of logic as they carry strings of degrees and honorary doctorates. Unlike Edison, they had the privilege to study for many years at universities and colleges both at home and overseas. They bear no signs of handicap or deformities that could be attributed to their disservice to the Basotho nation.

Dr Pakalitha Mosisili’s rhetoric in Mokholondi recently was one of his many misguided speeches in his long political career. He continued to talk to the people about millions of maloti the Democratic Congress (DC) would spend on road construction if it won elections, failing to grasp the logic behind such a project for a rustic audience, the majority of which is immobile. He went on a feeding frenzy of figures to some of the poorest people in Lesotho, who cannot afford bus fare, let alone an ox-pulled carriage.

Years of aloofness and materialistic lifestyle have left people like him obsessed with huge sums of money and highways, forgetting millions go hungry everyday because they are broke. Ordinary citizens are afflicted with pain and sorrow when someone who is supposed to be head of government, boasts about spending when they are starving.

We have experienced a long period of ignorant people who go to political rallies to show-off their egos and arrogance. We are tired of a ruling class that is incapable of understanding roads are built to create jobs first, and comfort next, in a country where the majority is unemployed.

After a disgraced term of political infighting and irrelevance, the All Basotho Convention (ABC) wants Christianity to become part of our Constitution. It is amazing how some Basotho are so indoctrinated from religious propaganda of the fallen Roman Empire, whose power the prophetic agents of our time are trying to resuscitate. A redeeming feature for the DC, we are surprised at the foolishness of the ABC to scoff at other religions with the hope they would win an election for using Christianity as their wild card.

We know all the dark history of Christianity. We know its campaign of torture, mutilation, mass murder and destruction of human life. We cannot be infiltrated by some of the pagan symbols and practices it adopted. We cannot flirt with Christianity laws.

Similarly, Wednesday this week was a nightmare. Anybody who watched Lesotho Television that night would conclude democracy is a pathetic phenomenon with self-proclaimed politicians wanting to quarantine people living with HIV/AIDS. Although Lesotho has yet to benefit from leaders with great education, Basotho are often ensnared by individuals such as these, whose lack of education has exposed their danger and disasters nature to society.

There is too much freedom of speech in this country because that night we were fed with insanity and reckless thinking. We do not mind that the secretary general is the wife of the party leader. Nor do we care much that the party structures comprise family members. But we scorn at mediocrity of regression when the world progresses.

Do not be fooled that Lesotho is far from primitive years as we were made to believe the country would become a better place without Indians and Chinese because they are suicide bombers and worship a dragon, respectively. We were made to believe whites are infecting us with AIDS. How do we describe all these theories? What sort of political leaders do we have?
Appendix F: Excerpts taken from the Lesotho Global AIDS Country Progress Report
documenting 8 significant development partners the types of activities they were
supporting and the financial commitment reported

<table>
<thead>
<tr>
<th>Development Partner</th>
<th>Types of Activities Supported</th>
<th>Financial</th>
</tr>
</thead>
<tbody>
<tr>
<td>JOINT UN COUNTRY TEAM</td>
<td>Capacity development within the health sector, particularly for provision of high quality ART to adults and children; systems strengthening both within the national HIV and AIDS response and across the health sector; support for evidence-based programming planning, implementation and review; advocacy and law and policy development; support to vulnerable groups; and, strengthening of country capacity to effectively coordinate the national multi-sectoral response to HIV and AIDS for high impact results.</td>
<td>Approximately 25% of the USD85 million budgeted within the UNDAF are targeted towards its HIV and AIDS priorities.</td>
</tr>
<tr>
<td>Global Fund.</td>
<td>Round 6 grant supports capacity-building for TB prevention and treatment. Round 7 grant paediatric HIV treatment, interventions for youth, both in and out of school, including high school bursaries for OVC. The Round 8 grant, the largest and most comprehensive in the country’s portfolio, support all aspects of the HIV and AIDS response, including prevention, treatment and care. Health system strengthening, primary focus on improving health service delivery and health human resource retention. Round 9 grant primarily supports high school bursaries for OVC and basic education for children and adolescents not enrolled in primary school.</td>
<td></td>
</tr>
<tr>
<td>PEPFAR</td>
<td>PEPFAR support assisted the country to provide HTC, to enroll adults and children on ART, to manage HIV/TB co-infected individuals, to provide PMTCT and to support OVC. Going forward, PEPFAR will focus its support on HIV prevention interventions, care and support for OVC, and health systems strengthening. PEPFAR has assisted the MOHSW to establish the Institute for Health Measurement as way of institutionalizing the collection and use of comprehensive, valid and reliable data on health system and public health trends, more particularly HIV and AIDS.</td>
<td>5-year partnership agreement covering the period 2010-2015. The nominal value of the partnership is USD29.2 million per year;</td>
</tr>
<tr>
<td>Millennium Challenge Account (MCA)</td>
<td>Infrastructure projects, including refurbishment of health centre, construction of a national reference laboratory, expansion of facilities at the country’s tertiary health training facilities, and construction of a new central blood bank. The MCA programme also has a substantial health systems strengthening</td>
<td>Country Compact with the US government in 2007, the implementation of Lesotho’s USD362 million Millennium Challenge Account (MCA)</td>
</tr>
<tr>
<td>Clinton Health Access Initiative</td>
<td>Assisting the MOHSW to strengthening and expand paediatric HIV treatment, strengthen and improving quality assurance for country-wide laboratory services, strengthening the ability of health providers to provide high quality care to HIV-positive adults and children,</td>
<td></td>
</tr>
<tr>
<td>Organization</td>
<td>Contribution</td>
<td>Details</td>
</tr>
<tr>
<td>-------------------------</td>
<td>--------------------------------------------------------------------------------------------------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>(CHAI)</td>
<td>contributing to health human resources recruitment and retention through the Rural Health Access Initiative, supporting the expansion of PMTCT, and assisting the country to develop operational research capacity.</td>
<td></td>
</tr>
<tr>
<td>World Bank</td>
<td>Systems strengthening interventions for NAC, primarily in the domain of coordination and expenditure tracking, capacity strengthening for LCN in its role as a PR under the Global Fund Round 8 grant, and strengthening the capacity of the MOHSW to manage and promote health-related research programmes. In 2011, the World Bank began an initiative with the MOHSW in order to strengthen compliance with PMTCT protocols at the community level.</td>
<td>Starting in 2010, the World Bank launched a second HIV and AIDS Technical Assistance Project. The 5-year programme, worth USD5 million,</td>
</tr>
<tr>
<td>Irish Aid (IA)</td>
<td>Contributes to the national HIV and AIDS response through three main priorities: PMTCT, health human resources, and education sector programmes, support for HIV and AIDS programmes within schools. This includes support for the MOET’s life-skills curriculum taught at all levels of primary and secondary school. The programme combines information about general health and well-being with specific information on sexual and reproductive health and prevention of HIV-infection. IA also partners with a number of faith-based organisations, teachers unions and other grassroots groups to strengthen their response to HIV and AIDS.</td>
<td></td>
</tr>
<tr>
<td>DEUTSCHE GESELLSC HAFT FÜR INTERNATIONALE ZUSAMMENARBEIT (GIZ)</td>
<td>Financial and technical support to ensure that response to HIV and AIDS is a priority within local governments’ community development and poverty reduction plans.</td>
<td></td>
</tr>
<tr>
<td>JAPANESE INTNRL. COOPERATION AGENCY (JICA)</td>
<td>CHAL and the National Health Training College, to strengthen their ability to collect, analyse and use data for the purposes of impact assessment and quality improvement.</td>
<td></td>
</tr>
</tbody>
</table>
Appendix G: Draft roadmap for the implementation of the 2011 Revitalized and Energized HIV Prevention concept note detailing activities, timeline, responsibilities and indicative cost.

<table>
<thead>
<tr>
<th>Activity</th>
<th>Time-line</th>
<th>Responsible</th>
<th>Indicative cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Finalize the concept note</td>
<td>4/04/11</td>
<td>drafting team</td>
<td>n/a</td>
</tr>
<tr>
<td>Concept note approved by the Hon. Minister</td>
<td>11/04/11</td>
<td>DGHS</td>
<td>n/a</td>
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<tr>
<td>Endorsement of the concept by the cabinet</td>
<td>19/04/11</td>
<td>Hon. Minister of Health &amp; Social Welfare</td>
<td>n/a</td>
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<tr>
<td>Establishment of high level steering committee &amp; follow up meetings</td>
<td>13/04/11</td>
<td>Cabinet Sub-Committee on HIV and AIDS</td>
<td>US$500</td>
</tr>
<tr>
<td>Conduct nation-wide consultations with stakeholders on accelerated HIV prevention strategies/ programs</td>
<td>30/05/11</td>
<td>High Level Steering Committee (HLSC)</td>
<td>US$150,000.00</td>
</tr>
<tr>
<td>Mapping of HIV prevention interventions and programs at the community and district council level</td>
<td>30/05/11</td>
<td>Open - TBD</td>
<td>US$50,000.00</td>
</tr>
<tr>
<td>Develop and implement national social mobilization strategy for revamped HIV prevention</td>
<td>30/06/11</td>
<td>Multi Sectoral Prevention TWG</td>
<td>US$200,000.00</td>
</tr>
<tr>
<td>National Partnership forum held</td>
<td>15/07/11</td>
<td>TBD (Under review)</td>
<td>US$30,000.00</td>
</tr>
<tr>
<td>Costed joint prevention operational plan developed</td>
<td>15/08/11</td>
<td>HLSC</td>
<td>US$10,000.00</td>
</tr>
<tr>
<td>Endorsement and approval of the operational plan</td>
<td>15/08/11</td>
<td>Cabinet Sub-Committee on HIV and AIDS</td>
<td>n/a</td>
</tr>
<tr>
<td>Capacity building for decentralized structures for revamped HIV prevention</td>
<td>30/08/11</td>
<td>M/S Prevention TWG</td>
<td>US$50,000.00</td>
</tr>
<tr>
<td>Roll out of operational plan (see Annex 1)</td>
<td>15/08/11</td>
<td>All Stakeholders</td>
<td>TBD</td>
</tr>
<tr>
<td>Champions identified and empowered</td>
<td>1/09/11</td>
<td>HLSC</td>
<td>US$25,000.00</td>
</tr>
<tr>
<td>National prevention symposium and launch of the revolution</td>
<td>30/11/11 - 01/12/11</td>
<td>Hon. Prime Minister</td>
<td>US$200,000.00</td>
</tr>
</tbody>
</table>

*Note: Key activities such as periodic media briefings and social/community mobilization strategies are running concurrent to many of these processes (Team 2011).*
Appendix H: University of South Florida Initial IRB Approval

January 17, 2012

Sharon Watson
Anthropology

RE: Expedited Approval for Initial Review
IRB#: Pro00006515
Title: Disseminating qualitative research and experience for practical use: A case study from an HIV project in Lesotho

Dear Sharon Watson:

On 1/14/2012 the Institutional Review Board (IRB) reviewed and APPROVED the above referenced protocol. Please note that your approval for this study will expire on 1/14/2013.

Approved Items:
Protocol Document(s):

Watson_IRB_protocol_12_04_11.doc  12/6/2011 11:59 AM  0.01

Please note: before the PI can proceed with the study, amendments must be submitted documenting local approval for each of the study studies. The PI can proceed with the study at each site when an amendment has been submitted and approved for that site.

Consent/Assent Documents:

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It was the determination of the IRB that your study qualified for expedited review which includes activities that (1) present no more than minimal risk to human subjects, and (2) involve only procedures listed in one or more of the categories outlined below. The IRB may review research through the expedited review procedure authorized by 45CFR46.110 and 21 CFR 56.110. The research proposed in this study is categorized under the following expedited review category:

(5) Research involving materials (data, documents, records, or specimens) that have been collected, or will be collected solely for nonresearch purposes (such as medical treatment or diagnosis).

(6) Collection of data from voice, video, digital, or image recordings made for research purposes.

(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Please note, the informed consent/assent documents are valid during the period indicated by the official, IRB-Approval stamp located on the form. Valid consent must be documented on a copy of the most recently IRB-approved consent form. **These watermarked forms can be found under the Attachment Tab.**

As the principal investigator of this study, it is your responsibility to conduct this study in accordance with IRB policies and procedures and as approved by the IRB. Any changes to the approved research must be submitted to the IRB for review and approval by an amendment.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely,

John Schinka, PhD, Chairperson
USF Institutional Review Board

Cc: Various Menzel, CCRP
    USF IRB Professional Staff

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Appendix I: Lesotho Ministry of Health and Social Work Initial IRB Approval

Ministry of Health and
Social Welfare
PO Box 514
Maseru 100

Date: 24 April 2012

Sharon Watson (MPH)
PhD Candidate
University of South Florida
Department of Anthropology

Dear Sharon,

Re: Disseminating qualitative research and experience for practical use: A case study from HIV project in Lesotho

Thank you for resubmitting the above mentioned protocol. The Ministry of Health and Social Welfare Research and Ethics Committee having reviewed your protocol hereby authorizes you to conduct this study among the specified population. The study is authorized with the understanding that the protocol will be followed as stated. Departure from the stipulated protocol will constitute a breach of the permission.

We are looking forward to have a progress report and final report at the end of your study.

Sincerely,

[Signature]

Dr. M. M. Moteete
Director General of Health Services and
Chairperson Research and Ethics Committee
Appendix J: Expanded description timeline of MCP research, policy, programming, funding dynamics and biomedical technological innovations in Lesotho (Figure 15)

<table>
<thead>
<tr>
<th>Short Title</th>
<th>Category</th>
<th>Start Year</th>
<th>End Year</th>
<th>#</th>
</tr>
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<tbody>
<tr>
<td>Quantitative studies document MCP</td>
<td>Research</td>
<td>1989</td>
<td>2004</td>
<td>1</td>
</tr>
<tr>
<td>Qualitative studies document MCP</td>
<td>Research</td>
<td>1991</td>
<td>2005</td>
<td>2</td>
</tr>
<tr>
<td>SBS studies documenting MCP in Lesotho (Spiegel 1991; Romero-Daza and Himmelgreen 1998; Magrath 2005).</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Foreign donors carry majority HIV/AIDS budget</td>
<td>Funding Dynamics</td>
<td>1990s</td>
<td>2008</td>
<td>3</td>
</tr>
<tr>
<td>Late 90’s through early 2000’s foreign donors carry more than half of the total HIV/AIDS national budget.</td>
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<tr>
<td>Know your status campaign, first univ. testing initiative</td>
<td>Biomedical Tech Innov.</td>
<td>2005</td>
<td>2007</td>
<td>4</td>
</tr>
<tr>
<td>2005-2007 first in the world to initiate the “Know Your Status Campaign” a universal testing initiative with door to door testing providing researchers with learning about testing outreach and testing technology.</td>
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<tr>
<td>Elizabeth Glaser Pediatric AIDS Foundation</td>
<td>Biomedical Tech Innov.</td>
<td>2005</td>
<td>through present</td>
<td>5</td>
</tr>
<tr>
<td>Elizabeth Glaser Pediatric AIDS Foundation (EGPAF), supported by PEPFAR, CDC, USAID controls over 220 sites in all ten districts of Lesotho trained over 3,000 medical staff and served on various advisory boards, “enrolled” more than 227,900 clients into HIV care and support programs, started 113,300 individuals on ART, provided PMTCT services to 183,000 women, screened 4,200 women for cervical cancer and treated 350 precancerous lesions</td>
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<tr>
<td>2005 Baylor College of Medicine Children's Foundation—Lesotho (BCMCF-L) operates the BCM/Bristol-Myers Squibb Children's Clinical Center of Excellence (COE) in Maseru, and five BCM/Texas Children’s Hospital/Bristol-Myers Squibb Satellite Centers of Excellence (SCOE)s (BIPAI 2016). The project is a private public partnership sponsored by Bristol-Myers Squibb and the Abbot Fund (from Abbot Pharma) in collaboration with the Lesotho national government. Provides medical expertise, training and help with decentralizing health care outside the capital through outreach programs, teen clubs, and educational efforts. Operational research.</td>
<td></td>
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<tr>
<td>SADC identifies MCP as key regional nuance</td>
<td>Policy</td>
<td>2006</td>
<td>2006</td>
<td>7</td>
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<tr>
<td>2006 SADC Think tank identifies MCP as key regional nuance of epidemic.</td>
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<tr>
<td>2006 ESP package initiated, 2009 integrates sexual behavior MCP</td>
<td>Programming</td>
<td>2006</td>
<td>2011</td>
<td>8</td>
</tr>
<tr>
<td>Essential HIV and AIDS services Packages initiated in 2006 begins to incorporate sexual behavior MCP in 2009 (2006-2011)</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>NAC, UNAIDS &amp; FHI MCP study--dissertation case study</td>
<td>Research</td>
<td>2007</td>
<td>2008</td>
<td>9</td>
</tr>
<tr>
<td>MCP study 2008 NAC, UNAIDS and FHI—dissertation case study</td>
<td></td>
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<tr>
<td>Lesotho spends 64% of Health expenditure on HIV/AIDS</td>
<td>Funding Dynamics</td>
<td>2007</td>
<td></td>
<td>10</td>
</tr>
<tr>
<td>Lesotho spends 64% of its health expenditure on HIV/AIDS in 2007 (Amico, Aran et al. 2010).</td>
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<td></td>
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<tr>
<td>2% prevention funding goes towards communication for SBC</td>
<td>Funding Dynamics</td>
<td>2007</td>
<td></td>
<td>11</td>
</tr>
</tbody>
</table>

485
The 2006/2007 NASA reports only 2% of prevention funding going towards communication for social and behavioral change (NAC/MoHSW/UNAIDS 2009).

| US MCA $362 million for ref lab, blood bank, medical university | Funding Dynamics | 2007 | 12 |


| National Strategic Plan for HIV/AIDS | Policy | 2008 | 2011 | 14 |
| The National Strategic Plan for HIV and AIDS 2008-2011 |

| GOL increase responsibility to HIV budget (unclear if through loans) | Funding Dynamics | 2008 | 15 |
| Government of Lesotho (GOL) took up more responsibility for the national budget averaging between 50% and 60% of the total HIV budget (unclear if through loans) |

| GOL invests most in provision of ART. International sources towards prevention | Funding Dynamics | 2008 | 16 |
| Global AIDS Country Progress Report (GAPR) report is “the GOL invests most is in the provision of ART. Funds from international sources are largely directed towards prevention” (MoHSW 2012: 76). |

| UN allocates 25% of $85 million towards high quality ARVs | Funding Dynamics | 2008 | 17 |
| The UN allocating 25% of its $85 million towards HIV and AIDS priorities particularly for the provision of high quality ARVs. |

| Baseline survey of MCP among Basotho men | Research | 2009 | 18 |
| A Baseline Survey of Multiple and Concurrent Sexual Partnerships among Basotho Men in Lesotho (Volle, Foreit et al. 2009) |

| Language of MCP, sex and HIV/AIDS--dialogue promotion | Research | 2009 | 19 |
| The language of multiple Concurrent Partners, Sex and HIV and AIDS: Opportunities for dialogue promotion (Sigamoney 2009). |

| DHS reconfirms high prevalence of concurrency | Research | 2009 | 20 |
| The 2009 DHS reconfirmed the high prevalence of concurrency |

| Lesotho HIV prevention response, modes of transmission | Research | 2009 | 21 |
| Lesotho HIV Prevention Response, Modes of Transmission Analysis (Study) highlights the significant role of MCP (Motlelepu, Tsehlo et al. 2009) |

<p>| C-Change, Soul City, CARE and PHELA MCP Campaign-Mass media &amp; community outreach | Programming | 2009 | 2011 | 22 |
| C-Change HIV MCP communications campaign using mass media and community based outreach. Lesotho campaign activities include a radio and a television talk show, public service announcements (PSAs), a radio drama, and 2 booklets and 5 billboards. The campaign was run by Phela Health and Development Communications along with C-Change and its member organisations Soul City, Social Surveys, and CARE. The OneLove, 2009 to 2011 by Soul City and UKAID. February to September 2009, 12 60-minute talk shows were broadcast on television stations in Lesotho. Onelove radio drama was broadcast in October 2009 45-episode drama supported by a marketing campaign including radio, sports events, and newspaper adverts. 15-minute radio talk show |</p>
<table>
<thead>
<tr>
<th>Event</th>
<th>Funding Dynamics</th>
<th>Year(s)</th>
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<tbody>
<tr>
<td>Increase prevention spending attributed to roll-out of PEP</td>
<td>Funding Dynamics</td>
<td>2009</td>
<td>23</td>
</tr>
<tr>
<td>2009/2010 increase in prevention spending is partially attributed to</td>
<td></td>
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<tr>
<td>the roll-out of post-exposure prophylaxis in medical</td>
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<tr>
<td>facilities for occupational safety as well as protocol for</td>
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<tr>
<td>victims of sexual assault (NAC 2011: 93)</td>
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<tr>
<td>The Clinton Health Access Initiative (CHAI) is also listed as one of</td>
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<td>through</td>
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<tr>
<td>the eight significant development partners, the actual amount of</td>
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<td>present</td>
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<tr>
<td>funding is not listed, but it too focuses on HIV treatment, PMTCT</td>
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<tr>
<td>better laboratory systems and increasing operational research</td>
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<tr>
<td>capacity in the country (MoHSW 2012: 77).</td>
<td></td>
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<tr>
<td>Relationships Intimacy Without Risk Dialogues</td>
<td>Programming</td>
<td>2010</td>
<td>25</td>
</tr>
<tr>
<td>Relationships: Intimacy Without Risk dialogue kit facilitator’s</td>
<td></td>
<td>2010</td>
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<tr>
<td>guide, a training manual and communications materials</td>
<td></td>
<td>2012</td>
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<tr>
<td>implemented in 5/10 districts in Lesotho. The project trained</td>
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<tr>
<td>350 facilitators and engaged 689 community members in</td>
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<tr>
<td>dialogue groups.</td>
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<tr>
<td>OneLove 10 short films &quot;Love stories in a time of HIV/AIDS&quot;</td>
<td>Programming</td>
<td>2010</td>
<td>26</td>
</tr>
<tr>
<td>OneLove campaign in Lesotho broadcast the &quot;Love Stories in a Time of</td>
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<tr>
<td>HIV and AIDS&quot;</td>
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<tr>
<td>Dissolution of NAC initiates</td>
<td>Policy</td>
<td>2010</td>
<td>27</td>
</tr>
<tr>
<td>AED contracts freeze</td>
<td>Policy</td>
<td>2010</td>
<td>28</td>
</tr>
<tr>
<td>National HIV budget increases by 140% only 12% allocated to prevention</td>
<td>Funding Dynamics</td>
<td>2010</td>
<td>29</td>
</tr>
<tr>
<td>National HIV and AIDS response budget increased by 140% but only</td>
<td></td>
<td></td>
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<tr>
<td>12% allocated for HIV prevention. (NAC 2011; MoHSW 2012: 74)</td>
<td></td>
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<tr>
<td>Prevention #4 funding--#1 Treatmt, #2 Orphan/vul child #3, Prog Mgmt</td>
<td>Funding Dynamics</td>
<td>2010</td>
<td>30</td>
</tr>
<tr>
<td>Prevention is in 4th place in terms of funding by thematic area (1.</td>
<td></td>
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<tr>
<td>Treatment, care and support, 2. Orphaned and Vulnerable Children, 2.</td>
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<tr>
<td>Program Management) (NAC 2011; MoHSW 2012: 74)</td>
<td></td>
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</tr>
<tr>
<td>PEPFAR provides $29.2 million per year for testing, counseling,</td>
<td>Funding Dynamics</td>
<td>2010</td>
<td>31</td>
</tr>
<tr>
<td>ARV’s, and TB</td>
<td></td>
<td>2015</td>
<td></td>
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<tr>
<td>PEPFAR providing $29.2 million per year 2010-2015 for testing,</td>
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<tr>
<td>counseling, ARV’s and TB treatment.</td>
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<tr>
<td>Lesotho government provides ART to all pregnant women</td>
<td>Biomedical Tech Innov.</td>
<td>2010</td>
<td>32</td>
</tr>
<tr>
<td>In 2010, Lesotho first country to revise their PMTCT policies,</td>
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<tr>
<td>based on WHO recommendations, to providing antiretroviral treatment</td>
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<td>for all pregnant women regardless of their CD4 count or viral load—</td>
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<td>making it possible to implement in facilities stocked with the</td>
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<td>treatment (MoHSW 2012).</td>
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<tr>
<td>National Strategic Plan for HIV/AIDS</td>
<td>Policy</td>
<td>2011</td>
<td>33</td>
</tr>
<tr>
<td>The National Strategic Plan for HIV and AIDS 2011-2016</td>
<td></td>
<td>2016</td>
<td></td>
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<tr>
<td>National Prevention Symposium</td>
<td>Policy</td>
<td>2011</td>
<td>34</td>
</tr>
<tr>
<td>National HIV Prevention Symposium 300 delegates from public and</td>
<td></td>
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<tr>
<td>private sectors, signed a statement of commitment, inclusive of</td>
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<tr>
<td>MCP prioritization.</td>
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<tr>
<td>LETLAMA New Revitalized and Energized Prevention Response</td>
<td>Policy</td>
<td>2011</td>
<td>35</td>
</tr>
<tr>
<td>LETLAMA. PSI took the lead in designing and implementing the New</td>
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<tr>
<td>Revitalized and Energized Prevention Response.</td>
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<tr>
<td>Under this umbrella, LETLAMA had a five-year project (2011-2016)</td>
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<tr>
<td>Pusha Love.</td>
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<tr>
<td>MOHSW assumes NAC responsibilities</td>
<td>Programming</td>
<td>2011</td>
<td>36</td>
</tr>
<tr>
<td><strong>FHI assumes AED</strong></td>
<td>Programming</td>
<td>2011</td>
<td>37</td>
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<tr>
<td><strong>Pusha Love Brand Promotion</strong></td>
<td>Programming</td>
<td>2011</td>
<td>38</td>
</tr>
<tr>
<td>Biomedical</td>
<td></td>
<td>2016</td>
<td></td>
</tr>
<tr>
<td>LETLAMA (2011-2016) Pusha Love brand promotion—Services promoted HTC, PMTCT, Couples Testing, VMMC; Products: condoms; Supporting Messages: stigma, inter-generational sex, concurrency, alcohol. Focus is more on connecting people to services. MCP message present but community dialogue about message topics not part of the activities.</td>
<td></td>
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<tr>
<td><strong>New Revitalized and Energized Prevention Response Budgets…</strong></td>
<td>Funding</td>
<td>2011</td>
<td>39</td>
</tr>
<tr>
<td>Dynamics</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>New Revitalized and Energized Prevention Response budgets $25,000 for identifying and empowering champions and the $200,000 budget to the Prime Minister for the “launch of the revolution” (Team 2011).</td>
<td></td>
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<tr>
<td><strong>$112.9 million spent for condoms (1/2 of $241 million prev. strategy)</strong></td>
<td>Biomedical</td>
<td>2011</td>
<td>40</td>
</tr>
<tr>
<td>Tech Innov.</td>
<td></td>
<td>2015</td>
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<tr>
<td>Between 2011 and 2015, $112.9 million US dollars were spent for the provision of condoms, that is nearly half of the entire $241 million prevention strategy (NAC 2011: 98)</td>
<td></td>
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</tr>
<tr>
<td><strong>600 HIV NGOs - 250 focus on prevention–only 1 on MCP</strong></td>
<td>Programming</td>
<td>2012</td>
<td>41</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2015</td>
<td></td>
</tr>
<tr>
<td>600 HIV NGOs registered with Letsema/Sentebale’s website, of which, 250 organizations self-identifying as working in prevention. 30 organizations explicitly self-identified as working on Behavior Change and Communications, and eight of these organizations mentioned one of the words MCP, dialogues, life skills, community mobilization, education or Sex/STI but only one organizational project description clearly associated their work with the aim of targeting MCP.</td>
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<tr>
<td><strong>RIWR community dialogues, funding ending</strong></td>
<td>Funding</td>
<td>2012</td>
<td>42</td>
</tr>
<tr>
<td>Dynamics</td>
<td></td>
<td></td>
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<tr>
<td>Relationship Intimacy Without Risk community dialogues was cut down into a shorter program, support for in country expansion and reach decreased and funding coming to an end. Program implementers PHELA searching for new funding sources.</td>
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<tr>
<td><strong>C-change evaluation of RIWR comm. dialogues</strong></td>
<td>Programming</td>
<td>2012</td>
<td>43</td>
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<tr>
<td></td>
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<tr>
<td>C-Change evaluation of the Relationship Intimacy Without Risk community dialogues, (Meyanathan and Rogers 2012).</td>
<td></td>
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<tr>
<td><strong>Political unrest, lag in HIV response</strong></td>
<td>Programming</td>
<td>2012</td>
<td>44</td>
</tr>
<tr>
<td></td>
<td>2015</td>
<td></td>
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<tr>
<td>2012-2015 were marked by political unrest, and there was a lag in the overall HIV Response. At the end of 2015, the government started rebuilding the NAC.</td>
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<tr>
<td><strong>Option B+ initiated life-long ART to all HIV + pregnant women</strong></td>
<td>Biomedical</td>
<td>2013</td>
<td>45</td>
</tr>
<tr>
<td>Tech Innov.</td>
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<tr>
<td>2013 the government implemented option B+, providing life-long ART to all HIV+ pregnant women.</td>
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<tr>
<td><strong>First country in region to pilot UNAIDS cash transfers for prevention</strong></td>
<td>Funding</td>
<td>2014</td>
<td>46</td>
</tr>
<tr>
<td>Dynamics</td>
<td></td>
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<tr>
<td>First country in the region to pilot cash transfers for prevention (UNAIDS 2014).</td>
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<tr>
<td><strong>First Lesotho medical school</strong></td>
<td>Biomedical</td>
<td>2014</td>
<td>47</td>
</tr>
<tr>
<td>Tech Innov.</td>
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<tr>
<td><strong>PEPFAR provides total of $39 million for testing, counseling…</strong></td>
<td>Funding</td>
<td>2015</td>
<td>48</td>
</tr>
<tr>
<td>Dynamics</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>PEPFAR funding, in 2015, 118,428 individuals received antiretroviral treatment, 7,452 pregnant women received PMTCT prevention, testing and counseling were carried out for 549,913, and care and support were given for 20, 623 orphans and vulnerable children, totaling $39 million USD</td>
<td></td>
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<tr>
<td><strong>Lesotho first to adopt WHO pre-exposure prophylaxis</strong></td>
<td>Biomedical</td>
<td>2015</td>
<td>49</td>
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</table>
First country to adopt the WHO recommended use of pre exposure prophylaxis (PRE) (WHO 2015).

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<tr>
<th>Event</th>
<th>Year</th>
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<tr>
<td><strong>2014 DHS confirms ongoing prevalence of MCP</strong></td>
<td></td>
<td>50</td>
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<tr>
<td>“Seven percent (7%) of women and 27% of men reported that they had two or more sexual partners in the year before the survey…Among men, point prevalence was 8%, and cumulative prevalence was 19%. This means that at a specific point in time 6 months before the survey, 8% of men engaged in sexual relationships with two or more partners (point prevalence). The cumulative prevalence indicates that 19% of men had two or more concurrent sexual partners at any time in the 12 months before the survey. Among women, point prevalence was 2% and cumulative prevalence was 5%” (DHS 2014: 196).</td>
<td></td>
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<tr>
<td><strong>Lesotho first to roll out UNAIDS, WHO, PEPFAR guidelines…treatment regardless of CD4 counts</strong></td>
<td></td>
<td>51</td>
</tr>
<tr>
<td>In 2016, it was the first country in the world to roll-out the UNAIDS, WHO, PEPFAR promoted, “Test and Treat” guidelines for HIV throughout the country, a guideline that instead of waiting for the standard of treatment of significantly decreased CD4 counts, starts treatment upon testing positive regardless of CD4 counts</td>
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<tr>
<td><strong>NAC reinstated</strong></td>
<td></td>
<td>52</td>
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<tr>
<td><strong>Fast-Track Approach promoted by US and Lesotho Gov.</strong></td>
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<td>UNAIDS</td>
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Regards,

Jim

Jim Denton-MacLennan | Communications Manager (Editorial) | Communications and Global Advocacy | UNAIDS | Tel.: +4122 791 50 28

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<td>EGPAF</td>
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Dear Sharon,

Thanks for contacting EGPAF and I apologize for the delay. This e-mail will constitute official Foundation approval to reprint the map of CDC- and USAID- funded EGPAF sites from the "Country Spotlight: Lesotho" section on our website. Please contact me if you have additional questions.

Sincerely,

Chris

Chris Hudnall
Senior Program Coordinator, Research
Elizabeth Glaser Pediatric AIDS Foundation
16130 Ventura Blvd. #250
Los Angeles, CA 91436
T: 818.906.4525
E: chris@pedaids.org
Skype: chris.hudnall1

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<td>Newspaper</td>
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Giuseppe.Angelini@ec.europa.eu
Tue 4/18/2017 7:50 AM
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