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From Cancer to Sexually Transmitted Infection: Explorations of Social Stigma Among Cervical Cancer Survivors

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From Cancer to Sexually Transmitted Infection:
Explorations of Social Stigma Among Cervical Cancer Survivors

by

Karen E. Dyer

A thesis submitted in partial fulfillment
of the requirements for the degree of
Master of Arts
Department of Anthropology
College of Arts and Sciences
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From Cancer to Sexually Transmitted Infection: Explorations of Social Stigma Among Cervical Cancer Survivors

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ABSTRACT

This research project aims to examine the idea of stigma attached to cervical cancer in light of its association with HPV, a sexually transmitted infection (STI). The public recognition of this relationship appears to be increasing due to the current media attention surrounding HPV's causative role in the development of cervical cancer, and the newly-released HPV vaccine. Thus, this study explores the experiences and perceptions of cervical cancer patients and survivors living with this type of cancer at a moment in time when it is becoming a very visible manifestation of a sexually transmitted infection, versus one identified historically as a life-threatening cancer.

Disease-related stigma has vast individual, community, and societal repercussions: in the context of both cancer and sexually transmitted infections, it is broadly associated in the literature with decreased levels of screening, reluctance to seek treatment, decreased access to social support, economic discrimination, and major difficulties in implementing large-scale prevention efforts, such as contact tracing or name-based reporting. This study is premised on the belief that including the voices of patients and survivors themselves will provide a more holistic and complete understanding of the dimensions of cervical cancer-related stigma, which in turn will help

to inform future educational and prevention messages tailored to reduce its impact.

Additionally, it will illuminate the complexities and dynamics of how patients/survivors are able or unable to access social support—a first step in designing more effective and relevant support programs.

Chapter One:

Introduction

Much has been written on the subject of stigma and illness in recent decades. Contributions by sociologists and psychologists abound, spanning vastly different afflictions ranging from mental illness, to tuberculosis, HIV/AIDS, sex work, hepatitis C, and smoking (Collins, von Unger, and Armbrister 2008; Genberg 2008; Grow and Christopher 2008; Hallgrimsdottir, Phillips, Benoit, and Walby 2008; Macq, Solis, and Martinez 2006; Stuber, Galea, and Link 2008). Anthropologists in particular have offered meaningful and holistic documentations of the lives of those suffering with stigmatized conditions. Additionally, they have critiqued and expanded the stigma paradigm itself, arguing for the importance of the sociocultural, political, and economic context in which it is always and necessarily situated (Castro and Farmer 2005; Coreil 2008; Parker and Aggleton 2003).

It is from this anthropological lens that I examine the concept, presence, and effects of stigma in one particular case: cervical cancer. The public recognition of the relationship between cervical cancer and the human papillomavirus (HPV)—a sexually transmitted infection (STI)—appears to be increasing. This is due in large part to the current media attention surrounding HPV's causative role in the development of cervical cancer, and the newly-released HPV vaccine. Thus, this study explores the experiences and perceptions of cervical cancer patients and survivors living with this type of cancer at

a moment in history when it is becoming a very visible manifestation of a sexually transmitted infection, versus one constructed historically as a life-threatening cancer. This period in time, in which cervical cancer is being repositioned in and by educational and media messages, offers an opportunity to examine the rapid re-definition of a stigmatized condition as it occurs, and its subsequent impact on individuals previously diagnosed with cervical cancer. This study is premised on the belief that including the voices of those affected will provide a more balanced, holistic, and complete understanding of the dimensions of cervical cancer-related stigma and the potential ways that it can be alleviated.

CERVICAL CANCER AND SCREENING IN THE UNITED STATES

Cervical cancer is a major medical and public health concern around the world. The disease accounts for 3,870 deaths among over 11,000 cases diagnosed each year in the United States (ACS 2008). Mortality from cervical cancer is concentrated heavily in developing countries: indeed, it is the number two cause of cancer-related death in women globally (WHO 2008), affecting 510,000 and causing over 288,000 deaths each year (Ferlay, Bray, Pisani, and Parkin 2004).

Although once ranking among the most common causes of death among American women, the United States has witnessed a vast reduction in the rate of cervical cancer over the course of the last 50 years (ACS 2008). Indeed, the American Cancer Society reports that between 1955 and 1992, cervical cancer mortality rates declined by over 74 percent (ACS 2008). These improvements have been directly attributed to the increased utilization of the Papanicolaou (Pap) screening test, which is able to detect cell changes and abnormalities in the cervix before they advance to cancer (ACS 2008; Akers,

Newmann, and Smith 2007; Casper and Clarke 1998; Solomon, Breen, and McNeel 2007).

Developed by George Papanicolaou, a German medical doctor and zoologist, the Pap test was introduced as a screening tool in the mid-1940s (Casper and Clarke 1998). Sixty years later, it has become the most successful, widely used and “entrenched cancer-screening technology in the world” (Casper and Clarke 1998:255; Stoler 2005). Regular Pap screening is now firmly integrated into women’s preventive healthcare schedules—in one survey, nearly 85 percent of women born after 1930 had reported receiving a Pap test in the prior three years (Solomon et al. 2007). It is estimated that by the year 2010, 75 million tests will be performed annually (Solomon et al. 2007). Consistent and widespread use of the Pap test is extremely effective but also expensive, such that “a program of annual conventional Pap tests costs \$2,457 over the lifetime of a woman and reduces cervical cancer by 89%” (Goldie, Kim, and Wright 2004). Yearly, the economic burden of routine cervical cancer screening in the United States (direct medical costs) totals an estimated \$2.3 billion (Insinga, Dasbach, and Elbasha 2005).

HPV AND THE VACCINE

Over the last several years, two major scientific developments relating to cervical cancer have occurred: the discovery that HPV is a necessary factor in cervical cancer, and the development of the HPV vaccine. First, it has been recognized for some time that there is an association between cervical cancer and sexual activity, due mainly to studies demonstrating higher rates among sex workers and almost non-existent rates among nuns (Braun and Gavey, 1999a). However, scientists were recently able to isolate the agent that is the necessary factor in the development of 99 percent of all cervical cancers—the

human papillomavirus (HPV), a sexually transmitted infection (Parkin 2006). Two strains, 16 and 18, are direct factors in nearly 70 percent of all cervical cancers in the U.S. (CDC 2006). HPV can be transmitted by contact alone and does not require the exchange of bodily fluids. It is the most common sexually transmitted infection in the United States: epidemiological studies have documented infection rates in sexually active adults of 70 to 80 percent over the course of their lifetime (Burk et al. 1996; Koutsky 1997; Lorincz 1996).

Accompanied by stirring debate, controversy, fanfare, and sky-high expectations, the second vaccine to prevent a sexually transmitted infection was approved by the Federal Drug Administration (FDA) in June 2006¹. Released to the public by Merck Pharmaceuticals under the name Gardasil for females aged 9 to 26, the vaccine was advertised to prevent the four strains of the human papillomavirus (HPV) that together are responsible for 70 percent of cervical cancers and 90 percent of genital warts in the United States (CDC 2006; Merck Pharmaceuticals 2007a). Because of HPV's high prevalence rates (CDC 2008), the vaccine has the potential for widespread impact.

The ensuing years have been marked by as much controversy as they have by excitement. For the first time, a vaccine seemed poised to finally make a difference in the exceedingly high rates of cervical cancer mortality, especially in developing countries (Dailard 2006). It has been increasingly recognized among biomedical and public health professionals that cervical cancer is a “disease of disparity,” with steep gradations in socioeconomic status linked to greatly increased incidence and mortality rates stemming largely from constrained access to screening and treatment services (Akers, Newmann,

¹ Routine use of the *first* vaccine released to prevent an STI—Hepatitis B—began in 1991 among U.S. children (CDC 2007b).

and Smith 2007; Newmann and Garner 2005). Among women in the United States diagnosed with cervical cancer, the inequalities are clear: the greatest burden of cervical cancer falls on minority women, immigrants, older women, the uninsured, and those in lower income and educational brackets (Akers et al. 2007). Health disparity literature has extensively covered the barriers to screening and treatment that these same groups encounter; thus, for some, the vaccine's release represented a rare opportunity to challenge these inequalities in a cost-effective way by preventing cervical cancer's very occurrence (Saslow et al. 2007). In the U.S., steps were quickly taken in many states to consider potential vaccine mandates for school-age girls (Colgrove 2006).

Yet, just as quickly, another perspective arose and gained national recognition. The view that HPV is a result of lifestyle choices, and entirely preventable by responsible sexual behavior, led many to question the utility and ethics of the vaccine and in particular of mandatory vaccinations (Monk and Wiley 2006). A central argument in the mandatory vaccination debate was the prospect that vaccination against HPV would implicitly sanction improper pre-marital sexual conduct by adolescent girls (Dailard 2006; Monk and Wiley 2006). More specifically, it was theorized that vaccination would lead to their sexual "disinhibition," now that the vaccine would eliminate the threat of bodily harm that comes with an STI (Haber, Malow, and Zimet 2007). Thus, the vaccine was thrust into the spotlight in a national debate on morality, sexuality, and parental autonomy.

Meanwhile, Merck Pharmaceuticals had taken on the task of advertising with a vengeance, culminating in multiple awards at the 2008 Pharmaceutical Advertising and Marketing Excellence awards (Rosenthal 2008). Numerous television ad campaigns

were released that were intended to create a public awareness of HPV, and in particular, its significant role in the causation of cervical cancer. On November 13, 2006, Merck announced the launching of its now well-known campaign, *One Less*. In its press release, the company stated that this multi-media print, web and television campaign is designed to encourage Gardasil vaccination among eligible girls and women in addition to the maintenance of their regular screening routine (Merck 2006:1). Its most notable aspect is the “strong and positive message designed to empower them to want to become (or help their daughters want to become) ‘one less’ person who will battle cervical cancer” (Merck 2006:2)—specifically by learning about the connection between HPV and cervical cancer and getting vaccinated.

However, *One Less* was not the first advertising campaign initiated by Merck. A year prior to the approval of Gardasil and the subsequent launch of the *One Less* campaign, the company had already embarked on multi-lingual educational programs. Television advertisements entitled *Tell Someone* encouraged women to inform others about the link between cervical cancer and HPV, while *Make the Connection* (later *Make the Commitment*) emerged as a Merck-funded consumer-oriented campaign run by two non-profit organizations (Zimm and Blum 2006). Because Merck is prohibited legally from advertising its drug directly before FDA approval, the campaigns were designed instead to raise Americans’ awareness about the link between cervical cancer and HPV (Merck 2006)—a critical point given the company’s assertion that as of early 2005, only 20 percent of women in the U.S. were aware of HPV’s role in cervical cancer (Zimm and Blum 2006). However, critics contend that this was just a preliminary step in the roll-out

of the vaccine, a “priming of the market,” intended to create demand for the vaccine rather than reflecting a genuine concern for public health.

Merck’s intentions aside, this increasing publicity creates a predicament for women who have already been diagnosed with cervical cancer. For the first time, ad campaigns were demonstrating to the public the causal association between a sexually transmitted infection and their own cancer diagnosis—something that they may not yet have even known themselves. And, given our society’s historically complex and oftentimes stigmatizing views of women and sexually transmitted infections (Brandt 1987), it is indeed possible that this phenomenon will have unanticipated consequences on their quality of life.

RESEARCH PROJECT OVERVIEW

Thus, it is within this complicated context of national vaccine awareness campaigns, morality, stigmatization, disparities, and our cultural values regarding cancer patients and sexually transmitted infections that this research project is situated. Specifically, it is intended to examine the experiences of women who are survivors of cervical cancer, with a focus on possible stigmatization relating to the release of the HPV vaccine and the increasing publicity of cervical cancer’s connection with an STI. In short, it will document how these women view their own disease within this emerging public health framework of prevention and how—if at all—it has impacted their lives.

The following chapter, Chapter Two, will present a thorough overview of the current research on cancer, sexually transmitted infections and stigma. First and foremost, it will examine the ways that these diseases have been perceived historically in the United States, and the impact of stigma individually and from a societal perspective.

It will conclude by discussing cervical cancer's position at the intersection of chronic and sexually transmitted disease. This review will serve to situate the current project in both anthropological and public health research, while simultaneously drawing on important sources from other disciplines when necessary to illuminate the current state of the literature.

Chapter Three discusses the specific objectives of the research project, overall research design, and the methods employed to answer the primary research questions. Data were collected through four sources: key informant interviews, a website content analysis, semi-structured interviews, and an online survey. Accordingly, data collection and the participant selection procedures, recruitment strategies, and the data analysis plan are detailed for each method. The chapter will also address informed consent, confidentiality and compensation issues; and challenges encountered during the research process.

Chapter Four will systemically present all of the findings from the data analysis. The results are broken down first by methodology—key informant interviews, website content analysis, in-depth interviews, and online surveys. Then, within each of these sections, I detail the demographics of the participants and discuss major themes arising from the data. Both the key informant interviews as well as the content analysis were intended to provide a background picture of the issue as well as preliminary data that would structure the design of the interview guide. Because the overall focus of this research was to investigate the dynamics and subtleties of women's experiences with cervical cancer and stigma attached to the disease, the analysis puts its primary emphasis on qualitative methods, that is, the interviews. The major, interdependent themes

emerging from the analysis of the interview data were then tested through the use of the online survey.

Finally, Chapter Five will present a detailed synthesis and discussion of the key informant interview, content analysis, in-depth interview, and survey results, focusing on concrete areas for action and potential contributions to applied anthropology and public health. Here I will tie my findings both to previous literature as well as to my own research questions, outline current gaps in our understanding, and pose important future questions and avenues for anthropological and public health research. This chapter will conclude by outlining study limitations and offering recommendations gleaned from the insights of both the participants as well as myself, the researcher.

Chapter Two:

Literature Review

Much research has investigated the claim that both cancer and sexually transmitted infections carry significant societal stigma. The underlying premise upon which this research project is based is that cervical cancer's public perception as *both* a cancer and as a manifestation of a sexually transmitted infection impacts survivors' experience through the cumulative stigma borne from these conditions. This chapter first offers a brief background on the recent stigma literature, outlining critiques and contributions by anthropologists. It then examines the ways in which cancer and sexually transmitted infections have been perceived historically in the United States, and the impact of associated stigma both on individuals' lives and on prevention and treatment efforts. The chapter concludes by discussing cervical cancer's position at the intersection of cancer and sexually transmitted disease. When available, I have drawn from anthropological and public health sources in these areas; however, as will be discussed below, there are notable gaps in the literature addressing certain topics. In these instances, sources from other disciplines have been used in order to illuminate the current situation and thinking.

BACKGROUND ON STIGMA

The vast majority of literature reviewed that addresses stigma draws from the definition inspired by sociologist Erving Goffman and his seminal work *Stigma: Notes on*

the management of spoiled identity (1963). Briefly, Goffman defines stigma as the perception of what a person is *not*, but should be, based on societal standards—in other words, the stigmatization of an individual results when he or she possesses a trait or condition that is viewed negatively by society, and is thus rejected, ostracized, and discriminated against on the basis of possessing this trait. Especially salient for our discussion here is Goffman’s posited connection between stigma and personal responsibility: stigmatized conditions are often perceived by wider society as punishments for some moral (often sexual) misdeed, a point that is repeatedly returned to in later research studies (Das 2001; Gilmore and Somerville 1994; Newton and McCabe 2005). According to Lichtenstein, Hook, and Sharma (2005), most authors differentiate between enacted and felt stigma – “enacted stigma is when people who are considered to be morally, socially, racially, or physically tainted are actively discriminated against by so-called ‘normals’: felt stigma is the fear or experience of this type of discrimination” (2005:44).

The literature notes a plethora of negative social, psychological and physical consequences resulting from stigma. Importantly, a number of authors contend that stigma increases vulnerability to dangerous conditions or diseases because it mediates exposure and prevention opportunities, such as quarantine (Gilmore and Somerville 1994), while some “have gone so far as to suggest that stigma *causes* illness because ‘it generates and regenerates mechanisms that link it to disease’” (Link and Phelan 2001a:10, as quoted in Lichtenstein et al. 2005:44). The possibility that stigma can actually cause and perpetuate both the disease itself and resultant disparities among the afflicted makes the topic an exceedingly critical area for health research.

Thus, this volume of stigma research has expanded considerably in recent years, fueled primarily by researchers within the fields of sociology and social psychology along with some notable contributions by anthropologists. Stigma and its effects have been investigated in a huge variety of conditions across diverse populations around the world. Though plentiful, the cohesiveness of this body of work, according to some, has suffered from a vague definition and conceptualization of what exactly stigma is and what it encompasses (Castro and Farmer 2005; Link and Phelan 2001a). In 2001, sociologists Link and Phelan (2001a and 2001b) reviewed much of the multidisciplinary work on stigma and subsequently offered a useful conceptualization of stigma and its components in order to clarify the construct for future research:

In our conceptualization, stigma exists when the following interrelated components converge. In the first component, people distinguish and label human differences. In the second, dominant cultural beliefs link labeled persons to undesirable characteristics—to negative stereotypes. In the third, labeled persons are placed in distinct categories so as to accomplish some degree of separation of “us” and “them.” In the fourth, labeled persons experience status loss and discrimination that lead to unequal outcomes. Finally, stigma is entirely contingent on access to social, economic, and political power that allows the identification of differentness, the construction of stereotypes, and separation of labeled persons into distinct categories, and the full execution of disapproval, rejection, exclusion and discrimination (367).

According to the authors, much of the existing literature offered in psychology and sociology has offered a definition that does not necessarily take into account the convergence of all of these components, using one individual component interchangeably with stigma. For example, a study might assume that the existence of *discrimination* is the same as the existence of *stigma*. Over time, this has resulted in a body of literature that reflects the *effects* of stigma in many different populations without clearly articulating exactly what stigma constitutes in the first place. Thus, the authors call for

future research on stigma that takes into account the interplay of these components within an existing power structure that allows these processes to unfold.

Anthropological Contributions and Critiques

Anthropology in particular has offered numerous contributions to the existing literature on stigma. Much important work has centered on the design of culturally-appropriate interventions and care that mitigates stigmatization. For example, Coreil, Lauzardo, and Hertelou (2001) conducted a cultural feasibility study to inform the design of a tuberculosis healthcare program offered to Haitians in South Florida. The identification of social stigma and confidentiality breaches as major concerns among the participants led to a program design structured around minimizing and mediating the effects of stigma on this population. Additionally, numerous ethnographies have been conducted on the meaning and effect of disease-related stigma on specific populations (for examples on stigma and tuberculosis in Haitian populations, see: Coreil, Mayard, Lauzardo, Simpson and Hamilton 2005; Coreil, Lauzardo, Mayard, Hamilton and Simpson 2007).

Still other work has challenged and extended the theoretical foundations of Goffman's work. For example, in their writing on AIDS-related stigma, Castro and Farmer (2005) have expanded on Link and Phelan's (2001a) discussion of the necessity of power in stigmatization. According to them, the issues of power, dominance, and oppression have been virtually ignored by many stigma scholars, who choose instead to focus on individual and micro-level traits and interactions—this has subsequently led to findings that are “decontextualized from larger social processes...[and] the social inequalities in which stigma is invariably rooted” (Castro and Farmer 2005:53-54). They

call instead for a return to analyzing Goffman's original focus on the interplay of relationships, social change, and stigma. Accordingly, these authors offer structural violence as a conceptual framework for understanding the concept of stigma, arguing that "every society is shaped by large-scale social forces that together define structural violence. These forces include racism, sexism, political power, poverty, and other social inequalities that are rooted in historical and economic processes that sculpt the distribution and outcome of HIV/AIDS" (Castro and Farmer 2005:54-55). In turn, these forces also determine who suffers from stigma and discrimination (McMullin in press). For example, in many studies the consequences of stigma appear to be gendered and it is women who suffer disproportionately—for instance, "it may limit their marital prospects; constrain their participation in community, household and family roles; and diminish their quality of life" (Jones, Weil, Coreil, and Shoush 2004).

Other anthropologists have offered similar critiques of the highly individualistic nature of research on stigma. For example, Parker and Aggleton (2003), in their analysis of the stigma concept in HIV/AIDS, argue that a reading of Goffman himself might suggest that "as a formal concept, stigmatization *devalues relationships* rather than being a fixed attribute" (Parker and Aggleton 2003:14) that is mapped onto an individual. However, subsequent researchers' tendency to approach stigma as if it were a static individual attribute or interaction rather than a "constantly changing (and often resisted) social process has seriously limited the ways in which stigmatization and discrimination have been approached" (Parker and Aggleton 2003:14). Rather, these authors believe that "it is vitally important to recognize that stigma arises and stigmatization takes shape in specific contexts of culture and power" (Parker and Aggleton 2003:17), and that,

drawing from a combined analysis of Goffman and the work of Michael Foucault, its strategic deployment serves to establish social control and maintain the social order.

Similarly, Das (2001) argues that Goffman's focus on the *individual* as the only bearer of stigma's burden leads to the neglect of the community- and society-wide production and consequence of stigma. She also challenges Goffman's conceptualization of "resistance" to stigma as appearing only in the form of individual action against wider society and its values. This dichotomous view necessarily precludes both a recognition of how cultural values are embodied and negotiated within an individual, and a discussion of the mechanics of *collective* action and resistance to stigmatization.

A contribution emerging from both anthropology and sociology concerns voice and perspective (Castro and Farmer 2005; Kleinman, Wang, Cheng, Dai, Li, and Kleinman 1995; Link and Phelan 2001a, 2001b; Parker and Aggleton 2003; Whittaker 1992). Many have challenged scholars who write about stigma without being informed by the lived experiences of those who are most affected by it. According to Schneider (1998), a majority of researchers give priority "to their scientific theories and research techniques rather than to the words and perceptions of the people they study" (Link and Phelan 2001a:365), resulting in theorizations about stigma that are divorced from the realities of its occurrence in individuals' lives. Instead, the main focus of research on stigma has been on the attitudes and beliefs of *stigmatizers*—or those that produce stigma—rather than the perceptions of those stigmatized. This has resulted in a plethora of knowledge, attitude, and belief surveys that aim to generate some kind of assessment on the level of stigma that exists for a given condition in the general population instead of exploring the personal impact on afflicted individuals' lives (Parker and Aggleton 2003).

One concept that is critical to our discussion on stigma is cervical cancer's identification as a "disease of disparity." Much public health and biomedical literature has called attention to the fact that cervical cancer incidence reflects underlying socioeconomic disparities and inequalities, such that it strikes primarily women of lower income levels whose class status restricts their access to healthcare (see, for example, Akers, Newmann, and Smith 2007; Newmann and Garner 2005). From an epidemiological perspective, cervical cancer incidence is indeed much lower among middle- and upper-class women who presumably have much easier and affordable access to the United States' vast screening system, allowing for early detection before cell abnormalities progress to invasive cervical cancer. Yet, as some anthropologists and stigma scholars have argued, labeling a certain condition as a disease of poverty—whether it be tuberculosis, HIV/AIDS, or cervical cancer—has dramatic implications for its stigmatization (Baral, Karki, and Newell 2007; Castro and Farmer 2005; Macq et al. 2006; Noyes and Popay 2007). Because poverty in itself "already represent[s] an almost universal stigma" (Castro and Farmer 2005:55), the association between it and a certain affliction can exacerbate the disease-related stigma already present. One study on stigma and tuberculosis in Nepal found that a root cause of discrimination against those suffering from the disease was the "perceived link between TB and other sources of discrimination, particularly poverty and low caste" (Baral, Karki, and Newell 2007:211). In other words, the threat of being labeled "poor" in addition to "TB patient" added another layer of perceived negative experience.

In summary, this particular research project is situated well within the anthropological literature on stigma. First, it is designed to be thoroughly informed by

the voices of those who have experienced cervical cancer. Second, its focus is applied and thus has been positioned from the start to offer concrete recommendations. Third, cervical cancer is aptly suited for analysis within the structural violence/inequality framework because of its designation in public health and biomedical literature as a “disease of disparity.” And finally, a succession of researchers, including anthropologists, has argued that many conditions become stigmatized because they are perceived to have been caused by a violation of a sexual taboo. Thus, those conditions that biomedicine has demonstrated to relate directly to sexual behavior “bring questions of guilt and shame much more to the surface” (Das 2001:8)—an assertion that is highly salient for a discussion on cervical cancer.

CANCERPHOBIA AND THE MORAL ORDER

Having explored the general background literature on stigma and anthropology’s contributions to this volume of work, we now turn our attention to briefly analyzing two health conditions within this stigma framework: cancer and sexually transmitted infections.

According to one author, the phenomenon of “cancerphobia” has marked the history of the disease in the United States (Patterson 1987). One hundred years ago, a physician described cancer as “a loathsome beast, which seized upon the breast, drove its long claws into the surrounding tissues, derived its sustenance by sucking out the juices of its victims, and never even relaxed its hold in death” (Patterson 1987:vii). According to Patterson (1987), the explicit nature of cancerphobia has relaxed a bit throughout the course of the twentieth century, alleviated by several factors: the search for biomedicine’s “magic bullets,” the dramatic hope in new experimental treatments, and the recognition

that oncology has made inroads with increasing survival rates, especially among children. However, even in contemporary times, it remains a feared and dreaded disease (Ablon 2002). The lingering perceptions of cancer as the “leprosy of modern times” (Weiss 1997:458) are most likely due in large part to cancer’s still notoriously high mortality rate, the life-threatening, disfiguring and aggressive therapies required to treat it, and the difficulty biomedicine has had in preventing it or even explaining away with certainty its ultimate cause (Gregg and Curry 1994; Weiss 1997).

Hunt (1998) argues that “science strives to translate observed phenomena into a value-free framework, removing it from the elements of ordinary existence” (1998:309); thus, in the absence of biomedicine’s explanations of cancer’s ultimate cause, individuals must create *meaning* about why they themselves became sick—meanings that often reflect personal experiences and how these may or may not have contributed to the development of their own cancer. As she goes on to note, “biomedical concepts are silent on this moral plane” (Hunt 1998:309). Several anthropological studies conducted both in the U.S. and other countries highlight the moral overtones inherent to cultural meanings of cancer, especially those cancers of the reproductive organs (Chavez, Hubbell, McMullin, Martinez, and Mishra 1995; Hunt 1998; Martinez, Chavez, and Hubbell 1997). For example, Hunt’s (1998) study in southern Mexico among women diagnosed with reproductive cancers (breast, cervical, uterine) found that the cause of these cancers was usually explained through “concepts of breaches in the social order, and of proper and improper behaviors ... [and in particular] interpersonal aggression and improper reproductive behaviors” (1998:303) in that individual woman’s life. Chavez and colleagues (1995) revealed similar findings in their U.S.-based study on the perceptions

of breast and cervical cancer risk factors among Latinas, Anglo women, and physicians. Although there were marked differences in the cultural models of cervical cancer espoused by each group, a recurrent theme was that of sexual behavior that did not conform to social norms. This conceptualization of cancer as a consequence of deviation from accepted cultural standards and the moral order is reflected in other writings by Brandt (1987), Erwin (2007), Gregg (2003), McMullin (2007 and in press), McMullin, Chavez, and Hubbard (1996), Patterson (1987), and Sontag (1978), among others.

Interestingly, it seems that moralistic beliefs surrounding cervical cancer have been documented to a much greater extent among Latinas than among other specific populations; this might be accounted for by the increasing number of studies addressing Latina beliefs about cancer (Chavez et al. 1995; Erwin 2007; Hunt 1998; Martinez et al. 1997; Chavez, McMullin, Mishra, and Hubbell 2001; McMullin, de Alba, Chavez, and Hubbell 2005). One of the few studies that focused on explanatory models in Caucasian women was the above article conducted by Chavez and colleagues (1995). As noted previously, the authors investigated the cultural models of breast and cervical cancer among Chicana, Mexican, and Salvadoran women living in the United States, using Caucasian women and physician as comparative groups. They found that Caucasian women most frequently viewed family history as the predominant risk factor for cervical cancer, and overall their views paralleled physicians' most closely than the other groups. Although the women did list several lifestyle risks for cervical cancer such as multiple sexual partners and STIs, they did so "less often than the Latina immigrants, for whom perceived non-normative or morally tinged behaviors were associated with cancer, especially cervical cancer"—for example, rough sex, sex during menstruation, or

abortion (Chavez et al. 1995:54). Among the Latina groups, the risk that irregular sexual practices presented for cervical cancer related more to the moral component of that particular behavior rather than the possible exposure to a sexually transmitted infection, which was more the case for the Caucasian women.

Conceptions of Cancer Patients and Stigmatization

In many respects, as illness itself can be seen as socially constructed, *any* illness represents a deviation from the norm. However, Fife and Wright (2001) argue that some illnesses, such as cancer or HIV/AIDS, are “imbued with cultural meanings that result in a ‘spoiled identity’ and the stigmatization of afflicted individuals” (2001:52). These associations of cancer with death, disorder, extreme suffering, and moral deviation are critical elements in the stigmatization of cancer. For example, participants in one study, when asked to draw their conceptualization of a cancer patient, invariably created illustrations of patients that were “embodiments of chaos... Images of them were fragmented and distorted. The outlines of their bodies were drawn with gaps; their internal organs were often hanging out. They were represented as without hair, without gender, and without any surrounding context. In short, respondents’ depictions of...cancer patients evoked a sense of entropy and of bodily fragmentation and dissolution” (Weiss 1997:470). Ablon (2002) contends that cancer, along with homosexuality and mental illness, constitutes what might be termed a “master stigma,” an affliction that can seemingly “be used to define a person, discounting his or her other more relevant-to-the-context characteristics” (Ablon 2002:S4).

A number of authors note that moral theories surrounding causation, as well as the persistent association of cancer with death and disorder, have had negative impacts on the

lives of cancer patients (Braun and Gavey 1999a; Chapple, Ziebland, and McPherson 2004; Gregg and Curry 1994; Patterson 1987). Indeed, illness-related stigma can result in reluctance to seek treatment or fear of treatment itself (Katz, Wewers, Single, and Paskett 2007), as exemplified by Gregg and Curry's (1994) study on explanatory models for cancer among African American women undergoing screening for breast and cervical cancer at community health clinics. In another study on the stigma and shame experienced by lung cancer patients, it was found that many were concerned that "diagnosis, access to care, and research into lung cancer might be adversely affected by the stigma attached to the disease and those who smoke" (Chapple, Ziebland, and McPherson 2004). Furthermore, psychosocial and advocacy literature has paid much attention to the economic discrimination that survivors face in the United States: difficulties accessing health insurance, job discrimination, and the impossibility of securing life insurance are just a few consequences of the "financial risk" that many employers assume survivors pose (Hoffman 2004). These economic repercussions can seem insurmountable when added to the vast debts often incurred by the treatment alone.

SEXUALLY TRANSMITTED INFECTIONS AND THEIR VECTORS

Few anthropologists have focused their writings and research on sexually transmitted infections in a broad sense and almost none on stigma attached to them, apart from those exclusively addressing HIV/AIDS. Given this gap in the literature, this section draws from complementary work in a variety of disciplines in addition to anthropology, specifically feminism, public health, and history.

Notable in all the literature reviewed for this section is the pervasive association of sexually transmitted infections with dirt, filth, uncleanness, and immorality (Ablon

2002; Brandt 1987; Ehrenreich and English 1973; Inhorn 1986; Lichtenstein et al. 2005; Pliskin 1997; Wailoo 2001). Similar to the causal explanations of reproductive cancers as rooted in a deviation from moral norms, STIs in American society have come to be seen as “an affliction of those who willfully violated the moral code, a punishment for sexual irresponsibility” (Brandt 1987:5), and since the late 19th century have “been used as a symbol for a society characterized by a corrupt sexuality” (Brandt 1987:5). This association between sexually transmitted infections, uncleanliness and immorality is just as strong as the complicated relationship between STIs and women in the popular imagination. Although this belief has ebbed and flowed over the course of the last century, women traditionally have been characterized as the vectors of disease, or ‘natural reservoirs’ (Lichtenstein et al. 2005), as one author puts it (Brandt 1987; Ehrenreich and English 1973). Additionally, a moral division between “good” (pure and chaste) and “bad” (dirty, dangerous and sexualized) women has been noted extensively in the feminist literature exploring sexuality in the American Victorian era (mid-19th century) through to the present (Amaro, Raj, and Reed 2001; Braun and Gavey 1999a; Leonardo and Chrisler 1992; Nack 2002; Wahab 2002). This moral dichotomization of women according to sexual behavior and perceived promiscuity serves to identify a woman with a sexually transmitted infection as “bad”, and thus contagious and responsible for her own condition.

Also important to note is the persistence of the association between STIs, poverty, and ethnicity in the United States. A number of authors argue that STIs are associated in the popular discourse with urban poor minorities (Brandt 1987; Ehrenreich and English 1973; Pliskin 1997; Wailoo 2001). Brandt (1987) notes that, traditionally, “venereal

disease has engaged a number of social fears about class, race, ethnicity, and in particular, sexuality and the family. Venereal disease—in its social constructions—has been used during the last century to express these anxieties” (Brandt 1987:6). Historically, immigrant classes were often singled out for this moral label: according to Ehrenreich and English (1973) in their classic feminist analysis of the relationship between biomedicine and women, “the working class woman might not faint, or get ‘uterine disease’ [as the upper class woman did], but she undoubtedly harbored germs of typhoid, cholera or venereal disease” (1973:14). Furthermore, Pliskin (1997) goes on to argue that contemporary STI prevention programs often further this stereotype by targeting minorities, prostitutes, and adolescents in their quest to identify and isolate high-risk sexual behaviors.

STIs and Stigma

As conditions that spring from perceived immoral sexual behavior, Brandt (1987) points out that “individuals [with STIs] often have suffered a double jeopardy: the physiological consequences of the disease itself, as well as the deep psychological stigma” (1987:5) attached to it. This stigma in itself has consequences that are outlined by several authors (Brandt 1987; Fortenberry et al. 2002; Lichtenstein et al. 2005; Newton and McCabe 2005; Perrin, Daley, Naoom, Packing-Ebuen, Rayko, McFarlane, and McDermott 2006; Pliskin 1997; Woods et al. 1999). For example, embarrassment or shame might inhibit individuals from seeking or continuing treatment and accessing necessary social support; furthermore, diagnosis with an STI often creates major conflicts in intimate relationships. Importantly, stigma attached to STIs has impeded the success of large-scale public health prevention efforts, most notably contact tracing and name-

based reporting (Fortenberry et al. 2002; Woods et al. 1999). Lichtenstein and colleagues (2005) note that “as a contributor to STI control, partner notification has had little success in the USA, perhaps because stigma has complicated every aspect of control and elimination” (2005:44).

Newton and McCabe (2005) contend that a discussion of the effects of stigma is particularly relevant for HPV, given that it “can be physically evidenced on the body, may often result in physical pain, and [is] transmitted to others through sexual contact” (Newton and McCabe 2005:63). When discussing implications for screening related to HPV and cervical cancer, Braun and Gavey (1999a) argue that the good girl/bad girl discourse can effectively prevent the success of screening efforts, in that women need to first identify themselves as “promiscuous” (in accordance with the “bad girl” label) and then based on this must recognize that they are at risk for cervical cancer and in need of screening.

CERVICAL CANCER: INTERSECTIONS OF CANCER AND STIs

The preceding two sections have examined the perceptions of cancer and sexually transmitted infections separately. However, as will be discussed below, the current media attention surrounding the HPV vaccine has made explicit the causal link between sexual behavior and cervical cancer. My contention in this research is to position cervical cancer at the intersection between both conditions, as it is now at once perceived as both a cancer *and* as a sexually transmitted infection. I argue that this position heightens the stigmatization of patients and survivors in two ways: first, as theories of causation for both cancer and STIs are characterized by moral overtones, patients and survivors deal with the cumulative stigma borne from both; and second, with the advent

of the HPV vaccine, cervical cancer is now identified as a *preventable* disease, which positions it under the public health paradigm of personal responsibility and accountability.

It has long been recognized that there is a murky association between cervical cancer and sexual activity, principally heterosexual activity (Braun and Gavey 1999a; Wailoo 2001). As Braun and Gavey (1999a) note, “much attention has been given to differences in cervical cancer incidence between nuns (very low) and prostitutes (very high)” (1999a:203). However, the explicit relationship between sexual behavior and cervical cancer has remained unclear until the last several years, when it was discovered that strains 16 and 18 of the human papillomavirus (HPV) directly cause nearly 70 percent of cervical cancer cases in the United States, while strains 6 and 11 cause 90 percent of genital warts (CDC 2006; Calloway, Jorgensen, Saraiya, and Tsui 2006; Merck Pharmaceuticals 2007a). HPV is a necessary factor in the development of 99 percent of cervical cancers, 90 percent of anal cancers, and 40 percent of vulva, vaginal, and penile cancers, as well as certain oropharyngeal and oral cancers (Parkin 2006). Currently, there are 100 strains that are known to researchers, but their role in cancer and genital warts remain unclear; thus, it appears as if the majority of HPV infections are cleared from the body of the individual without known consequences, and most often, without symptoms (CDC 2006; Calloway et al. 2006). HPV is, importantly, the most common sexually transmitted infection in the United States: it is reported that up to 70 to 80 percent of sexually active adults will contract at least one of the strains at some point in their lifetime (Burk et al. 1996; Koutsky 1997; Lorincz 1996). In a recent point prevalence study, the National Institutes of Health discovered that 26.8 percent of

sexually active females between the ages of 14 and 59 tested positive for one or more strains of HPV at any given time (National Institutes of Health 2008a).

This causative role of HPV in cervical cancer has taken on new significance in the last two years with Merck Pharmaceuticals' release of the first vaccine to prevent its transmission, in June 2006. The vaccine has shown in clinical trials to have a 100 percent efficacy rate in preventing the four strains of HPV that cause cervical cancer and genital warts. Currently, it is approved *only* for young girls and women aged 9 to 26 and no clinical trials have been completed in men, even though it is estimated that at least 50 percent of sexually active men and women have been infected with HPV at some point in their lives, and the virus is known to cause anal cancer, penile cancer and oral cancer in men (CDC 2008). Many states have pending legislation to mandate the vaccine for girls in 5th and 6th grades; the rationale behind this age is based on the fact that the vaccine will be most effective if given to girls who have not yet been exposed to the virus (CDC 2006)—thus, in girls who are not yet sexually active. This is an example of legislation that is based upon sexual behavior, and in turn, it makes the discourse about the vaccine sexual.

Interestingly, although this recognition of the association of cervical cancer and sexual activity has existed for quite some time, some authors have noted that suppressing this information in the past has served useful purposes. Lovell, Kearns, and Friesen (2007) have noted that the tendency of public health discourse on cervical cancer screening has been to avoid disclosing this information because it “eliminates any association in the public eye between sexual practices and cervical cancer” (Lovell et al. 2007:4). Braun and Gavey (1999b) contend that the lack of attention on behavioral risk

factors for cervical cancer, such as multiple partners, first intercourse at a young age, and unprotected sex, has been due to three reasons. First, HPV is extremely prevalent within sexually active populations. Second, it can be transmitted through skin-to-skin contact (not just intercourse), rendering barrier contraceptive methods such as condoms less effective than for other sexually transmitted infections. Third, and perhaps most importantly for this research project, practitioners have feared that “highlighting this association with sexuality may be in direct conflict with the promotion of cervical screening, and that it may deter some women, particularly older women, from having smears” (Braun and Gavey 1999b:1464). It seems that only with the release of the vaccine, and the implementation of the pharmaceutical companies’ marketing campaigns, have these risk factors and the link to sexual activity become more explicit than in the past.

The educational and media blitz surrounding the release of the HPV vaccine, and the controversies about access, female adolescent promiscuity, school mandates, and vaccine ‘acceptability,’ have heightened exposure to dramatic levels (Calloway et al. 2006). In turn, this has served to solidify the relationship between cervical cancer and sexual behavior in the public consciousness. Pliskin (1997) contends that “only recently, mainly since the beginning of the AIDS epidemic, has the subject of STIs been pursued consistently by the media. For years the subject was avoided” (1997:102), although there is a precedent to HPV’s current attention in the media. In her ethnographic study on genital herpes in American society, Inhorn (1986) contends that the media played a pivotal role in the public awareness of herpes, and the extreme fear and stigma subsequently attached to it: “the reason for [genital herpes’] notoriety is believed to be

due to the media—and a process of stigmatization that took place almost overnight” (1986:61), with herpes quickly becoming the “new scarlet letter.”

I argue that this recent attention to the HPV vaccine with regards to cervical cancer emerges within the framework of the good girl/bad girl discourse, and engages the historical construction of women as the traditional vectors of sexually transmitted infections. By focusing primarily on the consequences of HPV in the woman—cervical cancer—and the fact that adolescent girls are the *only* targets for the vaccine, the educational and media message enforce traditional notions of (1) women as the reservoirs of infection, (2) cervical cancer as punishment for ‘immoral’ or improper behavior, and (3) women as responsible for protecting both themselves and thus the rest of the population—i.e., men—from the ravages of this virus by getting themselves vaccinated.

As previously discussed, sexually transmitted infections share with cancer decidedly moral overtones regarding causation: in the public consciousness, both conditions are associated in some way with deviation from the moral order and the sexual expectations attached to women in society. Thus, the woman with cervical cancer finds herself in a peculiar position, bearing the brunt of two stigmatized conditions. In the category of a cancer, cervical cancer is associated with death, suffering, disorder, and improper behavior. Simultaneously, as associated with a sexually transmitted infection, cervical cancer is imbued with meanings about the proper sexual behavior of women in contemporary American society, and the consequences associated with deviation from these standards (Martinez et al. 1997). “Product of a metaphorical double whammy, cervical cancer, as a cancer, [is] considered deadly, horrifying and possibly contagious; as an STI, it [is] shameful and indicative of sexual misconduct” (Gregg 2003:130).

Furthermore, racialized stereotypes about women with cervical cancer exist, having apparently bled over from the negative assumptions that have become so much a part of contemporary American discourse about STIs. As noted earlier in this chapter, historically STI's have been associated most closely in the popular discourse with women, minorities, immigrants and the urban poor, which has ultimately served to shape approaches to STI prevention with the increased targeting of "high-risk" groups (Pliskin 1997). This pattern is highly relevant for a discussion on cervical cancer, as educational and awareness messages aggressively broadcast the association with HPV in an increasingly public way. McMullin's (in press) study on the diagnosis experiences of Latina cervical cancer patients provides an instructive parallel between racial stereotypes of STI carriers and, now, increasingly racial stereotypes of cervical cancer patients. Latinas bear the burden of cervical cancer incidence and mortality rates that are twice the national average (Canto and Chu 2000, as cited in McMullin in press). Yet, despite the structural, political-economic inequalities and racism that are at the heart of these disparities, the social construction of Latinas as promiscuous and irresponsible is used instead throughout popular and biomedical discourse as an explanation (McMullin in press).

One final thought deserves mention. The HPV vaccine has now served to position cervical cancer as a preventable disease. Lupton (1993), in her article on the discourses of risk in the public health paradigm, discusses the increasing emphasis on lifestyle risks—those risks created by an individual's life choices regarding sex, nutrition, exercise, reproduction, or any number of things. These are the risks to which society can assign blame should an individual develop obesity, or be diagnosed with lung cancer, a

sexually transmitted infection, or HIV/AIDS. Responsibility is assigned to the individual to both avoid and to minimize (Ablon 2002). I see this paradigm as one that engages moral theories about the causation of disease by focusing on the lifestyle component as a principal means of disease development, one that effectively divides “those who don’t take care of themselves and become sick” from “those who take proper care of themselves, and thus stay well.”

This is an important concept that plays into a new understanding about cervical cancer in two ways. First, because cervical cancer is now definitively attached to sexual behavior in the scientific literature, a woman is expected to be sexually responsible to avoid contracting HPV and thus developing cancer. Second, she will be expected to get the vaccine to avoid being infected at all. The woman who does develop cervical cancer failed in those *two* ways, because cervical cancer is now positioned as entirely preventable both by responsible sexual behavior and by the new vaccine. Thus, cervical cancer *remains* a punishment for immoral or improper behavior, despite the change in rhetoric to ‘lifestyle risks’. As Newton and McCabe (2005) note, much research has suggested that “when a person is perceived to have been responsible for the acquisition of their stigmatizing condition, they are more likely to be treated negatively than someone who is not perceived as being responsible for the stigmatizing condition” (Newton and McCabe 2005:66). Thus, I do not argue about the necessity of prevention in the case of cervical cancer; however, it can be a double-edged sword, and the discourses on preventability, individual responsibility and blame, can serve to stigmatize women who have already been diagnosed with it and those who will in the future.

SUMMARY

This chapter has outlined the ways in which our historical perceptions of cancer and sexually transmitted infections are associated with moral transgressions, sexual misbehavior, and deviation from the social order, which has resulted in the stigmatization of both conditions. With cervical cancer's increasingly recognized association with HPV, a sexually transmitted infection, the disease is now situated in the intersection of these two conditions. Thus, survivors experience stigma borne from cancer and STIs. This can have dramatic implications for their quality-of-life and access to treatment. Indeed, this chapter has demonstrated the vast individual, community, and societal repercussions of disease-related stigma: in the context of both cancer and sexually transmitted infections, stigma is broadly associated with decreased levels of screening, reluctance to seek treatment, decreased access to social support, economic discrimination, major difficulties in implementing large-scale prevention efforts, and in extreme instances, denial of basic human rights. A fuller and more holistic understanding of the dimensions of patients' and survivors' experiences with cervical cancer and disease-related stigma will help to inform future educational and prevention messages tailored to reduce its impact. Thus, the remaining chapters will detail methods and findings of this research project, and offer a concluding discussion and set of recommendations.

Chapter Three:

Methods

In order to get as complete a picture as possible about the effect of the HPV vaccine on the lives of women who have experienced cervical cancer, it was necessary to employ a variety of anthropological methods in this study. This chapter will discuss the specific aims of the research as well as the methods used to answer four primary research questions. The chapter is sub-divided into four sections: the first addresses the overall research design and the four methods utilized—key informant interviews, website content analysis, in-depth interviews, and an online survey. Data collection and the participant selection procedures, recruitment strategies, and the data analysis plan are detailed in turn for each method. The second section, Ethical Conduct, discusses informed consent, confidentiality and compensation issues. The third section focuses on challenges encountered during the research process; specifically, recruitment issues and elements of the researchers' personal experience that required attention during the initial stages of the project. Study limitations are briefly outlined in the final section.

RESEARCH DESIGN AND METHODS

This was an exploratory study utilizing both qualitative and quantitative methods, including key informant interviews, content analysis, semi-structured interviews, and an online survey. These methods were employed to address research questions formulated

from a review of the anthropological and public health literature on cervical cancer as well as input from key informants, faculty advisors, and colleagues:

1. How do women diagnosed with cervical cancer experience the media attention surrounding the HPV vaccine and cervical cancer's link to sexual behavior, and how has this affected their perceptions of their own diagnosis and survivorship status?
2. How do cervical cancer patients/survivors perceive and experience stigma, if any, attached to this piece of their identity? What is the nature and origin of this stigmatization?
3. According to patients and survivors, what are the important aspects involved in minimizing stigmatization? How can educational and prevention messages be designed to reduce it?
4. How do cervical cancer advocacy groups, pharmaceutical companies, and commercial websites providing information on cervical cancer represent the link between HPV and cervical cancer, and what are their educational messages on this topic?

Key Informant Interviews

Interviews were conducted with three key informants prior to the initiation of research. Two of these informants were prior work contacts, one of whom is a cervical cancer survivor herself and heavily involved in advocacy efforts for this population. This woman was instrumental in the initial conceptualization of the project prior to the proposal, and offered continuing assistance throughout the course of the study by reviewing draft instruments and helping with recruitment for the online survey. The third informant was a woman previously diagnosed with cervical cancer who was an acquaintance of one of my committee members, and expressed interest in the direction of the study. These conversations were not tape-recorded although thorough notes were taken during and afterwards, which I referred back to during the development of each instrument.

Website Content Analysis

In order to address research question #4, I conducted a content analysis of the websites of selected cervical cancer advocacy organizations, commercial groups, government agencies, and pharmaceutical companies from June through August 2007 to generate preliminary data. The aim of this phase was three-fold: first, to assess how these entities present information to the public related to HPV and cervical cancer's connection to a sexually transmitted infection, and the degree to which this link to sexual behavior may or may not be made apparent in their educational messages. Also of interest was the organizations' treatment of the current controversy surrounding the vaccine's availability and administration to adolescent girls. Most importantly, findings from this exercise were used to guide the development and revision of the in-depth interview guide.

Sampling

A total of seven websites were sampled: three advocacy organizations, one commercial group, one government agency, and two pharmaceutical companies. The inclusion of not-for-profit, non-governmental organizations in this analysis was based upon the assumption that these organizations represent, more or less, public extensions of patients and survivors. As these organizations' messages are targeted both at this population and the wider public, it was assumed that analyzing their approach to this topic would shed additional light on how patients and survivors experience their own disease in the context of public education and advocacy messages. Three organizations were included in this phase: the *National Cervical Cancer Coalition (NCCC)*, *Tamika & Friends*, and the *American Cancer Society (ACS)*. The first two organizations were selected because they are the most visible players in the cancer community that target

only cervical cancer, while the ACS is one of the largest non-profit cancer advocacy organizations in the country and very widely known.

The websites of one commercial company (*WebMD*), one government agency (*Centers for Disease Control and Prevention*), and the two pharmaceutical companies currently marketing the HPV vaccine (*Merck Pharmaceuticals* and *GlaxoSmithKline*) were included to contrast the content and presentational style of the information.

WebMD was selected due to its prominence as a commercial health information company. The CDC was chosen because it is the primary public health arm of the federal government, and thus is most responsible for providing consumer health information.

Finally, Merck Pharmaceuticals and GlaxoSmithKline (GSK) were natural candidates for inclusion because they are the two companies that currently manufacture the HPV vaccine and that are responsible for the current media campaigns on the topic. At the time of data collection, GSK's vaccine, Cervarix, had not yet been released to the public, although information on it was available through their website. Data collection took place from June through August, 2007.

Data Analysis

All content pages on each website were printed and included in the analysis; this also included pages addressing the mission and structure of each organization. Sections that detailed organizational contact information, links, and additional resources were left out of the analysis. Following Bernard (2006), who described content analyses as deductive procedures, I developed a set of hypotheses to apply to the data based on a thorough review of the literature and informal conversations with key informants.

Specific questions were formulated within each hypothesis in order to measure the

number of times a certain piece of information occurred, and then, in combination with a qualitative review of website text, these were used to extract key themes emerging from the data. Findings were then used to develop the preliminary interview guide and to provide overall background information on the issue.

Specific questions that were developed to guide the website review included:

- How many times does the website state that HPV causes cervical cancer?
- Does the website state that HPV is transmitted sexually? If so, how many times do they mention this?
- What is the ratio of mentions of “HPV causes cervical cancer” to “HPV is sexually transmitted”?
- How many times is HPV mentioned as *the* causative factor, and how many times is it mentioned alongside *other* factors?
- Does the website discuss prevention strategies that involve modifying sexual behavior? If so, what kinds of strategies are mentioned?
- How often does the website state HPV incidence/prevalence rates in conjunction with their explanations of cervical cancer’s causes and/or HPV’s causes?
- Does the website have a section for men and HPV?
- Do these groups provide information on the HPV vaccine?
- Do they offer a position on the vaccine or vaccine mandates?

The size of the websites varied considerably, ranging from a minimum of five pages of relevant content addressing cervical cancer and/or HPV (in the case of GlaxoSmithKline) to 105 pages for the National Cervical Cancer Coalition’s website. Five of the sites recorded the last date that each page was modified or reviewed. The ACS last modified all of their pages between July 2006 and March 2007; the CDC between June and July 2007; GSK in March 2007; and Merck in November 2006. WebMD had last modified most of their pages in December 2004, with one related to the vaccine updated in September 2006. The NCCC recorded the most recent revision

date—between September 2005 and March 2006—on approximately half of its pages, while Tamika & Friends website did not record a date on any of their pages.

Semi-Structured Interviews

A total of 19 in-depth interviews were conducted using a semi-structured, open-ended interview guide. Each interview lasted between 45 and 90 minutes, with most interviews concluding after one hour. Ten interviews were conducted face-to-face in a location of the participant's choice: most commonly, participants selected a public space for their interview, such as a coffee shop or a park picnic table. Due to recruitment challenges (discussed later in this chapter), it was necessary to include nine non-local participants and these interviews were conducted over the telephone. All interviews were tape-recorded for later transcription and analysis. Data collection took place over a course of six months from October 2007 to March 2008.

As noted above, the open-ended interview guide (see Appendix A) was developed using data gathered from the key informant interviews and content analysis. The study began by using a draft guide and items were refined through pre-testing and expert review by thesis committee members and key informants. The final guide consisted of 23 items in addition to several demographic questions.

Broadly, the interviews addressed how cervical cancer survivors perceive their own experience in the context of public educational and media messages that emphasize the link between sexual behavior and cervical cancer; whether or not they experience stigma and how this has impacted their own sense of their diagnosis and survivorship status; and what they believe are the important steps involved in minimizing this stigmatization in relation to educational, prevention, and outreach efforts.

Participant Selection and Recruitment

Interview participants must have fulfilled all of the following inclusion criteria. They must have: (1) experienced a diagnosis of cervical cancer at some point in their lives; (2) been between the ages of 18 and 75; (3) been fluent in English; and (4) have given their consent to participate in the study.

Participants were recruited locally in Tampa Bay and surrounding counties using four strategies: (a) through the offices of gynecologic oncologists in Hillsborough County; (b) through local non-profit organization addressing cervical cancer; (c) via flyers sent out electronically through organizational listservs, and (d) by snowball sampling through personal contacts. Personal contacts include those made through the researcher's thesis committee members and faculty advisor, previous work experiences in cancer advocacy organizations, and word of mouth. Difficulties in recruiting local participants necessitated a change of approach midway through the interview process, and several non-local survivors were included through the use of telephone interviews (for a more detailed discussion, see Section III: Challenges).

In strategy (a), gynecologic oncologists in Tampa and surrounding cities were mailed a letter of introduction, describing the study and providing sample recruitment materials (specifically, a study flyer). This letter of introduction described the study and asked for the oncologists' assistance in passing along flyers to their patients, or to display them in clinic waiting rooms. Contact with the potential participant was made in one of two ways: the participant either contacted the researcher directly after receiving the information, or, the provider retained the names of participants who stated that they were interested in being contacted about participation. The researcher then followed up with

the potential participant directly using the contact information that they provided. During that initial contact, the researcher would confirm that the woman met the inclusion criteria described in the project proposal and IRB application. Although this was both the most time-consuming and least successful recruitment method in terms of actual participants enrolled—only two—a total of seven gynecologic oncologists representing four different local practices agreed to collaborate and assist in recruitment.

Strategy (b) relied on the assistance of two local non-profit organizations addressing cervical cancer in some capacity. *Faces of Courage* is a Tampa-based organization providing support and resources to individuals diagnosed with any type of cancer. The founder, Peggie Sherry, was a tremendous help in sending out flyers through her listserv and otherwise getting the word out to members of her organization that had been diagnosed at some point with cervical cancer. Four participants were recruited in this fashion. The other organization, the Sarasota-based *Wellness Community*, was initially very supportive because of their weekly Gynecologic Cancer Support Group but turned out not to have any women with cervical cancer enrolled at that time.

Relatively speaking, strategies (c) and (d) were very fruitful in terms of the number of participants recruited—a total of 13. Study flyers were sent out electronically through the *USF Health* listserv, the *USF Anthropology Department* listserv, the *University of Florida Anthropology Department* listserv, and the *University of Central Florida Women's Studies Department* listserv. Additionally, an announcement was sent to the membership of *Fertile Hope*, a national non-profit organization providing infertility resources to cancer patients and survivors with whom I was employed for several years prior to graduate school.

Data Analysis

All interviews were tape-recorded so that I was able to focus more closely on the actual interview and conversation; immediately afterwards they were transcribed verbatim and interview notes were recorded. After all of the interviews were completed, the transcripts were reviewed and a set of codes based on the interview topics was developed and used to partition the interviews. Then, coded transcripts were analyzed for frequently expressed themes.

Online Surveys

In order to reach a wider range of participants, a final method utilized in this research project was a short online survey administered to 70 non-local cervical cancer patients and survivors between March and May 2008. In an attempt to streamline the administration process and include participants residing nationwide, the survey was offered electronically through Survey Monkey, a free web survey software program.

The preliminary online questionnaire was developed after most interviews had been completed, and thus, key themes emerging from the interviews structured the design of many questions. In addition, a survey in an ongoing study by Coreil (2008) on tuberculosis and stigma was used as a general guide, and several items were inspired by an HIV-stigma scale developed by Berger, Ferrans, and Lashley (2001). The items were refined through pre-testing and review by thesis committee members and a key informant, and the final survey (see Appendix B) included a combination of 38 close-ended and open-ended items. All close-ended questions included an optional text box for additional comments, which were later analyzed in the same manner as the open-ended items.

Participant Selection and Recruitment

As in the interview phase, all survey participants must have fulfilled all of the following inclusion criteria. They must have: (1) experienced a diagnosis of cervical cancer at some point in their lives; (2) been between the ages of 18 and 75; (3) been fluent in English; and (4) have given their consent to participate in the study.

Participants were primarily recruited via listserv and website advertisement through four sources: the *National Cervical Cancer Coalition*, *Tamika & Friends*, *Women in Government*, and the *National Council of Women's Organizations*. Located in Los Angeles, the *National Cervical Cancer Coalition* is the largest national non-profit organization addressing cervical cancer. A link to the survey was posted on their patient and survivor message board. *Tamika & Friends* is a national Washington, DC-based non-profit advocacy group representing cervical cancer patients and survivors, and the Executive Director of this organization sent the survey link to their member listserv. *Women in Government* is a national organization also headquartered in DC that represents women state legislators; the survey link was posted on the homepage of their national "Challenge to Eliminate Cervical Cancer" program website. The *National Council of Women's Organizations*, also in DC, is an umbrella organization uniting non-profit groups that address issues of concern to women in the United States. An email containing the survey link was sent to their member listserv after one of their staff members received the email from *Tamika & Friends*.

Data Analysis

Results from the survey were handled in two ways. First, quantitative items were entered into SPSS in order to obtain descriptive statistics. Second, qualitative items

(including both open-ended questions and the optional comment boxes for the close-ended questions) were analyzed using the same coding scheme developed for the in-depth interviews.

ETHICAL CONDUCT

This research study was approved by the University of South Florida Institutional Review Board on June 20, 2007 (Protocol 105855). Subsequent modification applications addressing recruitment sites, recruitment procedures, and revisions of study instruments were approved on July 27, 2007; September 19, 2007; October 25, 2007; November 21, 2007; and March 26, 2008. A continuance was issued on June 3, 2008.

Informed Consent

All study participants gave their consent via several IRB-approved methods. Interviews were conducted either in-person or over the phone; as such, consent procedures differed slightly between the two. For in-person interviews, a written informed consent form was read and given to participants prior to the beginning of every interview, allowing time for questions and the option of refusing to participate in the project. Willing participants were then asked to sign the consent form. For telephone interviews, a consent script approved by the IRB through a Waiver of Informed Consent Process was read to the participants over the phone. The participants were allowed time for questions and the option of refusing to participate in the interview, and then were asked explicitly if they gave their consent to proceed. In both cases, participants were clearly notified of their right to stop the interview at any time without any adverse consequences.

Participants completing the online survey read the posted IRB-approved informed consent prior to the start of the survey and indicated their consent by checking a box. All interviewees and online survey participants received the same consent information and the option to refuse or discontinue participation.

Confidentiality

The last name of the participant and other personal identifying information was not recorded on study notes, in the tape-recorded sessions, or on surveys. Participants were assigned numerical codes, and the only instance in which their last name was recorded was on the consent form and in an enrollment codebook. Only the researcher and Faculty Advisor had access to these data, and no copies were made of the consent forms. All participants were assured that any publications resulting from the collected data would be presented in aggregate form and would thus be anonymous. Pseudonyms have been used throughout this paper.

Compensation

No compensation was offered to participants. However, no cost to participants was incurred because of their participation in the study. All interviews were conducted at a location of the participant's choice, such as home, office, or public space. In this case, the researcher traveled to the site, and in the case of telephone interviews, the call was made at the expense of the researcher. All questionnaires were completed online through a web survey software program that was free to participants.

CHALLENGES

Recruitment Issues

Recruitment for the interview phase was a significant challenge, and necessitated changes in strategy several times. An entire chapter could likely be written on recruitment strategies alone; thus, for considerations of space I will not detail every attempt or change of course but rather will discuss the underlying factors that I believe played a role in it. Suffice it to say that it was necessary to conduct many interviews over the telephone because participants did not live locally, and these women were recruited through previous work contacts in New York. Rather than label these “study limitations,” as some may consider them to be, I believe that this challenge does shed a brighter light on the predicaments facing women with cervical cancer and it is fruitful to consider these limitations within the overall context of the study objectives and findings.

First, from an epidemiological perspective, cervical cancer incidence in this country is now relatively low. With the increasingly widespread use of the Pap smear between 1955 and 1992 in the United States, overall cervical cancer incidence rates declined by 74 percent (National Cancer Institute 2008a). While this represents an excellent success story in preventive medicine, it also means that it is more difficult to locate study participants.

However, this fact alone does not mean it is inherently difficult to recruit participants. Just as importantly, the Tampa Bay area—and, as far as I can tell, the entire state of Florida—has no organized community of cervical cancer patients and/or survivors. Many cancer type-specific support groups do exist in Hillsborough County

and surrounding counties, such as breast cancer, prostate cancer, lung cancer, leukemia, and childhood cancers. However, no such group exists solely for women with cervical cancer despite the presence of multiple community organizations whose primary mission it is to provide support to cancer patients and survivors. Yet even in general cancer support groups, there is very rarely even one member who has had cervical cancer. This discovery is important to the study in two very significant ways. First, it challenges our traditional concepts of ethnographic research that have typically relied on the identification of a bounded community to study, such as a school or neighborhood. Second, it has overall significance for the ways in which the participants have conceptualized their cancer experience as frequently alone and isolated within the general “cancer community,” overlooked even more by funding and research initiatives that tend to glorify “favored” types of cancers (see *Chapter Four: Results* and *Chapter Five: Discussion and Recommendations* for a lengthier discussion on this finding).

It seems that the only instance in which a critical mass of women with cervical cancer gathered at any one time was in the offices of gynecologic oncologists. This presented its own challenges not unique to research with clinical populations: health privacy laws intended to protect the confidentiality of the patient. As a graduate student with limited amounts of time and funding (read: a low priority researcher), it was virtually impossible to navigate successfully through all the requirements of various institutional ethics boards and compliance committees in order to have a personal presence in the clinic.

Further, being granted permission to advertise in some of these doctors’ offices raised additional considerations from both the provider and participant perspectives.

Providers had to “agree” with my study; some did not see the relevance, and others did not want me to discuss HPV because they had consciously shielded their patients from information about the link between HPV and cervical cancer in an attempt to avoid stigmatizing them. On the participant side, the participant and I would have made contact within a clinical context where the focus is on a biomedical model of disease causation, whereas a major purpose of my study was to find out about their *own* ideas about causation and how these interact with both biomedical reasoning and their own bodily experience and knowledge. I did not want them to feel as if I was quizzing them on their medical knowledge, and this might be confusing given the fact that I appeared to be working with their doctor. In addition, contacting participants through their own healthcare providers always runs the risk of inadvertently making them feel obligated to participate because their doctors seemed to be asking them to do so.

And finally, as the title of this thesis suggests, cervical cancer can frequently be a stigmatizing condition for those who have been diagnosed with it. Because of this, one might assume that those with the condition might be more reluctant to be in the public eye or to take the necessary steps in reaching out to speak with a researcher about it. Accordingly, in summary, my challenges with recruitment largely reflect how difficult it can be to research a sensitive, stigmatized topic such as this in a location where there is no organized, identified community. There exists no easy opportunity to establish rapport with women in an ongoing, consistent fashion, and because of health privacy laws it was often necessary to rely on a third party (healthcare providers) to make the initial contact for me.

Subjective Experience

Another significant challenge for me throughout the course of the study, but particularly in the beginning, was my own personal history as an adolescent cancer survivor and as someone who has been involved with several cancer advocacy organizations. There were two dimensions to this. First, many aspects of my own identity are intertwined with my cancer experience, and I found that some of my unproblematically-held assumptions about “cancer survivorship” were constantly challenged. For example, I have always identified myself as a cancer “survivor,” and had, for the most part, taken this label for granted when referencing myself and others I knew that had cancer. All of my friends who have had cancer do the same. Thus, it came as a surprise to me that within the first couple of interviews this label was resisted and critiqued by some participants. In some instances, a seeming hierarchy of cancer experiences appeared, with those people who had gone through the most difficult treatments resting comfortably at the top of the ladder. They were—at least in some people’s minds—the “real” survivors and the ones most deserving of that designation. Additionally, the “taking-on” of that label for many women was a very deliberate decision made at a particular time, and it spoke volumes about the meaning that that experience held for them. This realization led me to ask a separate question in both the interviews and the survey in order to shed light on the use of this label and what it meant for those affected. Although these types of realizations were surprising to me at times, in a personal sense they allowed me to reflect more deeply, critically, and positively on my own beliefs and experiences, and—equally as important—to try to apply these considerations back to my own research and interactions with the participants.

Second, I had to devote much thought and attention to whether or not I should disclose this piece of information about myself to participants—and if so, how I should go about doing it. In the end, I opted for disclosing it in the beginning of the interview before the informed consent, while emphasizing the motivation behind these interviews: that my own experience had made me interested in hearing other people's stories. For the most part, this mutual sharing was a very positive experience and I believe that it helped put the women (and myself) at ease, especially during those interviews conducted over the phone. Rarely did it have one of the effects that I had been concerned about—specifically, having the interview turned around on me. Overall, I believe that both this sharing and questioning of my own experience strengthened my research project, by increasing its reflexivity, and—I hope—by allowing women to feel more comfortable sharing an exceedingly private and often painful experience with a total stranger.

SUMMARY

Data were collected in this project through four primary sources: key informant interviews, a website content analysis, semi-structured interviews, and an online survey. The key informant interviews as well as the content analysis were intended to provide both a background picture of the situation as well as preliminary data that would structure the design of the interview guide. Seven websites were ultimately included in this phase. Nineteen semi-structured interviews were then conducted with women who had been diagnosed at some point in their lives with cervical cancer, both in person in the Tampa Bay area as well as over the telephone. Findings from the interviews were then used in the design of a 38-item survey, which was administered online to an additional 70 women

residing nationwide. Data collection for all three phases took place from June 2007 through May 2008, while analysis of the data was ongoing throughout the project.

Chapter Four:

Results

As addressed in detail in Chapter Three, a variety of methods were employed in this project to create a holistic picture of the views of cervical cancer survivors on their illness and its association with HPV. This chapter will present in detail the findings from the data analysis. It is sub-divided into four sections. First, findings from key informant interviews and the website content analysis will be briefly outlined. Next, the semi-structured interviews will be discussed in-depth, including the demographics of the participants as well as major themes that emerged from the data. Many of these themes were incorporated into the survey questions, and findings from these data will be addressed in the fourth section.

KEY INFORMANT INTERVIEWS

Interviews were conducted with three key informants at the very beginning stages of the project, and were influential in the initial conceptualization of the research topic. Two of the informants resided in Tampa and the other in Washington, DC. These three women had very different experiences with cervical cancer and so shed light on a diverse set of issues related to the disease. Two had experienced diagnoses: one with invasive cancer and the other with pre-cancer. Two were also heavily involved in providing cancer support services through non-profit organizations and thus were very knowledgeable about specific resources available for cervical cancer patients and

survivors, both locally and nationwide. One of these interviews was conducted in-person in Tampa; the others took place over the telephone. Two of the women were Caucasian and one was African American; and all women were under the age of 50.

Because these informants had either been previously diagnosed with cervical cancer themselves or were involved in advocacy efforts for this community, the objective of these initial interviews was to learn more about the major issues confronting women with cervical cancer. Several important ideas arose through these conversations, one of which became the principal focus of this study, while the other two subsequently appeared repeatedly throughout the in-depth interviews.

First, two of the initial interviews took place in the months following the release of the Gardasil HPV vaccine (June 2006). At that time, the story—and subsequent controversy over school mandates—was appearing frequently in the news, and the advertisements for the vaccine had just commenced. Therefore, it seemed to these women that HPV was more clearly in the public eye than ever before, and they were in the midst of negotiating a situation where they felt “exposed” by the media attention on HPV’s link to cervical cancer. They spoke about feeling acutely ashamed whenever these commercials came on television, wondering if everyone thought they were now “dirty” or promiscuous, or had contributed to the creation of their own disease. The idea of moral labels being attached to cervical cancer had been an initial research idea, and the strength of this theme emerging in the key informant interviews served to sharpen and focus it more towards the ways in which women negotiated these labels in the face of ever-increasing media attention and awareness of HPV.

These interviews were also where a challenge to the concept of “cancer survivor” first arose, something that I had not considered before in my initial conceptualization of the project (discussed in-depth in Section III, this chapter). One of the informants questioned the relevance and application of this term to herself, given that she had not experienced debilitating treatments like other, more seemingly legitimate, cancer survivors. She had only undergone “a procedure,” and thus would never classify herself as a true survivor. She was concerned that if I used this phrase in my study, I would lose many potential participants who would never have considered themselves eligible in the first place. Her concern merited serious consideration, and following this I modified many of my recruitment materials so that they advertised for “women who have experienced cervical cancer” rather than using the more contested phrase.

Another idea that came up very strongly was that of infertility. Given the physical location of cervical cancer, fertility is inherently a concern for this group of women, especially considering its demographics—peaking in a woman’s reproductive years. Although this was not a principal focus of this study, this issue was consistently a particularly painful and poignant one throughout the course of the study (please see Section III this chapter for a more detailed discussion). The combination of a life-threatening illness with the ending—in some cases—of a dream or expectation that had been held since childhood created a huge amount of distress and this is certainly an issue that merits further study consideration.

WEBSITE CONTENT ANALYSIS

Next, a website content analysis was conducted to provide preliminary data between June and August of 2007. As detailed in Chapter Three (Methods), the goals of

this analysis were three-fold: first, to assess how these groups present information to the public related to HPV and cervical cancer's connection to a sexually transmitted infection, and the degree to which this link to sexual behavior may or may not be made apparent in their educational messages; second, to determine the organizations' position on the HPV vaccine; and finally, to guide the development of the in-depth interview guide.

Four groups of websites were included: non-profit advocacy groups, commercial groups, governmental agencies, and pharmaceutical companies. Three non-profit groups were sampled: the American Cancer Society, National Cervical Cancer Coalition, and Tamika & Friends. WebMD was selected to represent a commercial health information company, while the CDC was chosen because it is the public health agency of the federal government. Merck Pharmaceuticals and GlaxoSmithKline Pharmaceuticals were both selected because they are the two companies currently producing a vaccine for HPV.

Bernard (2006) describes content analyses as deductive methods, and following this I developed a set of hypotheses from which to examine the data. Close-ended questions were generated in order to measure the number of instances a certain piece of information occurred; a combination of these and a qualitative review of website text were useful in extracting key themes. As size and the amount of content naturally varies from website to website, it is important to note that the conclusions reached are preliminary—they are intended to provide both a background picture of the issue as well as to guide the direction of future questions meant to be answered by the interview and survey portion of the study.

Major Themes

Causation

All websites stated that HPV causes cervical cancer, occurring most often within the advocacy and pharmaceutical websites. Further, to varying degrees, all stated that HPV is sexually transmitted (American Cancer Society 2007; CDC 2007a; GlaxoSmithKline Pharmaceuticals 2007; Merck Pharmaceuticals 2007b; National Cervical Cancer Coalition 2007; Tamika & Friends 2007; WebMD 2007). However, certain types of websites—specifically governmental and commercial ones—seemed to place more emphasis on HPV’s *sexual transmission*. For example, they described both what HPV is, and that it is transmitted sexually (CDC 2007a; WebMD 2007). For example:

“The virus that causes cervical cancer is spread through sexual contact. The best way to avoid getting a sexually transmitted disease is not to have sex” (WebMD 2007:Topic Overview).

“Genital human papillomavirus (HPV) is the most common sexually transmitted infection in the United States” (CDC 2007a:Reducing Risk).

Conversely, advocacy groups and pharmaceutical websites placed a good deal more emphasis on HPV’s *causative role* in cervical cancer—for example, they often stated that cervical cancer is caused by HPV, but did not as frequently discuss what HPV is or how one gets it (Merck 2007b; NCCC 2007; Tamika & Friends 2007). In doing this, organizations avoid mentioning cervical cancer in conjunction with loaded terms such as “STI” and “sexual behavior.” For example:

“Cervical cancer is caused by certain types of HPV. When a female becomes infected with certain types of HPV and the virus doesn’t go away on its own, abnormal cells can develop in the lining of the cervix. If not discovered early and

treated, these abnormal cells can become cervical precancers and then cancer” (Merck Pharmaceuticals 2007b:FAQs).

“Unlike most types of cancer, the cause of cervical cancer is known. Almost all cases of cervical cancer are caused by high-risk types of the human papillomavirus (HPV)” (Tamika & Friends 2007:Myths and Facts).

De-Stigmatization

The above comment plays into this next theme of de-stigmatization. By not pairing the concepts of HPV and sexual transmission, the emphasis on sexual behavior is lessened, and thus—if we are assuming that the stigma of cervical cancer is related to this—stigmatization might be minimized. Advocacy and pharmaceutical websites most often utilized what might be interpreted as attempts at de-stigmatization: these websites do not as frequently discuss prevention strategies that involve modifying sexual behavior (GSK 2007; Merck 2007b; NCCC 2007; Tamika & Friends 2007); tend to mention HPV as only *one* potential factor among *several* (ACS 2007); and state HPV’s high prevalence rates in relation to cervical cancer (ACS 2007; GSK 2007; Merck 2007b; NCCC 2007; Tamika & Friends 2007), in addition to the more infrequent pairing of HPV and its sexual transmission (Merck 2007b; GSK 2007; NCCC 2007; Tamika & Friends 2007). For example:

“Even though HPV is an important risk factor for cervical cancer, most women with this infection do not get cervical cancer. Doctors believe that other factors must come into play for this cancer to develop. Some of these factors are listed below: smoking, HIV infection, Chlamydia, diet, birth control pills, having many pregnancies, low income, DES, and family history” (ACS 2007:What Causes Cancer of the Cervix?)

“Cervical cancer is caused by the human papillomavirus (HPV). Only some high-risk types of HPV cause cervical cancer. Most adults will have high-risk HPV at some point in their lives and are able to clear the virus through their body’s normal immune response. Most women will clear an HPV infection within 9-15 months” (Tamika & Friends 2007:The Facts).

Focus on Women

With the exception of two websites (ACS 2007; NCCC 2007), there is an exclusive informational focus on women. While this may seem obvious given that many of these websites specifically target a woman's cancer, most of these websites do not even mention the fact that HPV has health consequences for men, or that they can even carry it. For example, on the WebMD (2007) website, a good deal of discussion is devoted to risk reduction for women by modification of specific sexual behaviors and choices: *"the virus that causes cervical cancer is spread through sexual contact. The best way to avoid getting a sexually transmitted disease is not to have sex. If you do have sex, practice safer sex, such as using condoms and limiting the number of sex partners you have"* (WebMD 2007:Topic Overview). However, there is no discussion of HPV's potential adverse effects on men (such as genital warts, anal cancer or penile cancer), their ability to carry or infect others, or the need for men to practice safer sex to protect themselves against the health consequences of HPV.

This is perhaps a little dangerous—as cervical cancer has become a gendered disease, by not mentioning men, these websites represent HPV as a woman's disease too when it is clearly not. Thus, women become both the target of the disease and the source from which it springs, running the risk of furthering stereotypes of female sexual dirtiness and disease.

Presentation of the HPV Vaccine

The underlying motivation behind this objective was to get an overall picture of the ways in which these groups presented information on the vaccine, and whether or not they had adopted a pro-vaccination stance. With the exception of the two pharmaceutical

websites (GSK 2007; Merck 2007b), it appeared that all other websites attempted to offer unbiased information about the HPV vaccine (ACS 2007; CDC 2007a; NCCC 2007; Tamika & Friends 2007; WebMD 2007). The FDA guidelines were cited often, and somewhat surprisingly, none openly advocated a position either pro- or anti- mandatory vaccination.

“A new vaccine called Gardasil protects against four types of HPV, which together cause most cases of cervical cancer and genital warts...The vaccine is recommended for girls 11 to 12 years old. It is also recommended for females 13 to 26 years old who did not get the vaccine when they were younger” (WebMD 2007:2-3).

None acknowledged the mandatory vaccination “controversy,” then ongoing in the news. On the other hand, the pharmaceutical websites, not surprisingly, were essentially long advertisements for the vaccine.

“Gardasil is the only vaccine that may help guard against diseases caused by HPV Types 16 and 18, which cause 70% of cervical cancer cases, and HPV Types 6 and 11, which cause 90% of genital warts cases” (Merck 2007b:Know the Link—Cervical Cancer and HPV).

SEMI-STRUCTURED INTERVIEWS

Participant Demographics

A total of 19 women participated in the interview phase of this study. Ten of these interviews were conducted in-person with women who resided in the Tampa Bay area; the remaining nine were conducted over with phone with participants living outside of Florida (specifically, in California, Georgia, Michigan, New York, Pennsylvania, and Texas). Participants were recruited through a variety of sources: two women were recruited through doctors’ offices, four women through a local Tampa-based cancer support organization, and 13 through various organizational email listservs. The median

age was 39, although women ranged in age from 24 to 65. Nine of the participants were married, four were unmarried but in long-term monogamous relationships, four were single, and the relationship status of the remaining two participants is unknown. An equal number of the women had children as did not (eight each), while one woman was currently in the process of adopting and another was expecting a baby through a surrogate.

Women were asked to self-identify by ethnicity: the greatest proportion (12) identified as Caucasian, three as Latina with different countries-of-origin, two as African American, and one each as Polish and Asian. Occupations were diverse: five worked in administrative positions while four were healthcare professionals; three worked in media (television and magazine), one was involved in community services/outreach, one in the travel industry, and one worked as an animal trainer. Four were students, either part-time or full-time, and many were involved to some degree in advocacy for the cancer community—three working full-time for non-profit organizations while others on a more informal level. One woman did not report an occupation.

Relatively speaking, the women who participated in the interview had been diagnosed recently: the median time since diagnosis was two years. However, there were large differences in the time-since-diagnosis among the women, ranging from 33 years to 2 months prior to the interview. Cervical cancer had been discovered during the course of regular Pap screening in eight of the women, and in three others it was discovered in the middle of lengthy fertility treatments. Seven others had been experiencing either worrisome or life-threatening symptoms, and in one participant the reason for discovery was unknown. The women's stage of disease at diagnosis ranged from very early (Stage

0 or I) to advanced (Stage IV), although in the greatest proportion of cases the cancer was caught at Stage I.² Types of treatment were varied and included some type of surgical procedure (i.e., hysterectomy or trachelectomy) in 11 of the cases, internal radiation (4), external radiation (10), and/or chemotherapy (10).

Major Themes

Causation

“Causation” is a complex category reflecting various, and at times conflicting, ideas about the root causes of both cervical cancer and HPV. Incorporated in the responses within this theme are first, biomedical theories of disease development—presented by participants as objective and scientific notions—and second, personal explanations about why participants themselves became sick, which were behavioral in nature and often tinged with moral judgment. As discussed earlier in Chapter Two, Hunt (1998) argues in her work that “science strives to translate observed phenomena into a value-free framework, removing it from the elements of ordinary existence” (1998:309). In the absence of biomedicine’s explanations of cancer’s fundamental cause, individuals must create *meaning* behind their own illness, and indeed, these ideas seem to be reflected within the stories of these interviews. Within these broad strokes lie differing explanations about the cause of, first, HPV, and second, cervical cancer—in general and then within themselves. Simply put, these responses answer the questions, “What do you

² In Stage I cervical cancer, the cancer has not spread outside the cervix. Stage II indicates that the cancer has spread beyond the cervix but not yet to the pelvic wall or bottom third of the vagina. In Stage III, the cancer has spread either to the pelvic wall or to the lower third of the vagina, while Stage IV cancer is the most advanced stage in which the cancer has spread to a close organ, such as the bladder or rectum, or a distant part of the body, such as the lungs, liver or brain. Stage 0 indicates carcinoma-in-situ—a “pre-cancer” that has not yet become invasive (National Cancer Institute, 2008b)

think causes HPV? Cervical cancer?” and then, “How do you think that *you* developed HPV? Cervical cancer?”

HPV: Theories of Causation

Overall, participants’ explanations for the cause of HPV in general tended to reflect the current biomedical discourse surrounding HPV as a sexually transmitted infection. The majority spoke of HPV as sexually transmitted, and specific behaviors that might lead to catching it. For example, when discussing who was more at risk for getting HPV, one participant noted that, “*They say that certain women, like younger women if you're first sexual experience is below a certain age and if you smoke, and if you've had a lot of sexual partners*” (Kate, 25 years old). Other women spoke about the seemingly high-risk nature of HPV, and how even one act is enough to contract the virus: “*We know that you can have sex one time and be exposed to the virus*” (Amanda, 45 years old).

Explanations for how people *in general* contract HPV were remarkably similar to the explanations participants shared for how they *themselves* contracted HPV—both reflected current biomedical theories surrounding the virus. For example, one participant replied:

“Um, yeah, sex. I was pretty sexually active when I was younger, so I'm sure it was from sexual partners, and it was probably several sexual partners ... multiple partners. So I definitely think that was where it was from” (Christina, 24 years old).

In addition, many of the women’s stories reflected confusion about the actual event—or, more frequently, person—through which they contracted HPV:

“And as soon as she said [it was HPV], I started thinking back and I'm like ‘which one of those sons-of-bitches gave me HPV? You bastards! Which one of

you is the reason that I'm in this room right now?' The thing is that I don't know ... I never had any STD; I've never had anything my whole life -- I could have gotten it from my high school boyfriend; I could have gotten it from my husband. I have no idea. I guess I could take my husband down there, but I guess at this point it doesn't matter. There's no way to know. So, did he get it from me? It's so hard to know. Because when I think about other boys, I'm like, "All your fault!" (Kate, 25 years old).

Cervical Cancer: Theories of Causation

Participants' responses about the potential causes of cervical cancer were almost identical to their explanations about the potential causes of HPV. For example, many cited specific behaviors—frequently sexual behaviors—as a potential cause, and almost seemed to take for granted HPV's role in cervical cancer, using the two terms almost interchangeably. For example, one woman replied that:

"If you have multiple sex partners, it increases the chances of having [cervical cancer], but I guess the HPV [...] has now been identified as relating to that. And so women who are exposed to that, and I guess if they have more partners they are more likely to be exposed to that – those are the ones who are more likely to get cervical cancer" (Helen, 61 years old).

On the other hand, personal theories about the cause of that individual woman's cervical cancer are on the whole much fuzzier and reflect varying degrees of uncertainty. In general, women's explanations about why they themselves became sick tended to fall into two broad categories: the first, which I refer to as "Individual Behavior," explains cervical cancer as resulting from choices on the part of the woman herself. For example, women spoke about not going to the doctor enough, not getting Pap smears as frequently as they felt they should have, sleeping with the wrong man, smoking, or just generally not taking care of oneself properly.

"I have all of the risk factors, you know. I had sex before 17, I have multiple partners and you know basically the only one I didn't have was that I didn't smoke." (Joyce, 39 years old)

“It is my fault that I had cervical cancer, because I have never had a Pap smear” (Beatrice, 65 years old).

“Well, I guess I had the HPV, because I'd had the abnormality a long time ago, and I think that my immune system was just really run down. That's my feeling. I think that my typical self was very different from my self when I got diagnosed, because I'd lost the pregnancy and that was really really really hard physically and emotionally, and my body was just really run down” (Amanda, 45 years old).

The second category includes “External Factors”—these explain cervical cancer as a result of external forces acting upon the individual in such a way as to cause the disease. For example, some women described their cancer as resulting from the actions of a philandering husband or from a rape that took place a couple of years prior—in both of these instances, the man had been the one to pass HPV onto these women. Several others believed that the fertility treatments they were undergoing had played a central role. One woman suspected that her tampons had been the primary cause of her disease:

“I think that [my experience with cervical cancer] started when I was 12 years old and my menstrual cycle began. At first I used sanitary pads, but then before my 13th birthday, I decided to switch to tampons...I religiously used tampons from that time on until a year before I was diagnosed with cervical cancer. A little bit later I started to notice there were publications on findings that there were traces of asbestos found in certain brands of tampons... Now that's considered very dangerous in air filtration systems, and in building structures. So I started researching that. And I started to discover that it was because the asbestos being present in the tampon causes more bleeding. When more bleeding is produced, more tampons are purchased. The market profits. And that's a risk to women that are using tampons.” (Kim, 57 years old)

No matter some women's assurance about the overall cause of their cervical cancer, its diagnosis seemed to cast a shadow of uncertainty onto everything from their past behavior to the behavior of others. Many spoke about the difficulty of living without a clear answer as to how it arose, and whether or not it will return. Still others raised the

issue of trust in marriage, and how this diagnosis had raised some doubt as to their partners' fidelity over the years. For example, one woman confided that:

“Well, that's a weird one, and to me there's kind of like a stigma with cervical cancer, because you know, the whole HPV thing, which is basically like a sexually transmitted disease. So, I've been married for 15 years, and I had my last child about 11 years ago, and I'm not unfaithful. I don't know, I'm thinking it had to come that way cause it's not the type of cancer that generally ... it's not a breast cancer. I don't know how long the HPV virus would be there, they never really said if it was like HPV, from that strand or not” (Candace, 36 years old).

Sexuality

A prominent theme emerging out of the interviews was sexuality. In particular, participants' narratives touched upon the idea that there are aspects of female sexuality and the female body that predispose certain women to developing cervical cancer by increasing their risk of contracting HPV—whether it be actual physical attributes, or subjective judgments about female sexual nature. For example, one woman believed that the relative uncleanliness of female genital anatomy as compared to males' was a contributing factor to her condition, stating that:

“It's definitely because of my sexual history [rather than my husband's] because I don't think that men can carry the virus that long... The male organs...are definitely cleaner, you know, there are no places for bacteria or germs to hide” (Meredith).

Another participant commented upon society's judgments about the type of woman who gets cervical cancer, noting that:

“We do assume that if you get HPV, you're a slut. Any kind of sexually transmitted disease, you're a whore. Unless you're a guy, and then it's some girl's fault” (Kate, 25 years old).

Another important idea revolved around the tension between the public and private aspects of female sexuality. Many women tended to regard the female sexual and reproductive organs, and further, sexual behavior, as extremely private. At the same

time, however, a diagnosis of cervical cancer presented a big dilemma because it required them to become public about a part of the body that they are not used to being public about. One woman said:

“I think that there is a much smaller percentage of women talking about cervical cancer than talking about breast cancer...Breasts have a very different feeling about them. In a way they are considered a sexual part of the body but then at the same time they’re kinda not. Whereas the cervix, vagina and all that are very private, very sexual... so a lot of women would tend to keep it to themselves. ‘This is my personal part of my body, not for anyone else. It’s for me to witness’” (Kim, 57 years old).

“When I was diagnosed, I felt that a lot of my sexual life [was] under investigation...That has been really, really uncomfortable...And you start explaining [to your friends and family], but a lot of things are private, so you have to open your sexual life” (Carmen, 28 years old).

The private nature of this area of the body seemed to influence many women’s ability to get support during the experience, and the degree to which they thought their family was responsive to their needs. Speaking about her experience with dysplasia, one participant explained that:

“My mom has been very supportive; I certainly cannot talk to my dad about any of it. My dad does not care about what’s going on in my lady parts -- he doesn’t want to hear it! As far as he’s concerned, they do not exist. Unless I drop dead on the floor, he doesn’t want to hear about it...It is not in his realm of existence” (Kate, 25 years old).

Less often mentioned were the sexual effects of having had cervical cancer, even though a large proportion of women had undergone treatment that might permanently affect the sensation and functioning of organs in that area of the body—such as internal radiation, external radiation and surgeries that produce scarring. If it was mentioned at all, it was touched upon very briefly and with some resignation. It is a topic, perhaps, that might be a little too sensitive or private for a one-time interview.

Prevention

Two aspects of the concept of prevention were salient in these interviews: “preventability” as a (newly recognized) quality of cervical cancer itself, and prevention via the new HPV vaccine. First, women spoke frequently about the idea that cervical cancer is preventable by “responsible sexual behavior” and how this knowledge can impact them in adverse ways because people now see them as responsible for their cervical cancer. Several argued that this recognition of cervical cancer’s preventability is recent, and due largely to new discoveries about HPV and about the vaccine.

“Because it's preventable, then they feel like [the fault] is kind of on you. That's the way I think people might see it. No one's ever said it, but that's the way I think” (Candace, 36 years old).

“It is pretty prevalent, and still preventable -- and that can add to the stigma too, because if you had gone in to get your Pap, you might not have cervical cancer” (Christina, 24 years old).

Or, conversely, women noted that this piece of knowledge has contributed to a personal sense of blame:

“You feel embarrassed about it; you feel guilty thinking that ‘I could have done something about this.’ Wishing that I would have. It makes you feel a lot of regret as far as prolonging the visit to the doctor, not getting my Pap smear -- it's like, God, if only I would have” (Candace, 36 years old).

This concept of preventability also influenced the ways in which women conceptualized cervical cancer and themselves in relation to the outside world. For example, in some instances, cervical cancer’s “preventability” was blamed for a lack of research and medical attention on this issue—one woman reported that a grant-making agency denied her request because “*cervical cancer is preventable*” along with the fact that it only affects a small proportion of women compared to breast cancer. On the other hand, many women cited this aspect of preventability as a reason behind their own

involvement in raising awareness of cervical cancer, the need for screening, and importance of the vaccine.

“I feel like the medical community should reach out, because if it is really preventable, then why not really teach people? [...] If this is preventable, why isn’t this like breast cancer [in terms of the resources committed to it]?”(Candace, 36 years old).

“[Cervical cancer] is a disease that you don’t have to get. You don’t have to get it; they don’t talk about it enough. Cervical cancer is one of the issues that we need to be talking about [...and doing] exactly what I’m doing right now: talking and running your mouth to anybody that will listen. Talk on TV, talk on the radio, talk at speaking engagements, talk about motivational events...talk everywhere. Keep sharing, keep hearing—that’s the way we’re going to get the word out” (Tanya, 41 years old).

Second, this code also encompassed discussion of the HPV vaccine, and the fact that cervical cancer has now been made preventable by the vaccine itself. The vast majority of women were very supportive of the vaccine, and of making it as widely available as possible. Only one participant took issue with the vaccine, explaining that she has mixed feelings given the danger that certain vaccine components pose to developing body tissues. Several women were somewhat whimsical in their discussion of the vaccine, commenting that *“I wish I could have gotten this when I was 18” (Heidi, 41 years old).*

Many favored mandatory vaccination for all girls, explaining that if mandatory vaccination is what it takes to prevent other women from repeating their own experience, then it is worthwhile. In addition to this support, there was widespread discussion and denouncement of the current controversy surrounding mandatory vaccination. It is important to note here that, on the whole, participants’ opinions regarding the effect of the publicity and media attention surrounding the HPV vaccine were extraordinarily complex, and will be addressed in-depth later in this section. For our purposes here,

though, it remains that the majority of participants supported the widespread use of the vaccine on principle.

Awareness

The code of “awareness” referred to either positive or negative aspects of awareness about HPV, cervical cancer, or screening. This theme arose either in the context of its impact on one’s *own* experience, or in the context of its impact on *others’* experiences—either loved ones or wider society.

In relation to the self, awareness about HPV and cervical cancer was often spoken about in “then and now” terms. Specifically, the majority of women lamented about how little they knew about HPV before they were diagnosed—a good proportion of women had never even heard of it before that moment. These comments were often made in juxtaposition with a description of how much they *now* know about both HPV and cervical cancer, and how important it was for them to have that information—either by getting it from their providers, or, failing that, by seeking it out on their own. “Raising awareness” was often referred to by survivors as an overall personal goal, something in which they saw themselves participating on a long-term basis. A common effect of cervical cancer seemed to be an increased sense of responsibility and activism; women frequently discussed how they had felt compelled by their own experiences to help others through awareness-raising, and the large need that they were now responsible for addressing.

On the other hand, survivors also spoke about awareness in terms of its impact on others. First, their loved ones’ “increasing awareness” about cervical cancer and the need for screening was commonly cited as a positive by-product of witnessing their own

experience with cancer. For example, one woman noted that, after her diagnosis, *“a lot of ladies at work have daughters, [and they will] pay more attention to that when their daughters get of age. Just being more aware of getting Pap tests like we’re supposed to”* (Mary, 57 years old). Second, increasing awareness was seen as the positive consequence of the media attention surrounding the HPV vaccine—although this media attention was often seen as a double-edged sword (to be discussed more in the next section), the positive side of the equation was consistently and almost predictably stated to be awareness on the part of the public: as one woman notes, *“I think [the media attention] makes [cervical cancer] more difficult to hide ... With any issue brought to the forefront, it’s harder to pretend that it’s not there anymore. Which is good”* (Kate, 25 years old).

Media

Many women also spoke about the impact of the current media campaigns surrounding the HPV vaccine and how they are publicizing the link between HPV and cervical cancer. Media attention was frequently discussed as a “double-edged sword.” The positive side effect was always presented as an increased awareness of cervical cancer, while the negative side effect surfaced as one of two potential consequences. First, in many women the current media attention seemed to create an anger or bitterness that this particular knowledge or awareness had not been around before they were diagnosed; thus, they could not themselves directly benefit from it. In fact, many had had the experience of learning about HPV for the first time when they saw the commercials on television, and were dealing with the anger of feeling misled by their healthcare providers. For example, one participant responded that:

“Well the ads, half of me [thinks] it’s like great. I’m glad that it’s getting out there. ‘Cause the more people that it reaches the more people it can save from the experience like mine. And the other half, you know I get pissed because if those ads had been around before, I probably maybe would have looked into this a bit more. Maybe it would have sparked something. ‘Why don’t you get another Pap? Why don’t you get that checked out?’ So it’s a good thing...It’s like half angry and half good” (Samantha, 38 years old).

Second, many women pointed out that the increasing recognition of the link between an STI and cervical cancer negatively impacted other peoples’ perceptions about them. For example, one participant explained that:

“I think it can be positive or negative...No one really talks about it. It's making people aware of the fact that having a simple STD or something like an STD like HPV can turn into cancer. It could make women more aware of the fact that they have this. That's the positive...You're hearing women talk about the fact that they have it, and they'll be more aware of it. But then I also feel that because of the advertisements, it can be a two-fold thing. That on one hand, they can be alerting the public that something is going on ... but on the other hand, it does affect us negatively because people basically do look at it like an STD” (Candace, 36 years old).

Some women spoke explicitly about their own experiences with the commercials creating personal feelings of embarrassment or shame. For example, one woman said, *“So I don't like what the commercials have done, because anyone who knows I had it thinks I'm this like diseased person. What my father thinks! That's what bothers me! I want to tell him, ‘Dad, I didn't have HPV’ — I hope he doesn't think that I did this to myself. [There is] this horrible stigma that goes along with it” (Sarah, 34 years old).*

Several women had had the uncomfortable experience of being in treatment for cervical cancer when the commercials for the vaccine were released, which had the effect of seemingly exposing how they developed cervical cancer in the first place. One woman described her experience with her father:

“The hardest part was facing my dad when the commercials came out. When I came home and told him I have cervical cancer, I told him—‘it's not genetic, and

it's not from smoking, and it's not from this and it's not from that. We don't know what it's from' —and then a week later, all these commercials come out saying that 'If you have cervical cancer, then it's from HPV, and it is a sexually transmitted disease.' And I was sitting in the living room with him the first time I saw the commercial, and it was just ... (long pause) ... It was just hard. He has never brought it up to me, but on my end, I just got the impression that he was looking at me differently from that” (Holly, 30 years old).

Stigma

Stigma and feelings of stigmatization seemed to be generated through several mechanisms: first, by survivors' assessment of the place of cervical cancer in our society; second, by their perceptions of other people's beliefs; third, by the actual treatment by and the reactions of others; and finally, by their own feelings and reactions to these assumptions and incidents.

Cervical Cancer in Society

In large part, participants believed that cervical cancer is a stigmatized condition in American society. This stigmatization is due, they felt, to two things: first, its association with a sexually transmitted infection, and second, to the fact that it is now recognized as having been caused by an individual's actions. This aspect of preventability adds a whole new layer of personal responsibility to their situation that most were not comfortable with. Indeed, it led many to compare cervical cancer to lung cancer—a type of cancer that has historically been stigmatized because of its association with the personal choice to smoke.

“It's interesting; I met this woman this year who's doing her PhD dissertation on the stigma of lung cancer. People think you got it because you deserved it because you smoked. I think there's a stigma with cervical cancer. That you got it because you, you know...And that's far from the truth” (Amanda, 45 years old).

“When people say they have lung cancer, the next question is ‘did you smoke?’ That type of mentality, like you have cervical cancer – ‘oh, did you ...?’ Whereas if it were liver, it would be a different reaction” (Holly, 30 years old).

The consequences of this stigmatization are numerous—many pointed out how cervical cancer is ignored in funding and research circles in comparison to more “socially acceptable” forms of cancer, such as breast cancer, and how these conceptions result in the subsequent stigmatization of the HPV vaccine.

“It's almost a bitter-sweet victory because we've done so much research and we know so much about cervical cancer now, that they know it's coming from HPV...But because now we know that it's caused by HPV, now we've changed the way people look at it. So, before, if you could say ‘I'll come up with a cure for cervical cancer. I could come up with something that would reduce cervical cancer by 80%’ -- people would jump all over it! But now that we know that it's caused by a virus, and that it's an STD, and we have a vaccine that could reduce cancer rates by 80% -- now that we know it's a sexual disease, now we're like, ‘oh’ -- you know what I mean? It's TOTALLY different...It's a HUGE stigma. A huge stigma. Otherwise, they'd all be vaccinated. Everyone would be vaccinated” (Kate, 25 years old).

In addition, participants felt that cancer as a whole was stigmatized. The negative connotations around cancer, they felt, were not so much due to the origins of the disease as is the case specifically for cervical cancer, but because of its enduring association with death. This conception of cancer seemed to impact them doubly—it generated fear and anxiety in themselves related to their *own* mortality, and also anxiety and discomfort because they assumed that others were thinking the same thing and believed that they were going to die.

“I think when people hear the word cancer [...] everyone gets really off-put...Mostly people, when they hear you have cancer, can't believe that, and they see it as a death word. ‘Cause like on every TV show, if someone's gonna die of an illness, it's generally going to be cancer. And that's one reason I didn't want to tell my kids, because I didn't want them thinking that it was a death issue. For me, I just didn't want to see it that way. And it was great, because I never saw it in them when I was with them -- it was like, ‘oh, mom's not feeling well. She hasn't been feeling well a lot lately.’ And they kind of felt that something may be wrong,

but not having that word kind of let them feel like it was going to be okay” (Candace, 36 years old).

“I think [that the general public thinks that cancer] is an equation to death. A death sentence. And it’s scary” (Joyce, 39 years old).

“[I didn’t think about cancer patients too much before I was diagnosed]. Except for you pass somebody on the street who’s obviously going through chemotherapy or something...you know they have a headscarf, they look terrible...except to be scared shitless when you see people like that...Yeah, just imagining how awful the treatment must be and how scared they must be and how shitty it must be to feel how they must feel, which is probably scared for their lives” (Samantha, 38 years old).

Perceptions of Others’ Beliefs

More prominent a theme than any actual incident or treatment by others was participants’ *belief* that others think negatively of them. Many of the women were certain that negative, judgmental thoughts were constantly running through the minds of people who found out about their diagnosis, because they had had the same thoughts and assumed others would have them too. Many assumed that others blamed them for getting the disease because they were irresponsible or had sex with many people, something that was particularly relevant now because of the HPV vaccine commercials. This is an important pattern to note—not so much because of what others are *actually* thinking—but because of what it reveals about a survivors’ own conception of self and assessment of the situation, and the ways in which we internalize society’s judgments about a stigmatized condition.

“You know, I think they think...that you’re promiscuous, which is a little unnerving. I think that it’s kind of a drag that I feel like I’m admitting that I played around or something. I don’t think anybody has said ‘Oh, were you just so sexually active that you caught this?’ specifically, but they probably think it. I’d probably think it too, if I was just exposed to what you’re exposed to about this disease now. Especially with this new vaccination, that it can prevent it” (Amanda, 45 years old).

“As soon as you say cervical cancer to people, they automatically ... you get this response like, it's your fault. Like, ‘you must have been sleeping around’...But I've met people who haven't had sex, and they have HPV. Or people who have been with one person, and they have HPV. But people automatically look at you when you say cervical cancer, and think that you must have been sleeping around and that must be why you have it -- because it's a sexually transmitted disease, and that's where their knowledge stops” (Holly, 30 years old).

Another interesting pattern to note was survivors’ reactions to questions from others. A number of women mentioned that a friend or family member had asked them about HPV, and this seeming audacity provoked an angry and defensive reaction from these survivors. They assumed that others were asking these questions in an accusatory manner based on the new information about HPV’s role in cervical cancer.

“I don't like it. One of my girlfriends asked me if I had HPV, because I had cervical cancer, and I said no. I understand why they're asking me that, but it's kind of a stigma. I caught something that gave me cancer--that's the only reason why someone would ask me that. NO, that was not a good feeling, that somebody asked me that. I did not like that at all...Disturbing! [This happened] probably whenever these ads started coming out, somewhere around that time. I remember one of my friend's sisters asking me, we had a conversation about why I was sick ... I guess, with what was going on in the advertising, maybe they didn't think it was wrong to ask me—but it was judgmental, and I didn't like it” (Sarah, 34 years old).

Reactions and Treatment by Others

Although most of the participants spoke hypothetically about other people’s beliefs and cervical cancer’s and HPV’s reputations in American society, a number of women actually experienced negative treatment. One woman related a story to me that when she told her friend about her diagnosis, the friend replied that *“well, I guess you know that you screwed up.”* Another woman told me a story about her so-called friend’s reaction, while another discussed her classmate’s frequent diatribes against women with HPV:

“The other women [at my job] when they found out about the cervical cancer, actually terrorized me, publicly humiliated me about that [...] This one woman who used to be my friend decided that she was not going to be my friend. She went on public boards and called me ‘warty pants’ and all kinds of things. And said I had a venereal disease, and was going on and on. So cervical cancer has a stigma attached to it. People are blaming you for getting it. I don't see with any other disease, whether it's HIV or anything, you get the sort of blame and some label attached to you. As if you were bad. And evil. And so now you get this thing, and you're dirty” (Heidi, 41 years old).

“I'm in the nursing program, and HPV and cancer and things like that come up a lot, just in the course of your studies. One of the girls in the study group, every time anyone would mention HPV or cancer, she would say things like ‘oh well only sluts get that. Basically, if you're not a really big slut, then you won't get cervical cancer.’ [...] She thinks that she's being funny, because she assumed that no one here would do something like that. No one here is slutty enough to get HPV [...] It's frustrating, because you have to deal with your diagnosis, and you're worried that something is going to come back [...] You also deal with the fact that people who don't know you or your situation will indirectly call you a whore while they're sitting next to you. But if I had stomach cancer, that wouldn't happen. Maybe gluttony, but they wouldn't call me a whore” (Kate, 25 years old).

Other women spoke about the ways in which they felt isolated as cancer patients.

One had had an encounter with a friend not long after she was diagnosed; this friend backed away as if she were contagious, all the while saying that *“I would hug you, but I don't think I should” (Mary, 57 years old)*. Another spoke of the cancer experience in relation to the staff at the hospital, who tended to keep her at arms' length and subtly treat her differently now that she was a cancer patient: *“all of a sudden you feel like you're in a box—the cancer box, and everybody else in the happy healthy box” (Samantha, 38 years old)*.

Self-Reflections

All of these previously discussed themes—ideas about causation, female sexuality, preventability, awareness and media influence—surface in the ways in which the women reflected on their own experiences with cervical cancer. Conflict emerged

between how these women viewed themselves and their own bodies and how those views interacted with both the disease as well as society's explanations for why the disease occurred in them. Much of the discourse on risk and individual responsibility emerged in their explanations, and many felt ashamed and embarrassed for having had cervical cancer—for example, one woman commented that *“I personally feel responsible for having made a decision and blame myself about that”* (Lauren, 41 years old). Another remarked that she felt as if she were *“wearing the scarlet letter”* (Joyce, 39 years old) and wondered whether cervical cancer was a punishment for not making the right choices in her life. Others spoke similarly:

“I know that I say uterine cancer instead of cervical cancer, because uterine cancer could have started from the inside versus the outside, and that's my way of dealing with it. Because I do feel, in myself, embarrassed about that. I don't know if anybody else sees it that way because no one's ever said anything negative to me about that. But in myself you know I do shy away from saying cervical cancer—I feel like it's the preventable cancer, and the only thing I've ever heard about cervical cancer is the HPV commercials” (Candace, 36 years old).

[Referring to HPV] “Yeah, I do [still feel embarrassed] because it is an STD, so it is embarrassing. It's like you did it to yourself. If you jumped off a bridge and broke your leg, nobody would have sympathy for you -- you did that to yourself. So, even though this is something that gives you cancer -- it is, it is embarrassing” (Kate, 25 years old).

At the same time, some also challenged these discourses in their explanations for other people's reactions to them, offering reasons for why they thought other people made the assumption that their cervical cancer was related to an STI. To them, it appeared almost natural that others must concoct stories about people with a scary disease, because it makes them feel safer, more comfortable, and less worried about getting it themselves. In the minds of several participants, this phenomenon was responsible for the parallel stigma of cervical cancer and lung cancer: both cancers are

seen as preventable because they are caused by “bad behavior” on the part of the individual—and others *need* to draw this distinction between “me” and “them” for their own sanity. For example:

“[Since it’s from sexual activity], I’m sure it’s running across their minds. Everybody’s mind. And in a way... if people think about it that way, it helps them feel secure and insulated because they can think, ‘you know this won’t happen to me because I didn’t have all those boyfriends in my twenties like she did’...

...It helps them. If they can blame the cancer on something the person did behaviorally it helps them feel safer. Oh, like, ‘that one had lung cancer.’ ‘Oh did she smoke? ‘Yeah for 20 years.’ ‘Oh, okay.’ And it’s almost like a sigh of relief” (Samantha, 38 years old).

Participants also expressed a discomfort with cancer in general—not just cervical cancer—because of its association with death and disability. Women did not necessarily feel embarrassed or ashamed for being termed a “cancer patient.” Rather, they expressed a heightened awareness of other peoples’ pity or fear, or an idea of themselves and other cancer patients as irreversibly altered, and negatively so—or, to use the frequently-mentioned term, “damaged goods.”

“I look normal from the outside as far as, a cancer patient is supposed to look normal. Yet if you could see me from inside out, you would see all the damage... all of the stuff they did from the inside of my body. Then maybe you would understand how the outside of me feels” (Tanya, 41 years old).

“I just felt diseased. Somehow I just felt really ugly and diseased” (Heidi, 41 years old).

Disclosure

The decision of who should be told about their diagnosis, when, and why was a very delicate one for participants. Topics ranged from the discomfort of revealing it to others because of negative assumptions about cervical cancer and indeed cancer in

general, to the distinction between voluntary and involuntary disclosure, to strategic ways to use disclosure for a purpose.

Often, choosing how and when to reveal their diagnosis to someone was difficult because of the stigma associated with the disease, and the experience was often uncomfortable even though participants related that the outcome was frequently positive. Nevertheless, participants were forced to confront this situation often, especially in the context of employment. For example, one woman related her experience with informing her employers when she realized that she would have to take a leave of absence from work. Though clearly uncomfortable, it ended supportively:

“I did feel embarrassed and ashamed when I had to tell them that I had cervical cancer. And the questions came that it was HPV. And I do remember being hunched over at work, huddled all by myself having to tell them and that was embarrassing, but they were very supportive and nobody said anything. But it did make me feel...here you are talking to a bunch of nurses, and physicians too. And they know [about HPV]. I was pretty close with them. But they were all awesome. They would help in anyway that they could help” (Joyce, 39 years old).

Due to cancer’s frequent association with death, women frequently chose not to disclose their diagnosis to loved ones—often older parents or younger children—because they did not want to worry them. Many times, they told them after treatment was over.

“It was hard to talk to my mom about anything, because as soon as I was diagnosed, she immediately went to ‘oh my god, she is going to die.’ So talking to her was just very difficult for me” (Holly, 30 years old).

Disclosure was a major issue among a couple of the unmarried women—decisions about whether to tell a potential partner, and at what point in a relationship, were difficult and without clear answers.

“Sometimes I say that I had girly cancer [...] When I say things like that, they leave it at that. They don't want to know. I would hate to lie, that's the thing. I don't want to say ‘I have ovarian cancer’ and then they find out later that I had cervical cancer. At first I felt like it was something I had to tell somebody, not that

I had cervical cancer, but that I was a cancer survivor. As if this was some significant thing, and that a partner would find you unlovable or not healthy. Then I realized, that maybe it's just none of their business. I just would hate to tell the wrong things...I would hate to tell a lie and then accidentally slip up. I don't think they deserve to know, but since it is such a significant thing...You couldn't date somebody, and have not told them the story of how you had cancer. Wouldn't it come out?"(Heidi, 41 years old)

Many women lamented the annoyance of being forced to disclose their diagnosis involuntarily—most often, these incidents occurred when they needed to fill out medical forms, insurance applications, or adoption forms. Although not a major problem, these occurrences were seen as an unwelcome intrusion and reminder that they had had cancer and thus were somehow “different.”

Another interesting theme was the strategic use of disclosure for a clear purpose. Women referred to telling people that they had had cancer only in the context of advocacy—when they were lobbying or writing letters to their legislators. Here, there was a clear identification with the term “cancer survivor.” Others frequently related stories of telling other women in the hopes of motivating them to follow-up on an abnormal Pap smear, or to comfort someone who was just diagnosed. Still others mentioned the “silver lining” of cancer—i.e., the gifts, free haircuts, discounted clothes, and other unexpected perks that come along with a cancer diagnosis. It seemed that some women had learned to use this strategically as a way to retain something positive out of an awful situation.

Support

Overall, participants spoke very highly of the support that they had experienced during their cancer treatment and beyond. Frequently, while undergoing treatment, participants were unable to talk about their experiences in-depth with others because it

was too mentally fatiguing, and they sought support mainly from those in their closest circle—parents, siblings, spouses, and a best friend or two. The strength and perspective offered by one’s faith and religious establishment was an enduring theme (discussed later in its own section).

Many participants’ stories reflected a sense of inevitable re-assessment and re-prioritization of their relationships with loved ones. For example, one woman reflected that *“I found out who my real friends were. Who stuck around and all the ones who didn’t...Kind of like an involuntary weeding-out in a way. So those few friends who stuck around are still there. They’re the ones who are real close to my heart”* (Kim, 57 years old). Several women related incidents where family members either did not believe them, or could not accept that they had cancer or HPV:

“It was scary at the time because I didn’t have a lot of support family-wise. My mother was really strange. We were never really that close, but when I told her she was like, ‘well, you don’t have cancer.’ I was like, ‘yeah, I do.’ And when I went into the hospital she didn’t even come and see me. I could never figure it out. I don’t know if it scared her. I don’t know what it really was. She never really explained that. My dad came” (Linda, 61 years old).

“It’s embarrassing. It’s embarrassing because ... I feel like if I had pre-cancerous cells in my bladder, my family would care. But because [HPV] is an STD, it’s just looked at totally different, totally different” (Kate, 25 years old).

Many women felt compelled to seek support from online message boards or support groups because there was no adequate in-person group available. Since many felt that other survivors have a unique capacity to provide support and understanding, they bemoaned the fact that there are an extremely limited number of in-person cervical cancer support groups. Meanwhile, breast cancer support groups flourish. To them, this is just another indication of how cervical cancer is ignored in the wider medical community because it is not a “socially acceptable” type of cancer. This is an interesting

contrast with how survivors felt about the effect of stigma on the level of personal support—when questioned directly about how it may have impacted the support they received, the vast majority replied that it had no effect. Their loved ones, they felt, knew them better than to be influenced by those ideas.

Resources

The theme of cervical cancer-specific resources has already emerged numerous times in this discussion; indeed, an apparent gap in resources is a topic that is interwoven throughout many of these subject areas because so many of the survivors see it as a direct result of how cervical cancer is viewed in American society. This perception of cervical cancer is not coming wholly from a negative place—there are both positive and negative dimensions to it.

First, the lack of resources centered around three main areas: first, information related to HPV, and in particular the connection between HPV and cervical cancer; second, the lack of cervical cancer-specific support groups and/or resources that are not online; and finally, the scanty research dollars that are devoted to investigating both the medical underpinnings of cervical cancer as well as the psychosocial and cultural dimensions of the disease. Throughout all of these interviews, women made a consistent and repetitive comparison to breast cancer and the resources that are available to patients stricken with that disease. Surprisingly, this was one of the most predictable patterns to emerge out of the data, and spoke to the survivors' feelings of marginalization in the cancer community because theirs—for varying reasons—is not a socially acceptable disease. This comparison between breast and cervical cancer is particularly significant because federal and state funding streams for these two diseases are usually merged

(usually in the context of grants for screening programs and community organization projects), and the participants viewed breast cancer as getting a disproportionate amount of these combined research dollars. They are competing for the same dollars, so to speak, and since cervical cancer is much rarer than breast cancer and is saddled with the stigma of a sexually transmitted infection, it usually ends up short-changed.

“With breast cancer, you can get a lot of support if you don't have health insurance. But with cervical cancer that is not the case. There was not a lot of financial aid out there for me” (Heidi, 41 years old).

“I was actually surprised initially that you were doing a study because there doesn't seem to be a lot of funding for that. Now I know that it's something that you're doing as a thesis, so you're doing it out of your own pocket. But there really isn't a lot of attention in that, only the pharmaceutical companies are putting it out there because that's how they make a lot of money, but as far as like going to the American Cancer Society, and getting grants or things to help with people who get cervical cancer, everything is geared towards breast cancer. Cause the rates are so much higher and the death rates are so much higher and everything. I guess it got me, you know, it hit 100% of me” (Candace, 36 years old).

Several participants acknowledged the fact that cervical cancer has become much less common than it used to be, due to the success of the U.S.'s screening system. They argue that, along with the release of the HPV vaccine and the recognition that it is now preventable, these decreasing rates are the reason why researchers and funders do not regard cervical cancer as important enough to invest in—in other words, it is no longer a big enough problem to merit their attention. One woman was in the midst of starting a non-profit organization that would provide resources for women going through cervical cancer, and has had trouble securing funding for it because of this:

“This one lady [at the funding agency] was like ‘you know, cervical cancer is preventable’—she made it seem like it was such a small population of women that it was basically not worth it” (Candace, 36 years old).

The lack of available cervical cancer-specific resources was an issue that greatly impacted the course of the research project itself. The single biggest issue throughout the entire study was the difficulty in locating a “community” of cervical cancer patients and survivors. Breast cancer support groups, programs, and community organizations were abundant, as well as groups targeted at much less common cancers. However, nowhere could I find a single cervical cancer-specific resource in all of Tampa Bay, Orlando, Naples, Sarasota, or indeed, the entire state of Florida (and I looked). The closest was a gynecologic cancer support group in Sarasota, but they could count no cervical cancer survivors as members. None of the participants that I interviewed knew of any other women with cervical cancer in the area, even through the clinics that they visited. I finally was forced to rely upon locating participants through online groups, listservs, and the sporadic referral from a clinic.

“KD: Did you meet anybody who had cervical cancer where you were being treated?”

R: That was another sucky part of it. Where I would go for chemo, most of the women who came in were there for ovarian cancer. Most of them were older. Most of them had grandkids my age—I would get in there, and I couldn't relate to any of them. I remember sitting down one morning waiting for the doctor to get there for chemo, and another patient looks at me and was like ‘you are too young to be here. You can't be here.’ And I wanted to look at her and say ‘no shit!!’ No, I'm here because I think this is enjoyable!’ I met some people online, but in person, you know they offered different things through the hospital, but most of the people that I was running into are all older. And I was like—‘why am I going to take more time and energy that I don't have, and go talk to people who are looking at me like I'm a freak, you know?’” (Holly, 30 years old).

Healthcare Providers

Care Experiences

The central role that healthcare providers played in the participants' cancer experience was a theme threaded throughout the interviews, and occurred mainly in the form of general satisfaction or dissatisfaction with the care that was provided. Many participants spoke positively of their providers, relating stories of caring, attentive physicians and immediate appointments. Many expressed a deep loyalty and bond with their oncologists.

"Her name is Dr. _____, she's amazing. She's fabulous. Even the doctors and the nurses, when you go into the hospital, they swear by her. Just being her patient you just get better treatment, you get your own room" (Candace, 36 years old).

"My oncologist was awesome; every time I called her, she called me right back. I know she answered the same question like 5 times, but I just had to keep asking her the same question, I guess for reassurance. But she never complained. And she never looked at me and was like 'uh, you already asked me this!'" (Holly, 30 years old).

One woman related how supportive and flexible her oncologists were, despite her limited ability to pay her medical bills:

"It works out that I owe \$50,000 in medical bills, which I can't pay. But my doctors in _____ were very supportive. They even said to me, 'Don't worry about the bills.' I didn't have to pay anything, not even one time...They said that they don't refuse treatment; they don't turn away cancer patients. And from what I hear that's not always the case. They take every cancer patient; they don't turn away anybody. Now I owe an arm and a leg, but that's life. That's not their fault, because we don't have social healthcare. I think that's a big problem, but at least they treated me. They were really positive and supportive" (Heidi, 41 years old).

Other women's experiences were more problematic, and many shared troubling stories about missed diagnoses, lack of information, insensitive treatment and poor communication between providers on the healthcare team. Six out of the nineteen

women had had diagnoses that were either missed or prolonged because of misinformation that they had received from a particular provider. Interestingly, three of the four women who had been under the regular care of a fertility specialist for months, or even years, experienced a late diagnosis. Another had been required to see her gynecologist every three months because she was on Depo Provera birth control, although she had already been experiencing symptoms that the doctor had not investigated by the time the cancer was diagnosed. Several had had experiences that were so questionable that they had looked into malpractice suits.

Most of the participants had at least one “bad doctor” story where one of their physicians was insensitive, arrogant, incommunicative, or, in some cases, bordering on unethical. These experiences motivated many to seek care elsewhere or to get second and third opinions.

“I hate the fact that doctors and caretakers do not inform you of everything that is going to happen. I really resent that. For instance, they had sit on the edge of a table and open my gown. He pulls out a Polaroid camera and takes a picture of my breasts. I’m like, ‘okay...what in the world is that for?’ ‘Oh it goes in your file... nobody sees it.’ I’m like, ‘yeah, did you maybe want to get my consent first?’” (Linda, 61 years old).

One of the most common complaints from women about their care was that their providers had given them an extremely limited amount of information, especially on HPV. Many of the participants had not even heard of HPV until months or years after they had completed treatment, and complained about being unable to get straight answers out of their doctors when they questioned them directly.

“It made me mad that I never heard of [HPV] before, that when I was young, when I was in my 20’s and I was in my teens that I never heard about it. Why didn’t somebody feel responsible enough to let us know? What—it’s got to be a secret? Doctors seem to feel like the more ignorant you are, the smarter they

seem. I don't know. I don't like that. I want to know at least as much as my doctor knows about my condition."

"It just made me feel angry. I never heard of it before...that it was an issue. I always considered myself well-educated so why didn't I know about this? Why hadn't I heard about this? Why haven't the doctors [said anything]? What logical reason could they have for not informing the patient? 'By the way you know this is HPV. Hey, watch out for this!'" (Linda, 61 years old).

System Breakdown

Participants perceived this inadequate information and education as stemming from reluctance on the part of their doctors to be open with them about their diagnoses, and concluded that the medical system was not fulfilling its obligation to educate patients. Thus, patients were forced to take matters into their own hands, and to seek out information on their own. Many talked about the need to be “your own advocate,” to “own” your own healthcare, and to be proactive. These necessary actions protected the individual from being lost in the large void that had opened up in the system—they provided the things (or knowledge) for themselves that the system, for varying reasons, was unable to.

"No matter what, no matter how many doctors you see, you really have to own your own healthcare. And I mean that was true all throughout the experience...Even though we rely on our doctors to tell us what to do and to give us the test that we need, we really need to take more ownership. I regret that I let the fertility issue—which was so uppermost in my mind at the time—I let it cloud the more basic care of that area. And I consider that my fault" (Samantha, 38 years old).

"It's our bodies and if we don't know to take care of it we're going to die. Whatever tests you can do, however many doctors you can see, even if it's a pain in the neck—go. Ask a bunch of questions. The best thing you can do is take a notepad with a bunch of questions on it so the doctor's not sneaking out of the room while you're trying to ask...Cause that's the whole thing with most doctors—they want to get in and get out, see as many patients that they can. But if they see you've got a list—okay!" (Linda, 61 years old).

A recurring theme was how little participants understood both HPV and cervical cancer when they were first diagnosed, and how it was only later that they were able to go out and research it on their own. It seems that a lack of knowledge—or confusion about—HPV and cervical cancer at once made them feel both vulnerable and disempowered. Respondents often look back upon their “early days” of diagnosis as being cloudy and confusing, and compare it to the present day when they know all they can and therefore are positioned to make the best decisions for themselves.

Recommendations

Women had a variety of suggestions for things that would have eased their experience during and after cervical cancer, including what they believe might reduce stigmatization of the disease. Recommendations centered around three common themes: vaccination, information, and support.

As mentioned previously, several women observed that the stigma associated with cervical cancer had extended to the HPV vaccine. These women believed that normalizing the vaccine would have a direct effect on reducing stigmatization, and thus decreasing the incidence of cervical cancer. Mandating the vaccine was a frequent suggestion. A number complained about the slant of the commercials—for example, that they were obviously motivated by the desire to make money from a drug rather than out of a concern for women’s lives. Others observed that targeting the commercials at mothers of girls was a natural way to raise everyone’s suspicions about the vaccine because of our society’s preoccupation with protecting the virginity of young females—it was necessary, they believed, to advertise directly to young women themselves. Another woman believed that extending the public discussion of HPV to men, and offering them

the vaccine, would remove some of the stigma associated with women and sexually transmitted infections.

“I'd like to see them come up with a way to test guys. Because I think that we put a lot on women. We have to bear the burden of things, and I think that just as many guys have it as girls, and I think that just because they're not getting cancer from it...If we could test guys, if we could mandate vaccinations for the HPV virus, I think that would help. Because it wouldn't be like, ‘well, you got the vaccine because your parents think you're going to have sex too early.’ If everybody going into 7th grade would have to get it, then it's just one more shot. And then I think some of the stigma about it would be lessened, because we'd be thinking about it just as a virus that you can catch” (Kate, 25 years old).

Numerous other suggestions revolved around information and awareness. In order to prepare women who have just been diagnosed with cervical cancer, one participant believed that an honest and candid conversation about stigma with one's healthcare providers was a necessary first step:

“Because there's such a stigma attached to cervical cancer, they need to prepare and help the women out in that way. I don't mean that they have to see a therapist; I don't think that the person becomes mentally ill because of it, or has to weep constantly. But it's something that you have to be prepared for and deal with. And if nobody tells you about it, you're really alone with that. But I think that that is more of a female discussion. I think it would be real hard for a doctor to just go through that. So I see a nurse maybe approaching that. Or just something written up about it. They could give you little information packets: ‘Talking About This With Your Partner’ or ‘Talking About This With Future Partners’... ‘Some women find that there's a stigma attached when discussing cervical cancer. Understanding the statistics of cervical cancer may make you feel a little better. 50% of the population of active Americans have HPV in their systems; it's really not something to feel ashamed about.’ So, if you know that statistics, and you hear that, it does make you feel better. It makes you not feel alone. It is feeling isolated about that, and feeling ashamed about that, which is not okay. And also this big association of warts being the same as cervical cancer, and it's not the same. It's sort of wart-like, but it's not a vaginal wart. But that doesn't mean that you should hate yourself because you have a vaginal wart, so they need a pamphlet. Or maybe someone should start something online, because you don't need a big group for this. If women could tap into something like that, and express themselves, and not feel alone. And know how to handle it socially for dating and future stuff” (Heidi, 41 years old).

Others preached the value of raising awareness, especially about the prevalence of cervical cancer—if people know how common it is, they argue, than it would not be stigmatized.

Women recommended a number of other strategies that would have made their lives easier. As discussed in the previous sections, information from doctors was a frequent suggestion, especially around the topic of HPV and causation. Many women had complained that their doctor had never even discussed HPV with them or had avoided the topic when broached, and consequently most of the women had been compelled to look elsewhere for information. This assertion is supported by several informal conversations that I had with gynecologic oncologists during the recruitment stage. One oncologist expressed a fear that I would create the actual problem that I was trying to alleviate—stigmatization. This doctor did not tell his patients about HPV because he did not want to make them feel any worse than they already did by adding the knowledge of an STI's role in cervical cancer. He worried that if I asked an interview question about HPV, they would get curious, look it up, and then find out that it is a sexually transmitted infection. Another rather prominent oncologist reflected that “we have not done a good job of this”—that is, informing patients about HPV, because oncologists have been uncomfortable as to how to handle this issue sensitively. Given this, it is perhaps not all that surprising that many of these women had learned of HPV for the first time months or years after they had finished treatment, and this created resentment among some. Indeed, if physicians hope to normalize HPV anytime soon, it seems evident that they must discuss it openly with their patients—avoiding the

conversation only reinforces the impression that it is something uncomfortable and shameful.

It is important to briefly touch upon the participants' other suggestions for improving their general experience that do not directly relate to the de-stigmatization of cervical cancer: they included universal health insurance; additional cervical cancer-specific support groups and resources; more research, funding and financial assistance for cervical cancer (or, at the very least, research, funding and financial assistance that is proportionate to the disease's burden); better communication between members of the healthcare team; and more information about what side effects to expect during treatment and beyond.

Survivorship

The following three codes emerged very strongly from the data. Some of these themes may not necessarily relate directly to stigma, but they are included because I believe they are important in painting a picture of the ways in which these women have experienced the disease and its repercussions.

One of these strong themes to emerge centered on the definitions of survivor and survivorship. Although I have frequently used the word 'survivor' unproblematically throughout this paper, I do want to acknowledge the diversity of perspectives and self-identification that people who have had cancer use to understand and communicate about their experience. My usage of the term has been utilitarian, meant only to identify those who have been diagnosed with cervical cancer at some point in the past, but who are still alive. While many of the participants use it in a similar fashion, a great many others employ it in such a way as to reveal meanings behind who is worthy to be identified with

this term, and more broadly, what having a cancer diagnosis means to them. Often in these instances, it is used to identify *not* the participant, but others whom the participant considers truly a “real survivor.”

Several of the women used the term unilaterally—meaning, anyone who has ever been diagnosed with cancer is a survivor, starting from the day of diagnosis onward. This usage established equality among survivors, no matter their stage or type of cancer, or the method of treatment employed. Strength, fight, self-assurance, and faith were qualities highly associated with all cancer survivors. One woman summed it up by saying,

“So that will always be in my life, from now on. And I think that yes, I will be a cancer survivor, not with the same experience that other people have, because I think that everyone's experience is really different. But yes, I think that every person that deals with cancer is a cancer survivor, emotionally, physically. All families trying, praying—families, friends, yourself, treatment, dealing with the doctors, dealing with emotions. You learn to survive. You are a cancer survivor” (Carmen, 28 years old).

A conception of cancer survivorship that was more common than the above attached conditions to whether or not one was a survivor—often, the types of treatment one experienced, or the number of years since diagnosis. Many women commented that they would be a survivor when they hit the 5-year disease-free mark, a highly significant cancer milestone before which most recurrences will happen, and after which many doctors consider you “cured.” Many reflected that it was still too early to consider themselves a survivor, and they needed time to process the experience and to re-adjust their identities. One woman commented that:

“I think it took time. I think it took feeling better physically after the surgery. I think it's almost like if you have a divorce. It takes a while to think of yourself as a single person again. A little of it is just the natural time involved in that kind of a life change, and I think it took a little bit of getting through that first anniversary.

Because you get those check-ups all the time—they're always scanning this or scanning that. You have to get a few of those under your belt. For me, it wasn't necessarily fear. [It was] that sense of 'I don't belong here' when I go to the oncology office. I still have that sense, 'I don't belong here.' But I think that all of a sudden, I do belong here, but as a survivor—not as a patient. For me it took time, it took emotional work, thinking it through, writing about it, talking about it. It took some clear results” (Amanda, 45 years old).

Others did not want to classify themselves at all as a survivor, because it meant that they were part of something that they had feared for so long:

“I do I feel almost strange putting that term on me. Like when I think of that term I think of...I mean even though my situation was horrible, the cancer was at an early stage and we just surgically removed it—presto! It's gone. When I think of cancer survivor, I think of somebody who's dealt with it for years. You know had chemo and all that. In a way it's like even using that term is a little scary to me—I like to rationalize to myself that I just had a little bit of cancer...I didn't want to like put myself into that category. The only time I even use that phrase, is if I'm like writing an email to a senator. I get these emails that are like 'write to your senator to tell them to fight global warming, or tell them to fight for organic food.' Sometimes I'll just stick that in at the beginning of the sentence just to get their attention. But personally I don't use that when I'm referring to myself...because it's too scary of a term for me” (Samantha, 38 years old).

Religious and Spiritual Faith

Religious and spiritual faith emerged as a major way in which these participants conceptualized, explained, and endured their trials with cervical cancer. It was mentioned often as an extremely important means through which participants coped with their illness, usually referred to early in the interview without prompting. For example, one woman summarized the meaning of spirituality for her by saying:

“Well, I think people that are spiritual -- and I don't mean religious, it doesn't matter if they have religion or not, whatever that is -- however it manifests in their lives -- if they are spiritual to begin with, than any experiences they have would be more positive. They'll deal with life better because they see meaning in it. They have meaning and purpose in their lives, in a way that with people that don't have that, things just happen to them [for no reason at all]” (Heidi, 41 years old).

Several participants made a brief reference to questioning God or their faith when they were diagnosed, or wondering even if it was some sort of punishment by God for improper behavior. One participant commented that:

“It was upsetting at first...and I asked my mom, why would God do this to me? Do you think it could be that I had premarital sex? And she goes, ‘God doesn’t punish that way.’ And thinking about it, you know she’s right...That is something I won’t know until I die—why I had to go through this. And that’s ok” (Joyce, 39 years old).

Several times, participants mentioned their religious affiliation in conjunction with their opinion on the vaccine—usually citing a disagreement with that denomination’s stated position. For example, one woman stated that:

“I think that every young woman should get [the vaccine]. If it can prevent what I had to go through, then definitely. I know being a Catholic I’m supposed to say abstinence, and absolutely not and it’s a bad thing. But you know from a reality-based [perspective]—I just think that every young woman should get it. And if I hear any of my friends or family that are that age, I’m saying ‘you need to get that vaccine’” (Joyce, 39 years old).

Fertility and Reproduction

A frequently-discussed side effect that caused participants an extraordinary amount of distress and mourning was the loss of fertility. Treatment for cervical cancer involves three modalities that can and do cause infertility—surgery removes the reproductive organs, chemotherapy and radiation can shut down ovarian function, and radiation can create so much scarring or alter the elasticity of the tissue so much that it is impossible to carry a pregnancy to term. Many of the women who participated in the interviews were of childbearing age, and in a cruel twist of fate, four out of nineteen of the participants had been undergoing fertility treatments at the time they were diagnosed. After years of unsuccessful fertility treatments, one woman had finally been four months

pregnant with twins when the cancer was discovered. Because of its advanced stage, she and her husband were forced to make the decision to have an emergency abortion and radical hysterectomy in the same day. Others had planned for children in the future, but their treatments left them prematurely menopausal.

Though neither a central focus of the study nor a direct question in the interview guide, the loss of fertility was one of the most distressing themes to emerge in many of these interviews. Above and beyond anything else, several of these women mentioned it as the single hardest aspect of their entire experience with cervical cancer—whether they were in the middle of treatment or years down the road.

“My friends are getting married, having children, and I just feel like I did everything right—go to school and try to make something of myself, while other people are going out, having babies, getting married in their early 20s. I didn't do that, and now I can't. At this point, I can't have a child. That means I have to get married first. [It was] taken away from me, and it's tough to deal with” (Sarah, 34 years old).

“I definitely have to say [that the hardest aspect of having cervical cancer] is the fertility-related stuff. Both losing the twins that we had, and then the permanent ending of my fertility thereafter” (Samantha, 38 years old).

Although this recurring theme of distress is not such a surprise given that some of these participants found out about the study from Fertile Hope, an organization focusing exclusively on cancer and fertility issues, many of the women discussing fertility had been recruited elsewhere. Given also that cervical cancer tends to strike most often within a woman's reproductive years, it is clearly an important issue to address given our society's emphasis on genetic constructions of parenthood and childbearing—and how these two often co-occurring issues can force some young women to redefine their lives and roles way beyond just dealing with a cancer diagnosis.

ONLINE SURVEYS

Participant Demographics

A total of 70 women participated in the survey portion of this study. They were drawn from a variety of sources, mostly non-profit advocacy organizations. Three groups sent listserv emails to their membership: *Tamika & Friends*, the *National Cervical Cancer Coalition*, and the *National Council of Women's Organizations*. Another group, *Women in Government*, posted a link to the survey on their website. Finally, other women who had contacted me about participating in the in-depth interviews after these had been completed were directed to the online survey instead.

The average age of the survey respondent was 39 years old, while the median age was 36 and a half. Participants hailed from 29 states and the District of Columbia. They were asked to self-identify their ethnicity—Table 4.1 below illustrates the breakdown. In terms of level of education, 2.9 percent (2) reported that they had received some high school education; 18.8 percent (13) had graduated from high school; 39.1 percent (27) held a Bachelors degree and 23.2 percent (16) had received a Masters degree; 4.3 percent (3) held a Doctorate or other professional degree; and 11.6 percent (8) reported that they had received some other type of education.

12.9 percent (9) of participants responded that they were single; 15.7 percent (11) had a boyfriend or girlfriend they did not live with, and an additional 8.6 percent (6) had a boyfriend/girlfriend with whom they resided; 48.6 percent (34) were married or engaged; 12.9 percent (9) were divorced; none were widowed; and one woman declined to answer that question. Roughly half of the women had children—25.4 percent (17) of the respondents had one child, 14.9 percent (10) had two children, 7.5 percent (5) had 3,

4.5 percent (3) of the women had 4 children, 1.5 percent (1) had five children, and the remaining 46.3 percent (31) of the women had no children.

Table 4.1. Self-Identified Ethnicity of Online Survey Respondents (N=70)

SELF-IDENTIFIED ETHNICITY			
Caucasian/White	51	Greek	1
African American/Black	9	Hispanic	1
Asian	2	Jewish	1
Caucasian & Asian American	1	Vietnamese	1
Chinese-American	1	Missing	1
Cuban & African American	1	TOTAL	70

Two questions about health insurance status yielded surprising results. Only 5.7 percent (4) responded that they currently do not have any type of health insurance, while 82.9 percent (58) of women had private insurance. Only 5.7 percent (4) responded that they were on Medicaid, 2.9 percent (2) reported “Other” and one declined to answer. These numbers were not all that different to those reported about past health insurance during their cancer diagnoses. 12.9 percent (9) did not have any type of health insurance while 77.1 percent (54) reported private health insurance at the time they were diagnosed; 2.9 percent (2) had Medicaid; 1.4 percent (1) had student insurance, 2.9 percent (2) reported “Other” type of insurance; and 2 declined to answer the question.

Subset 1: Invasive Cervical Cancer Participants

While current biomedical knowledge regards cervical cancer as developing along a spectrum, ranging from the presence of abnormal cells (dysplasia), to carcinoma-in-situ (CIS), to invasive cancer, there is a somewhat firm delineation between these types of pre-cancerous lesions and invasive cancer. This delineation determines the intensity and length of a woman’s treatment and her supposed prognosis; thus, I made the decision to

analyze separately the sub-sample of women who responded that they had either dysplasia or CIS. These women totaled 24 and will be discussed in a later section, while the total number of participants with invasive cervical cancer was 46.

Illness History

These women had, on average, first been diagnosed with cervical cancer a little over five years ago (63 months), although that number ranged from one month to nearly 24 years. The majority of these women—69.6 percent (32)—had been diagnosed with Stage I cervical cancer, in which the cancer has not spread outside the cervix. Eleven percent (5) had Stage II cervical cancer, indicating that the cancer has spread beyond the cervix but not yet to the pelvic wall or bottom third of the vagina. An additional 11 percent (5) had been diagnosed with Stage III cervical cancer, where the cancer has spread either to the pelvic wall or to the lower third of the vagina. None of the women had been diagnosed with Stage IV cancer, the most advanced stage in which the cancer has spread to a close organ, such as the bladder or rectum, or a distant part of the body, such as the lungs, liver or brain (NCI 2008b). Three of the participants either did not remember their stage or did not receive one from their provider, and one woman declined to answer this question. Most—76.1 percent (35)—had received this diagnosis from their gynecologist, while 8.7 percent (4) had been diagnosed from their primary care physician, an additional 8.7 percent (4) by an oncologist, and 4.3 percent (2) by another type of provider, such as Planned Parenthood. About half had known there was a problem through a routine Pap smear, while an additional 30.4 percent (14) had been experiencing symptoms, such as bleeding, painful intercourse, unusual discharge, abdominal pain, and severe anemia. Two of the women had received incorrect Pap

Table 4.2. Types of Treatment: Women with Invasive Cervical Cancer (n=46)³

TREATMENT TYPE		TREATMENT TYPE	
No treatment	2.2%	Pelvic Exenteration: A radical surgical procedure that removes the lower colon, rectum, and bladder, along with the cervix, vagina, ovaries, and nearby lymph nodes. Used to treat advanced/recurrent cancers.	0%
Conization (or Cone Biopsy): A surgical procedure in which a cone-shaped piece of tissue from the cervix is removed.	32.6%	Trachelectomy: An experimental surgery in which the cervix, lower uterus, and upper vagina are removed but the rest of the uterus is left intact. Because a stitch is used to close the uterus after the surgery, it is used as a fertility-sparing option for early-stage cancer.	10.9%
Cryotherapy/Cryosurgery: A surgical procedure in which abnormal tissue (such as carcinoma-in-situ) is frozen in order to destroy it.	10.9%	Internal Radiation: Radioactive needles, seeds, wires or catheters are inserted internally next to the cancer to deliver radiation directly to the site.	30.4%
LEEP: An electrical current is passed through a thin wire loop that cuts out the abnormal cervical tissue.	28.3%	External Radiation: External beams deliver radiation toward the cancer through other tissues.	41.3%
Laser Surgery: A surgical procedure in which a laser beam is used to cut out abnormal tissue.	4.3%	Chemotherapy: A therapy in which drugs are used to either kill the cancer cells or stop their growth—can be orally or intravenously delivered.	32.6%
Radical Hysterectomy: The uterus, cervix, and part of the vagina are removed surgically; sometimes the ovaries and fallopian tubes are removed as well.	50%	Other (such as cervical stenosis)	6.5%
Total Hysterectomy: The uterus and cervix are removed surgically through the vagina or abdomen, or laparoscopically through the abdomen.	10.9%	Decline to Answer	2.2%

³ Descriptions of treatment modalities were obtained from the NCI (2008c).

results from their doctors' office that later turned out to be cancer. Two women noted that they had had recurrences, and another had been diagnosed with breast cancer several years after her initial cervical cancer diagnosis.

Treatment varied considerably among participants. A variety of biomedical treatment modalities were employed; Table 4.2 below details these. Physical side effects, both from the cancer and from the treatment, were considerable. The most significant of these was general pain (54.3 percent: 25), and also included fatigue (50 percent: 23); painful intercourse and/or difficulty having sex (43.5 percent: 20); difficulty urinating or having a bowel movement (each 43.5 percent: 20); nausea/vomiting (39.1 percent: 18); diarrhea (39.1 percent: 18); cramping (37 percent: 17); dry, itchy or irritated skin (34.8 percent: 16); loss of appetite (32.6 percent: 15); vaginal discharge (23.9 percent: 11); hair loss (21.7 percent: 10); vaginal bleeding (15.2 percent: 7); frequent sickness/infection (15.2 percent: 7); and mouth sores (2.2 percent: 1). Thirteen percent (6) had no side effects at all, and several participants listed other side effects such as lymphedema, neuropathies, kidney and bladder problems (such as a ruptured bladder, cystitis, and loss of bladder control), weight gain, and difficulties coping emotionally, psychologically, and socially with the disease and treatment.

One survey item detailed several potential short-term and long-term repercussions of cervical cancer and its treatment, and the degree to which participants found these troubling in their own lives. The most frequently reported response to "physical symptoms before treatment" was *not at all* troubling (40 percent: 18); "physical side effects of treatment" were *somewhat* troubling (35.6 percent: 16); "loss of fertility or compromised fertility" was *extremely* troubling (37.8 percent: 17); "other long-term side

effects of treatment” were *extremely* troubling (27.3 percent: 12); “fear of recurrence” was *extremely* troubling (59.1 percent: 26); “effect on ability to perform job” was *not at all* troubling (37.8 percent: 17); “financial effects” were *extremely* troubling (37.8 percent: 17); “problems with health insurance” were *not at all* troubling (28.9 percent: 13); “difficulties in marriage or relationship with significant other” were tied for both *not at all* troubling and *extremely* troubling (both 33.3 percent: 15); and “difficulties in relationship with friends or family members” was *not at all* troubling (48.9 percent: 22). Five women added that they have had great difficulties with sexual intercourse and intimacy, due to both physical and psychological reasons. One woman related that “*I still bleed, have pain and sex has never been the same again,*” while another wrote, “*I haven’t been sexual with my husband for fear that any action could trigger HPV to become active again. All [doctors] say that couldn’t happen but they don’t have any proof that would encourage me to risk my life for sex.*” Several wrote that stigma was their biggest issue, one noting that this had created problems with her employer when she returned to work. Still others noted a loss of a sense of self and place in the world—for example, one woman wrote that “*the most profound effect has been the loss of emotional connectedness and inability to continue writing poetry,*” her livelihood.

Perceptions about Disease and Self

When asked about the cause of their cervical cancer, 25 out of the 45 who answered the question said HPV. Others suggested a variety of other potential causes or were unsure, such as a weakened immune system, family history, smoking, birth control, sexual abuse, and in one case, a “*doctor’s stupidity and not seeing the signs that were right there on the Paps and colpos.*” More than the actual causes mentioned, what was

most notable about these lists was how specific they were and how targeted to each person's individual life and behavior. For example:

"I have no idea! 1. Maybe a sexual partner (I had four relationships/partners) before my husband. I had one abnormal Pap smear about 6 years before my diagnosis...but was told all was fine and never informed of HPV or worries of cancer or dysplasia. 2. Maybe hormonal issues combined with lack of sleep/eating well. I had my son two years before my diagnosis. During birth I hemorrhaged because of retained placenta which left me sad/scared and required a few procedures during the first six months of my son's life (D&C and Hysteroscopy). 3. Maybe the puncture during my hysteroscopy. When I woke from the hysteroscopy the OB/GYN told me they were keeping me at the hospital overnight to monitor for bleeding because she had perforated my uterus on the way in. THANKFULLY I was not bleeding and from the pictures they found that she most likely perforated the upper/back part of my cervix (just before entering the uterus). This is the same area my cervical cancer was found. 4. Some days I will never know...I blame myself maybe it's because I drink coffee once a day, maybe it's because I wasn't sleeping enough with a new baby, I think the guessing might never end. :-)"

Thus, in the absence of a scientific explanation—or a scientific explanation that women did not feel “fit” their own situation, or that was unclear and not well-articulated by biomedicine—women had created personally meaningful hypotheses. Another quote illustrates this well:

"My physician said that my cancer was an adenocarcinoma, and that I tested negative for HPV. As far as a scientific cause of my cancer, I can't say. I've always felt, though, that getting cancer was sort of the universe's (God's, whomever's) way of saying 'You waited too late to have kids. Your options are now limited. You'll have to work a lot harder to make it happen now.'"

When queried about who they believe is at risk for cervical cancer, most women responded either “all females” or “all sexually active females” are the ones at risk. Some, however, qualified their responses further—most commonly, either people of color, the poor, the uneducated, or the uninsured were seen as at higher risk. These factors were thought to influence one's access to medical care and/or screening—whether it is because

one cannot afford it or because they are unaware of the risks and do not seek out screening measures.

Responses to the question “What are the first three words or things that come to mind when you hear the word cancer?” were illuminating and almost uniformly negative in their presentation. Death or some aspect of facing one’s mortality was mentioned 30 times, the treatments themselves as well as side effects such as vomiting and hair loss were mentioned 23 times, fear was used 21 times, and sadness and loss eight times. But, in the midst of these responses were nine that touched upon some aspect of “overcoming”—battle, fight, survival, life.

Seventy percent (35) of women identified themselves as cancer survivors. Many of these women offered the reason that they had made it through treatment, past their five-year mark, or were survivors simply because they were still alive after their diagnosis: “*Cancer is cancer, no matter where you got it or how you got it. I am a survivor!*” The same “conditional” concept of survivorship that appeared in the in-depth interviews is applied frequently in the responses to this question—that one is only a survivor if you had aggressive treatments or if you made it to the five-year mark, which implies cure. Responses from the remaining 24 percent (11) that did not identify themselves as cancer survivors are illuminating. One replied that she was “*not sure, actually. I feel a little presumptuous identifying myself that way, because I got off REALLY easy. So many friends went through so much more in terms of pain and treatment.*” Another woman recounted her feelings of ambivalence about the term:

“I vacillate on this one. On the one hand, in its most literal sense, a cancer survivor is someone who has been diagnosed with cancer, has been treated, and has survived. However, I sometimes think that “survivor” implies more of a battle with the disease than I experienced. I never felt any pain, nor did I experience any

symptoms. I feel like less of a survivor because I didn't have to undergo radiation, chemotherapy, or other non-surgical forms of treatment. Then, I decide that the radical hysterectomy, as major surgery, along with the inability to bear a child, was more than enough to make me a survivor. I survived the physical and mental effects of a life-threatening illness.”

Experiences of Stigma

The biggest proportion of women (26.7 percent: 12) felt that people looked at them differently *sometimes* because they had cancer; others felt that this happened *all the time* (11.1 percent: 5); *frequently* (24.4 percent: 11); *rarely* (22.2 percent: 10); or *never* (8.9 percent: 4). Four percent (2) did not know, and 2.2 percent (1) declined to answer. Women mentioned several ways in which they feel others look at them differently. Some wrote about their dislike of the pity that they feel from people—“*I hate the pity look*”—while others discussed how difficult it is for people to figure out how to relate to them. “*People [make] a strong association between cancer and death,*” and so women also experience their loved ones’ fear and anxiety about their diagnosis; for example, one participant noted that “*for quite a while [after my diagnosis], people would see me and the first question they would ask me was, ‘how’s your health?’*”

These answers contrasted slightly to responses to the more specific question, “How often do you feel people look at you differently because you had *cervical* cancer?” 13.3 percent (6) of women felt that this happened *always*; 20 percent (9) responded that it *frequently* occurred; 20 percent (9) that it *sometimes* occurred; 17.8 percent (8) that it *rarely* occurred; 13.3 (6) percent that it *never* occurred; and another 13.3 (6) percent did not know. 2.2 percent (1) declined to answer. Additional comments for this question tended to center around cervical cancers’ connection to a sexually transmitted infection: one woman wrote that “*when they found out what type of cancer I had, they look at me as*

though I'm a whore or dirty,” while another noted that “they either see you as this great inspiration or the slut that got HPV...either way it affects how others see you.” One woman recounted that stigma has impacted who she tells: “Part of the reason I am still ‘in the closet’ is because I fear that people will judge me. Cervical cancer is now associated with HPV and is considered to be a sexually transmitted disease. Because of the availability of the vaccine, people are now more aware of cervical cancer than they were 20 years ago. If they have read about it recently, they are probably also aware that it can be sexually transmitted.” Similarly, many women connected the presence of the “HPV ads” to others’ awareness and subsequently to a fear of judgment.

Table 4.3. Responses to Stigma Items: Women with Invasive Cervical Cancer (n=46)

	Never	Rarely	Sometimes	Frequently	Always	Don't Know
How often do you feel that people look at you differently because you have/had cancer?	8.9%	22.2%	26.7%	24.4%	11.1%	4.4%
How often do you feel that people look at you differently because you had/have cervical cancer?	13.3%	17.8%	20%	20%	13.3%	13.3%

A follow-up item posed the question, “How often do you feel that people *treat* you differently because you had/have cancer?” Here, the most common response was that this *rarely* happens (31.1 percent: 14). Others felt that it *always* occurred (8.9 percent: 4); *frequently* (13.3: 6); *sometimes* (28.9 percent: 13); or *never* (11.1 percent: 5). Two did not know, and 2.2 percent (1) declined to answer. More specifically, when questioned whether people treat them differently because of their *cervical* cancer, 28.9 percent (13) thought that this *sometimes* happened. A little over 13.3 percent (6) thought that it happened *always*; 11.1 percent (5) *frequently*; 13.3 percent (6) *rarely*; and 17.8

percent (8) *never*. An additional 11.1 percent (5) did not know, and 4.4 percent (2) declined to answer.

Table 4.4. Responses to Stigma Items: Women with Invasive Cervical Cancer (n=46)

	Never	Rarely	Sometimes	Frequently	Always	Don't Know
How often do you feel that people <i>treat</i> you differently because you have/had cancer?	11.1%	31.1%	28.9%	13.3%	8.9%	4.4%
How often do you feel that people <i>treat</i> you differently because you had/have <i>cervical</i> cancer?	17.8%	13.3%	28.9%	11.1%	13.3%	11.1%

The majority of women (64.4 percent: 29) were not afraid that others would have less respect for them if they knew about their diagnosis, whereas 33.3 percent (15) did. One woman agreed that *“because of the prevalence of information about cervical cancer and the connection to the HPV virus, which is sexually transmitted, I definitely think that some people would have less respect for someone who is diagnosed with cervical cancer.”* A number strongly resisted that idea; for example, one woman wrote that *“I could care less if they respect me less. I am a respectable woman and if they want to be ignorant or look at me different, they can carry that around with them,”* while another noted that *“if they do, that is their own ignorance.”*

Interestingly, these numbers were inverted for the question, “In your experience, do you feel that women with cervical cancer are stigmatized (in others words, looked down upon and negatively stereotyped because of their diagnosis)?” In this case, 64.4 percent (29) of the women responded that cervical cancer is indeed stigmatized, while 28.9 percent (13) did not feel that way. One woman explained her answer by saying *“I’m afraid they would think I was promiscuous or in some way ‘deserved’ what I got.”*

Others described how their feelings on this question have changed for the better: *“at first [I was afraid]. I didn’t tell my 3 best friends because I was ashamed and embarrassed because it came from HPV. However, my friends have all experienced this in the past so I felt good about that.”*

The elaborating comments for this question are powerful, almost more so than similar questions asking about stigma in the semi-structured interviews. Many comments reflected themes that arose during the interviews of cervical cancer being tied to promiscuity: *“People make assumptions about you and say derogatory things, like you were being a slut, whore, or that you have no shame.”* People who stigmatized were often labeled as ignorant or uneducated, and who did not know about the true prevalence of HPV and thus had an incorrect judgment of their own risk. A number of women explained that fear of stigmatization keeps many silent:

“Because cervical cancer is associated with an STI, people seem to think it is our own fault for getting it, like we asked for it. Not to mention, the statistics and info in the media tends to paint us all as poor, uneducated whores that will sleep with anyone and that we have no respect for ourselves. They are so misinformed and have no idea who the face of cervical cancer is because so many of us suffer in silence out of shame.”

“[Women with cervical cancer are stigmatized] especially if they come from a certain background, and now because of the HPV virus some women may never come forward to tell their experience for fear of being looked down on.”

Several others noted that they had personally not experienced it, but they knew of others who had. Those women that did not agree that cervical cancer is stigmatized explained that, because it is not visible to outsiders, no one knows that one has cervical cancer specifically—although they might think about the effects of treatment. Still others replied that they simply didn’t know.

Table 4.5 illustrates responses to several stigma items posed in the survey where participants were asked to rate how often they agreed with a specific statement. Women most frequently *never agreed* that “I blame myself for my condition” (28.9 percent: 13); *sometimes agreed* that “I think that others blame me for my condition” (31.1 percent: 14); and *always agreed* that “I think that this condition could have been prevented” (33.3 percent: 15). Most frequently women *never agreed* that “I am angry at myself” (31.1 percent: 14), “I feel embarrassed or ashamed” (31.1 percent: 14), “I am too embarrassed

Table 4.5. Responses to Stigma Items: Women with Invasive Cervical Cancer (n=46)

	Never	Rarely	Sometimes	Frequently	Always	N/A
I blame myself for my condition.	28.9%	15.6%	22.2%	15.6%	15.6%	2.2%
I think that others blame me for my condition.	17.8%	22.2%	31.1%	17.8%	4.4%	6.7%
I think that this condition could have been prevented.	8.9%	15.6%	22.2%	15.6%	33.3%	4.4%
I am angry at myself.	31.1%	11.1%	20%	22.2%	13.3%	2.2%
I feel embarrassed or ashamed.	31.1%	15.6%	24.4%	17.8%	8.9%	2.2%
I am too embarrassed or ashamed to tell someone about it.	42.2%	22.2%	15.6%	11.1%	6.7%	2.2%
I think less of myself because of my condition.	42.2%	15.6%	22.2%	11.1%	6.7%	2.2%
My family thinks less of me because of my condition.	51.1%	17.8%	6.7%	8.9%	2.2%	13.3%
I think that others pity me.	24.4%	20%	31.1%	11.1%	6.7%	6.7%
I think that others judge me negatively because of my condition.	26.7%	24.4%	31.1%	6.7%	6.7%	4.4%

or ashamed to tell someone about it” (42.2 percent: 19), “I think less of myself because of my condition” (42.2 percent: 19), or that “My family thinks less of me because of my condition” (51.1 percent: 23). Respondents *sometimes agreed* that “I think others pity

me” (31.1 percent: 14) and that “I think that others judge me negatively because of my condition” (31.1 percent: 14).

Support and Disclosure

On the whole, the vast majority of women had told others about their diagnosis. 91.1 percent (41) had told their spouse/partner/significant other, 82.2 percent (37) had told their parents, 86.7 percent (39) had told their siblings, 82.2 percent (37) had told other members of their family, 93.3 percent (42) had told their friends, 84.4 percent (38) had told their co-workers, 48.9 percent (22) had told members of their religious groups, 48.9 percent (22) had told neighbors or community members, and an additional 22.2 percent (10) had confided in other people not listed. None of the respondents hadn't told anyone. Many of the additional comments revolved around the need to speak out about cervical cancer in order to raise awareness; for example, one woman wrote that *“I have two published articles and will speak to anyone about this issue. We have to bring about change.”* There were a number of reasons why some women chose not to tell their family and friends, the most central one being fear of their reactions—whether it be concern, pity, or outright disapproval. One woman wrote that *“I do not want them to know what type of cancer I have. I have heard the jokes already.”* Another confided that *“I didn’t tell my parents and family right away because they are so conservative and religious. Even when I did tell them, they still looked at me different, like I was a slut or something. I could see it in their eyes...the contempt they had for me getting this affliction.”* Others felt differently: *“I am certainly not ashamed though. I would feel more self-blame if, say, I was a big smoker and got lung cancer, or a heavy drinker and*

got liver cancer. But to be ashamed that at my age of 57 that I had sex—my word! I'd be ashamed if I hadn't had sex!"

In line with these responses, the majority felt that they would *not* prefer to keep others from knowing about their diagnosis (48.9 percent: 22), although 20 percent (9) responded that they *would*, and an additional 28.9 percent (13) that they *sometimes* prefer to keep others from knowing. For those that did not prefer to keep others from knowing, it gave them a chance to, for example, *"remind others to keep up on their annual examinations"* and to be aware of their own health. Others felt that this was important to reduce the stigma associated with the disease: *"It is important for us to share our experiences. This will help people learn the truth about who gets this disease and how common it is. Understanding will help remove the stigma."* Other women, who preferred that people did not know, were uncomfortable with the visibility of the disease: *"some people think that since they know, any question about yourself, your history, your feelings are free game,"* or *"I would rather keep it to myself rather than risk being judged in personal relationships or possibly discriminated against in the workplace."* Some were torn about this issue: *"Sometimes I think it'd be empowering to educate people because I was not educated about this, but I do not want to subject myself to public criticism."*

In terms of the quality of support provided from the above parties, the most frequent response was that it *"exceeded my expectations."* 53.3 percent (24) felt this way about their significant other/spouse/partner; 40 percent (18) about their parents; 37.8 percent (17) about their siblings; 31.1 percent (14) about their other family members; 35.6 percent (16) about their friends; 28.9 percent (13) about their co-workers; 22.2

percent (10) about members of their religious groups; and 26.7 (12) percent about neighbors or community members. The remaining responses were spread rather evenly across the rest of the response categories: *good enough support*, *some support*, *not enough support*, and *no support at all*. Additional qualitative comments concerned the importance of support groups and the central role they have played for those participants.

Information-Seeking

The majority of women received information about cervical cancer either from their doctor or from the internet. Sources of information about the causes of cervical cancer were split evenly between the two (63.6 percent: 28 each). Information about treatment and side effects was obtained mostly from their doctor (81.8 percent: 36) with internet as a close second (50 percent: 22), and likewise for information on long-term side effects of treatment (60.5 percent: 26 and 39.5 percent: 17, respectively). Information on support groups and advocacy groups was obtained primarily through the internet (50 percent: 22 and 45.5 percent: 20, respectively). Other healthcare workers, organizations such as the American Cancer Society, and media sources such as magazines (other than television) were additional primary sources of information; less so were family, friends, or television. Disturbingly, a fair number of women did not receive information on any of these topics—13.6 percent (6) did not receive any information on causes, 9.1 percent (4) on treatment and its side effects, 25.6 percent (11) on long-term side effects of treatment; 20.5 percent (9) on support groups; and 36.4 percent (16) on advocacy organizations.

Although they were still primary sources of information about HPV, doctors did not play as much of a role as they did for information about cervical cancer. In terms of

information about causes, most women sought that through the internet (48.8 percent: 21), while doctors were second (39.5 percent: 17). Information about treatment and side effects were evenly split between the two (40.5 percent each: 17 each), while most women did not receive any information either about the HPV vaccine (42.9 percent: 18) or about support modalities (46.3 percent: 19).

Additional Comments

About half of the women offered additional comments at the end of the survey, some thanking us for doing it, and others offering suggestions for future research—such as more detailed research about long-term side effects of treatment. Many of the other comments tied into themes that were identified in the interviews: specifically, care experiences and resources. A good deal of women expressed frustration with the way that they were treated—whether it be missed diagnoses, misinformation, or just complete lack of information about HPV and what to expect. Others noted the lack of research and attention on cervical cancer, again comparing it to the wealth of resources available for those with breast cancer.

Subset 2: Dysplasia and CIS Participants

A total of 24 additional women responded that they had either Stage 0 cancer (known as carcinoma-in-situ or CIS), or some grade of cervical dysplasia (abnormal cervical cells). This was an interesting occurrence because the survey was clearly tailored to those with diagnosed invasive cervical cancer, and was titled “Women’s Experiences with Cervical Cancer.” Although many professed that their diagnosis was *not* cervical cancer—that there is, in fact, a firm delineation in some of their minds

between what they have and what “real” cervical cancer is—these women decided to complete the survey anyway. This sample has been included in the analysis because, first, their responses to the stigma items differed and in many cases were stronger, and also because their simultaneous rejection and acceptance of a cervical cancer designation in their lives blurs the biomedical distinction between these two diagnoses. It speaks to a larger societal conception about what it means to have *cancer*, and the motivation behind why people might identify with it in certain instances and not in others. In many instances, women marked that they were diagnosed at Stage 0, or left the question blank and wrote a response in the comment box. It is important to note that some of the questions that were more clearly suited to women with invasive cancer were not included here in this discussion.

In general, these women tended to be younger and were less likely to be married. While the average age of a woman with invasive cervical cancer was 41.5 years old, women with dysplasia or CIS were 34.6, on average. Only 20.8 percent (5) of these women were married, compared with 63 percent (29) of women with invasive cervical cancer. 62.5 percent (15) were either single or had a boyfriend/girlfriend, compared with 23.8 percent (11) of the other group. These women were also less likely to have private health insurance when they were diagnosed—66.7 percent (16) compared to 82.6 percent (38) of women with invasive cervical cancer. More of them tended to be on Medicaid, student health insurance, or to have no health insurance at all.

Illness History

These women had, on average, first been diagnosed with dysplasia or CIS approximately five years prior to the survey (57 months), with a range of one week

through 16 years. Most of the women in this group had been diagnosed by their gynecologist (83.3 percent: 20) through a routine Pap smear (87.5 percent: 21). Only one had been experiencing symptoms. These women had had much different treatment regimens, detailed in Table 4.6 below.

Table 4.6. Types of Treatment: Women with Dysplasia or CIS (n=24)⁴

TREATMENT TYPE		TREATMENT TYPE	
No treatment	8.7%	Pelvic Exenteration	0%
Conization (or Cone Biopsy)	21.7%	Trachelectomy	4.3%
Cryotherapy/Cryosurgery	4.3%	Internal Radiation	0%
LEEP	69.9%	External Radiation	0%
Laser Surgery	13%	Chemotherapy	0%
Radical Hysterectomy	4.3%	Other (such as cervical stenosis)	4.3%
Total Hysterectomy	8.7%	Decline to Answer	0%

Because treatment modalities differed between the two groups, side effects did as well: vaginal bleeding (39.1 percent: 9) and vaginal discharge (30.4 percent: 7) were the most common. Others mentioned weight gain, bloating, difficulties with sexual intercourse and sex drive, and menopausal symptoms. Several referred to psychological, social and emotional repercussions such as “*emotional trauma, loss of relationship,*” anxiety, and depression. Of several potential short-term and long-term repercussions of cervical cancer and its treatment, participants reported the following effects as *extremely troubling*: loss of fertility/compromised fertility (31.8 percent: 7), fear of recurrence (54.5 percent: 12), and financial effects (31.8 percent: 7). They noted that their diagnosis had caused difficulties in a marriage or relationship with a significant other that were *somewhat troubling* (36.4 percent: 8). A number of women commented that sexual side

⁴ See Table 4.2 for a full description of treatment modalities.

effects such as “*reduction in the strength of orgasm*” were the worst consequences of their experience, and still others were frustrated with the healthcare that they had received and the personal confusion they felt about their diagnosis: “*Frustrations with getting information from doctors and having things explained—EXTREMELY TROUBLING.*”

Perceptions about Disease and Self

The majority of women—19 out of the 23 who answered the question—believed that HPV had been the cause of their dysplasia or carcinoma-in-situ, and another two suggested that sexual contact had been the cause: in one case, “*sex with an idiot.*” Interestingly, many of the answers reflected a frustration with medicine’s lack of knowledge about HPV and its role in dysplasia and cervical cancer, and—similar to the findings in the interviews—women suggested a host of other causal factors they believed played a role in their condition. For example, women mentioned birth control pills, trauma to the cervix, second-hand smoke, weakened immune system, stress, and lack of knowledge. Three complained that their doctor did not follow the standard screening guidelines, either failing to inform them that they needed a Pap smear as frequently as they did, or not performing an HPV test.

Responses to a query about who is at risk for the disease were similar to the previous group with invasive cervical cancer. A majority answered that females, or more specifically, sexually active females, were at greater risk. Others qualified this response by saying that people of color, the poor, the uneducated, or the uninsured were at higher risk.

When asked about the first three words or things that come to mind when they hear the word cancer, the responses were quite similar to the other group. Death was

mentioned the most frequently—15 times—followed by fear (7), treatment and side effects (7), and impact on family (5). References to “overcoming” popped up occasionally (7)—for example, survival, fight, challenge, life-changing, strong, and “*I.am.fine.*”

Not surprisingly, fewer participants in this sample identified themselves as cancer survivors. 65.2 percent (15) did not think so. Most of these women reasoned that since they did not have *invasive* cancer, and as such their lives were not threatened, then they were not cancer survivors. Interestingly, however, a significant proportion did identify themselves as such—34.8 percent (8): “*So far I am. I’m still alive despite having a Stage 0 diagnosis. I’m hoping it doesn’t come back.*” Another woman commented that “*My doctor said that the piece from the cervix they removed was starting to form cancer so I do consider myself a lucky and fortunate cancer survivor!!!*”

Experiences of Stigma

There were four questions on this survey that inquired about whether or not participants felt as though other people looked at or treated them differently because they had/have cancer, and more specifically cervical cancer. These questions don’t directly relate to this sample, but some of the qualitative comments were illuminating. Instead of feeling as though people are looking at them differently because of their cancer diagnosis, a number of women felt this way because of their HPV diagnosis: “*I would say that they don’t look differently at me because I had pre-cancer, but rather that I have HPV.*” Two women mentioned this in the context of their healthcare: “*Sometimes I feel like the nurses and doctors may look at me differently because my cancer is caused by the HPV virus which is sexually transmitted.*” It may even affect the quality of their care. “*To clarify*

my situation, I asked them if they know what strain(s) of HPV I have. Instead of answering my question, the nurse asked me in a condescending tone if I know how HPV is transmitted. She went on to tell me that people with many partners are more likely to develop cervical cancer.”

While the majority of women with invasive cervical cancer had *not* feared that other people would have less respect for them if they knew about their diagnosis (64.4 percent: 29), this figure was inverted in this sample—57.1 percent (12) were afraid that this would be the case, while 33.3 percent (7) did not. Proportionately more women in this sample believed that those with cervical cancer are stigmatized—76.2 percent (16) compared to 64.4 percent (29). Respondents noted that this stigma tended to arise (or continue) because it is tied to an STI, that people think you brought it on yourself, and that educational and media messages created a “face” of cervical cancer that was stigmatizing—multiple sex partners, sex at a young age, and those that do not seek out screening.

“I'm not sure how much of the stigma comes from us and how much comes from outside of us. But I do believe that we feel a huge amount of stigma and shame. I'm not sure where this comes from. I think it's reinforced by constant messages that list risk factors as "multiple sexual partners", "smoking" and "compromised immune systems." It makes people feel like somehow it's their fault for not being able to clear the virus like 90% of other people -- like we somehow brought it on ourselves -- either by being promiscuous or having a bad lifestyle.”

Interestingly, there was much more mention about the HPV vaccine in this question—women linked the stigma of cervical cancer as directly impacting the way that people think about getting the vaccine. One woman noted that:

“This is one reason why the Gardasil vaccine has received so much negative media/government attention. Cervical cancer is a very misunderstood disease. On many websites about cervical cancer it states risk factors for the disease as having a high number of sexual partners, sex at a very early age, being minority

and other risk factors. While these are statistics, not all women with cervical cancer/precancer fit in these neat little categories. HPV is extremely common. Most people do not understand this and the stigma is just continually promoted.”

Table 4.7 below displays the detailed responses to specific stigma questions—on the whole, women with dysplasia or CIS agreed more frequently with certain items than women with invasive cervical cancer: specifically, “I blame myself for this condition,” “I think that others blame me for this condition,” “I am angry at myself,” and “I feel embarrassed or ashamed.” Some of the additional comments to this table centered on the

Table 4.7. Responses to Stigma Items: Women with Dysplasia or CIS (n=24)

	Never	Rarely	Sometimes	Frequently	Always	N/A
I blame myself for my condition.	9.5%	9.5%	33.3%	42.9%	4.8%	0%
I think that others blame me for my condition.	14.3%	23.8%	19%	33.3%	4.8%	4.8%
I think that this condition could have been prevented.	19%	4.8%	19%	28.6%	28.6%	0%
I am angry at myself.	23.8%	9.5%	33.3%	23.8%	9.5%	0%
I feel embarrassed or ashamed.	14.3%	19%	28.6%	33.3%	4.8%	0%
I am too embarrassed or ashamed to tell someone about it.	33.3%	23.8%	19%	23.8%	0%	0%
I think less of myself because of my condition.	33.3%	19%	19%	23.8%	4.8%	0%
My family thinks less of me because of my condition.	57.1%	14.3%	14.3%	4.8%	4.8%	4.8%
I think that others pity me.	47.6%	19%	19%	4.8%	4.8%	4.8%
I think that others judge me negatively because of my condition.	33.3%	23.8%	28.6%	4.8%	4.8%	4.8%

effects of increasing knowledge and research: *“If more people knew how cervical cancer can be started, I think I would be more embarrassed or ashamed. Not many people know that I have the HPV virus.”* One woman implied that the current research is stigmatizing

in itself: *“My parents judge me and I judge myself. Close friends and co-workers don’t, but the general messages in research studies and people I don’t know always seem to imply this resulted from promiscuity.”*

Support and Disclosure

Fewer women had disclosed their diagnosis to others: 85.7 percent (18) had told their spouse/partner/significant other, 81 percent (17) had told their parents, 76.2 percent (16) had told their siblings, 42.9 percent (9) had told other members of their family, 90.5 percent (19) had told their friends, 57.1 percent (12) had told their co-workers, 14.3 percent (3) had told members of their religious groups, 33.3 percent (7) had told neighbors or community members, and an additional 38.1 percent (8) had confided in other people not listed. In response to a question about why they may not have told family or close friends, women responded equally that they were embarrassed, ashamed, and afraid of being judged, and also that the uncertainty of their diagnosis and prognosis held them back. A few women reported negative experiences when they confided in others: *“I tell some and not others about my HPV. It’s also come back to haunt me—and a large group of people have found out and judged. At the end of the day, it seems to come down to an STD, not the fact that I had basically had pre-cancer.”*

A greater percentage of this sample would prefer to keep others from knowing about their diagnosis: the biggest proportion responded that they *sometimes* (47.6 percent: 10) or *always* prefer it (9.5 percent: 2). Many of these women argued that privacy was the motivation for this, feeling that it was not anybody else’s business. Others were frightened about being judged or stigmatized: *“I would be reluctant to tell my extended family because they are conservative Christians and would blame this on ‘promiscuity’*

because I'm 46, not married, and have had various relationships over the years." On the other hand, 42.9 percent (9) of this sample *do not* prefer to keep others from knowing. The underlying rationale behind this is that by being open about their diagnosis, they help others and raise awareness about HPV and cervical cancer: *"I am an open book and believe knowledge is key. I would tell anyone in the same situation of my experience to try to enlighten them and let them know it can be treated if caught early enough."*

In terms of support, many women responded positively, although less so than the women with invasive cervical cancer: 38.1 percent (8) felt that the support of their significant other/spouse/partner *exceeded my expectations*, as well as 28.6 percent (6) for siblings and 33.3 percent (7) for co-workers. Parents offered *some support* to 28.6 percent (6) of participants, and friends offered *good enough support* (38.1 percent: 8). One woman offered an enlightening comment about the support available to her: *"There is not enough understanding about HPV in the general community to provide the support you really need in these cases. I feel I am educating others more about it, and it's hard for them to really understand. It's hard to find sex-positive doctors that will help you through it as well."*

Information-Seeking

Similar to the other sample, women's primary source of information on cervical cancer—causes, treatment, side effects, long-term side effects, support groups, and advocacy organizations—were both doctors and the internet. A good many had not received any information on long-term side effects (30 percent: 6), support groups (45 percent: 9), or advocacy organizations (50 percent: 10). Information on HPV came mainly from the internet—73.7 percent (14) had accessed information about its causes

there, 57.9 percent (11) about the vaccine, and 47.1 percent (8) about support groups. A significant difference between the two groups was the central role television played in gaining access to information—52.6 percent (10) of this group, compared with 7 percent (3) of the other group, used television as a main source for information about the cause of HPV, while 52.6 percent (10) of this group versus 23.8 percent (10) of the other had received information about the HPV vaccine from television.

Additional Comments

Nine women volunteered additional comments at the end of the survey. It is interesting that many of these comments addressed HPV and dysplasia's relative "invisibility" among researchers, where these conditions are not seen as worthy of investigating (unless they turn into cervical cancer, that is) because they are preventable. There is not that much information available and the outcome is uncertain, and so these women are left in limbo for an indefinite period of time. This is clearly an area of necessary future research. One woman articulated her situation quite eloquently:

"I wish that we had better statistics on the cost of "preventing" cancer. Doctors downplay the morbidity involved in treatment of "pre-cancer" and people don't understand that "pre-cancer" is difficult, if not impossible, to fully prevent. We aren't counting the hundreds of thousands of women impacted by pre-cancer, so we don't even know the true cost of our screening programs. We are only counting elimination of cancer as the goal, and I wish we would focus on elimination of pre-cancers. I don't think the vaccine is enough, and we need an infection control strategy. The current messages do women a disservice because they state that almost everyone has HPV and almost everyone clears it on their own (if they have a normal immune system). This downplays the risk, so that no one takes HPV seriously until they have a bad outcome. Messages say to reduce sexual partners, but that's not really true prevention because you can't control how many partners your partner has had. It's very frustrating, and I just feel very angry and have not yet come to terms with my experience even though I'm more than a year post LEEP. I wonder if people with cervical cancer are doing better

emotionally than people with dysplasia, because maybe they have come to terms with life and death and feel grateful to be alive, but we don't feel that sense of relief, just more a sense of what we've lost."

SUMMARY

This chapter delved in detail into each of the themes emerging from the key informant interviews, content analysis, semi-structured interviews, and online survey. The content analysis of the websites contributed a number of insights that were then incorporated into both the interview and survey questions, such as causation, de-stigmatization, a focus on women, and perceptions of the HPV vaccine. Because the overall goal of this research was to investigate the dynamics and subtleties of women's experiences with cervical cancer and stigma attached to the disease, the analysis put its primary emphasis on qualitative methods, that is, the interviews. Major interdependent themes emerged from the analysis of this data that served to illuminate the complexities of each participant's experience with cervical cancer and stigma, such as their ideas about causation, sexuality, prevention, the role of the media, the HPV vaccine, and their perceptions about resources. Aspects of a number of these themes were then tested through the use of an online survey. Importantly, many participants from both the interview and survey phases offered suggestions to minimize stigma that will be incorporated into the next chapter's discussion and recommendations.

Chapter Five:

Discussion and Recommendations

Chapter Five will present a detailed synthesis and discussion of the key informant interview, content analysis, in-depth interview and survey results, focusing on concrete areas for action and potential contributions to applied anthropology. Although this study brought forth many issues and difficulties surfacing in participants' experiences with cervical cancer, its primary research questions concern the nature, origin, and consequences of stigma attached to the disease. Thus, for the purposes of space, this summary of results will be limited to a discussion stemming from this perspective. Indeed, many of the seemingly disparate themes surfacing throughout the results of these methods are, on closer inspection, not so disparate at all—and thus, many of them find their reflection in a discussion of these research questions. Others expose current gaps in our understanding while posing important future avenues for anthropological and public health research. This chapter will conclude by offering recommendations gleaned from the insights of both the participants as well as myself, the researcher.

SUMMARY OF RESULTS

The Nature of Cervical Cancer-Related Stigma

Erving Goffman—the sociologist famed for his examination of stigma in the 1960s, followed by successive waves of scholars in various social science disciplines building upon his theories—have differentiated between *enacted* stigma and *felt* stigma.

According to these scholars, enacted stigma refers to the active discrimination of people who are perceived to have a trait that is stereotyped negatively by society. Felt stigma, on the other hand, is a more internal-level phenomenon that reflects the individual's actual experience with this discrimination, or their anxiety and fear of its occurrence.

This kind of dual outward-inward experience of stigma is clearly reflected in these interviews and surveys. Indeed, in many instances there seems to be a disconnect between what the participants have actually experienced in terms of treatment by others, and what they perceive others to be *thinking* about them—or indeed what they think about themselves. Although there are some very notable exceptions, many of the women did not feel as though they had been treated poorly or that others had made negative or insinuating remarks to them about their cervical cancer. More frequently, they were certain that others were thinking about them differently and judging them—because, some argued, they might do the same given the information now circulating about HPV and cervical cancer. These assessments resulted in fear, increased stress, anxiety, and reluctance to share experiences with others not directly involved.

One of the most important points of Goffman's and successors' work, I believe, is that stigma is not just limited to actual negative and stereotyping *behavior* enacted against the individual with the unacceptable trait. Rather, participants are also looking outward to society's conceptions about cervical cancer and measuring themselves against it, creating a process of internalization that can have tangible repercussions on their physical, emotional, and social health. Although they might not all be actively experiencing discriminating behaviors from others, by reflecting on others' changed

beliefs and judgments about them, they are certainly perceiving cervical cancer's negative connotation in wider society and the existence of stigma attached to the disease.

Origins

Given that participants feel that, on the whole, cervical cancer is a stigmatized condition in the United States, what then are the origins of this stigmatization? The answer to that is multi-layered, and appears as though women's experiences of stigma are often tied to interacting and interdependent belief systems regarding causation, female sexuality, and prevention.

In her work on the moral reasoning of cancer, Hunt (1998) argued that individuals must create meanings behind why they themselves become sick, given that biomedicine has failed to articulate with certainty the fundamental cause of cancer. Considering this continuing ambiguity surrounding the scientific knowledge about HPV and its possible role in an individual's cervical cancer, participants in our study have likewise developed personally meaningful hypotheses that make sense in their own lives and situations. First, their theories of causation regarding HPV and cervical cancer in a *general*, abstract sense tended to reflect the current biomedical discourse and were almost identical to one another—for example, they frequently cited specific behaviors (mostly sexual behaviors) as potential causes of both conditions, and seemed to take for granted HPV's causative role in the development of cervical cancer. Second, these discourses were in many ways incorporated into their own individual theory of disease development, although not entirely. These personal explanations reflect varying degrees of uncertainty and tend to fall into broad categories of causation—individual behavior and external factors. Many felt that they were responsible in some sense for their cervical cancer by a certain

behavior, lifestyle, or choice—such as sleeping with the wrong person, smoking, not going to the doctor enough, or not taking care of oneself properly. This sense of guilt and personal responsibility frequently contributed to great deal of shame and embarrassment on the part of that individual woman.

The sexual nature of this causal relationship between HPV and cervical cancer frequently heightened this sense of shame and embarrassment for women, especially given that many women’s narratives touched upon the idea that there are aspects of female sexuality and the female body that predispose *certain* women to developing cervical cancer by increasing their risk of contracting HPV. Here one can see the moralistic overtones of biomedical discourse about HPV transmission and cervical cancer development reflected in a clear way. It is important to note here that these assumptions were not without critical reflection by the women themselves. A majority argued that the reason that cervical cancer is stigmatized in society is its association with sexual behavior, and because HPV is a sexually transmitted infection. Many acknowledged Americans’ discomfort with sexuality, or more specifically, female sexuality, simultaneously critiquing the reason behind the stigmatization while being forced to deal with its structural and individual-level consequences.

The concept of prevention was one that cropped up repeatedly throughout the interviews, and was itself seen as a large underlying factor in the generation of cervical cancer-related stigma. With continuing scientific discovery relating to HPV, “preventability” is now widely seen as a quality of cervical cancer in two ways. First, it is seen as preventable by “responsible” sexual behavior—participants spoke frequently about how this concept impacts them adversely because now others believe that they are

responsible for their own condition. Or, importantly, they believe that about themselves. Secondly, it is now recognized as being preventable by the existence of the new HPV vaccine. These beliefs combine to seemingly decrease others' sympathy towards the cervical cancer patient or survivor, and increase blame-finding. An interesting parallel was drawn between cervical cancer and lung cancer—a type of cancer that has long been recognized as stigmatized because of its causal association with a behavior that is socially unacceptable in contemporary American culture.

This increasing recognition of cervical cancer's preventability is recent and seen as due largely to new discoveries about HPV and the vaccine. These new developments are leading to a significant increase in the publicity surrounding the association between HPV and cervical cancer, which in turn is leading to a situation that many referred to as a "double-edged sword." In other words, this increasing awareness of HPV's role, and strategies that an individual can use to protect him/herself, is simultaneously creating both positive and negative change. Awareness is being raised, hopefully leading to a decreased incidence of both diseases and sparing many women from a cervical cancer diagnosis. At the same time, it is serving as fodder for further stigmatization—creating a scientifically proven link between sex and cervical cancer that leads to negative assumptions and stereotypes about those who are dealing with the disease.

It is critical to note that survivors' experiences with the disease are affected not only by society's assumptions about cervical cancer's cause, its association with sexual behavior, and its newly-recognized quality of preventability. They too are impacted by the wider negative connotations about cancer itself, and indeed, it is often impossible to conceptually separate the effects of the two. Participants argued that cancer on the whole

is stigmatized, not so much because of its origins, but because of its enduring association with death, disability, and suffering. The impact of this is two-fold: it creates fear and a sense of vulnerability in the survivors themselves because it challenges their *own* mortality, and also anxiety and discomfort because it is assumed that others must think the same thing—that is, they must believe that the patient was going to die, and pitied her because of it.

Consequences

The reported consequences of cervical cancer-related stigma are numerous and multi-faceted, ranging from individual-level effects to societal structures and policies that both respond to the stigma and perpetuate its existence. For example, individual-level consequences that have been threaded throughout this discussion include a heightened sense of fear, guilt, stress, anxiety, and personal vulnerability. Socially, many participants reported a reluctance to share their experiences with others not directly involved in their care, something which may impact their ability to access adequate social support.

Ironically, one of the consequences of cervical cancer-related stigma was seen as a positive rather than a negative—self-advocacy. In other words, the stigma that some women witness and experience is a powerful catalyst for their own involvement in the awareness-raising movement. Their personal experience created the realization that only by raising awareness of the devastation of cervical cancer and the true prevalence of HPV (i.e., the fact that it is so common) will the situation change for the better. Perceptions will improve once HPV and cervical cancer are normalized, and the only way to achieve this is by speaking out and being public.

Interestingly, the most frequently discussed consequences of cervical cancer's stigmatization were not strict individual-level effects such as discriminating treatment by others, but rather structural-level impact. Of course, these structural consequences have powerful trickle-down implications for an individual, and so these issues must be seen as multi-faceted. For example, a recurrent theme was the lack of clear information and candid conversations with participants' healthcare providers about the connection of HPV and cervical cancer and implications for their future. Many women learned about HPV for the first time months or years after their treatment had been completed, and attributed this omission to providers' discomfort with the topic. Furthermore, this assertion is supported by several informal conversations with gynecologic oncologists and gynecologists during the recruitment stage who stated that they did not want to create a feeling of stigmatization by informing their patients about HPV. In the end, these scenarios seem to both reflect and reinforce the idea that cervical cancer *is* something uncomfortable, secret and perhaps shameful, even though this is most likely the opposite of the providers' beliefs and intentions.

One of the most consistent themes to emerge from these data was the lack of resources available to cervical cancer patients and survivors. More often than not, these observations were juxtaposed with a comparison to the vast resources available for breast cancer, and many of the survivors see it as a direct result of how cervical cancer is viewed in American society. It is not a "culturally acceptable" form of cancer because of its apparent and increasingly recognized link to a sexually transmitted infection, and thus does not engender as much sympathy and goodwill among funders, researchers and the advocacy community as breast cancer, a seemingly "blameless" disease.

The implications of the above statement are numerous, and thus, the umbrella term of “resources” took many forms throughout the interviews and surveys. Lack of attention to cervical cancer in research of any persuasion—biomedical, psychosocial, or cultural—was a major grievance. According to participants, this disinterest appears to spring from the same sources as stigma itself: the recognition that it is preventable means that it no longer necessitates cutting-edge research, and its tie to a sexually transmitted infection makes it an “un-glamorous” topic to investigate.

Furthermore, survivors referenced the lack of financial assistance available to patients and survivors, and the dearth of cervical cancer-specific support resources. Indeed, one of the underlying challenges to this entire research project was an inability to locate any cervical cancer-specific resources in the entire state of Florida—a situation that has major implications for the ways in which survivors access support. There appears to be no organized community, and few of the participants knew even a single other person who had experienced cervical cancer. Thus, the majority used internet-based support groups to fill this need. Although most interview participants noted that they personally had not experienced trouble getting support from their loved ones, this need arose among survey respondents, and both groups cited the lack of specific support resources available to them.

Not only does the stigmatization of cervical cancer impact the resources available to those suffering from it, it extends to preventative measures such as the HPV vaccine. The current controversy over mandatory vaccination for school-age girls was attributed to Americans’ inability to accept the occurrence of pre-marital sex among women—something that is, according to many respondents, besides the point. In other words, does

it really matter where a disease might come from, as long as a vaccine for it can spare suffering for so many? It is not hard to imagine the vast policy implications that exist when laws based on moralistic expectations about female sexuality are passed and enforced.

FURTHER CONNECTIONS TO THE LITERATURE

Major findings from previous work on stigma, cancer, and sexually transmitted infections surface throughout the results of this study. One of the most predominant connections is that of the “immoral” underpinnings of disease. For example, many participants viewed cervical cancer as arising from a “moral” transgression that took place at an often unspecified time in their lives, many questioning whether or not it was a punishment for past behavior—a strong theme in much of the literature reviewed (Brandt 1987; Erwin 2007; Gregg 2003; Chavez et al. 1995; Hunt 1998; McMullin 2007; McMullin et al. 1996; and Patterson 1987). In the majority of instances, this transgression was presumed to be sexual, although others believed that not utilizing screening healthcare as expected and recommended was the primary reason for the development of their cervical cancer. Either case, though, portrayed an element of personal irresponsibility.

Extending this further, many stigma scholars have argued that the existence of stigma is highly tied to a perception that one has violated a moral—often sexual—taboo (Das 2001; Gilmore and Somerville 1994; Goffman 1963; Newton and McCabe 2005). Indeed, whether or not participants themselves viewed their cervical cancer as arising from their own sexual transgression, a more frightening idea was that others believed that this was the case. It often appeared that the negative assumptions of others was a more

disturbing and anxiety-producing scenario than the prospect that a participant's own behavior had created her predicament (whether or not that this was actually the case in a purely biomedical sense). Thus, a sexual taboo violation took place which then created an illness, setting the stage for stigmatization of that individual to occur.

As touched upon in an earlier paragraph, a theme woven throughout many of these explanatory models is that of personal (ir)responsibility. This is perhaps not surprising at all, given the lifestyle risk paradigm that has been centralized in much recent public health work—and which has often been the subject of critique and concern by public health scholars, anthropologists, and others (Lupton 1993). It is, perhaps, much more salient in this discussion now that cervical cancer has been increasingly positioned as a preventable disease—first, by responsible sexual behavior, second, by “proper” screening according to determined guidelines, and third, by the HPV vaccine. This recognition by participants spurred a comparison by several to lung cancer and its public perception as a disease arising from bad behavior. Not coincidentally, this is a subject that has been the target of recent interest by those linking the current lack of biomedical research and funding attention on lung cancer to its stigmatization and association with a culturally unacceptable type of behavior.

A further link to previous research concerns the role of media in generating unfavorable cultural perceptions of disease. A recurring grievance within both the interviews and surveys, media-generated stigma has also been the subject of anthropological research (Inhorn 1986; Pliskin 1997). Media involvement was a pivotal but complicated experience for many of the participants, something which does not necessarily arise in past literature. Often ill-defined and conveyed as a shape-shifting,

borderless goliath, “the media” was seen to be simultaneously positive and negative: it raised awareness, therefore saving lives, but it created a bad reputation for cervical cancer and thus complicated the lives of the participants.

This brings to the fore the related ideas of advocacy and resistance, a subject of recent stigma research (Gilmore and Somerville 1994; Parker and Aggleton 2003; Whittaker 1992). Advocacy—both individual-level and collective—was unilaterally conceived of as a positive thing. Simply put, it saved lives by raising awareness of cervical cancer and the need for screening—the lives of women who had not yet been diagnosed, but also, in an indirect way, those of the participants’ themselves. It was a way to resist the stereotypes of cervical cancer and its negative associations, and decreasing these stereotypes was presumed to have an inverse effect on the interest of scientists using their research dollars on cervical cancer—thus positively impacting the lives of the participants.

CONTRIBUTIONS TO ANTHROPOLOGY AND PUBLIC HEALTH

Viewing the subject of cervical cancer and stigma from within an anthropological framework poses many more questions than answers, and therein lies the value of this study. Cervical cancer can serve as a case study of those “diseases of disparity” (illnesses that are distinguished by great socioeconomic disparities among those affected) as well as those seen as resulting from failures of individual responsibility. It can help to explain why, on a cultural level, we are motivated to find explanations for disease that rest on the immoral—or, at the very least, culturally unacceptable—behavior of its victims. Of course, it is not a new idea in anthropology that certain illnesses spring from immoral sources—as a century of writing can attest. But, clearly, new forms of medical

interventions such as the HPV vaccine can have significant cultural impact, and so call for new research and new ways of understanding how we define health, illness and disease. These questions lie at the heart of medical anthropology, and this study contributes one example that has broader relevance to any number of biomedically-defined diseases that are seen as resulting from lifestyle choices.

This study further contributes to the anthropological literature in a number of ways. First, it has been thoroughly informed by the voices of people most affected by cervical cancer, a perspective that has often been neglected in previous stigma research and is something that has been the subject of recent anthropological critique (Castro and Farmer 2005; Kleinman et al. 1995; Link and Phelan 2001a, 2001b; Parker and Aggleton 2003; Whittaker 1992). Second, it adds to the volume of work currently ongoing on disease-related stigma as a case example of the nature, origins and effects of it on a specific population—women living with and beyond cervical cancer in a new era of vaccines. Finally, it helps to fill the large gap in the anthropological literature focusing on sexually transmitted infections outside of HIV/AIDS.

Simply stated, applied anthropology concerns itself with the application of anthropological theory and methods to real-world problems, with the overall goal of affecting some kind of positive change or solution. In this study, qualitative methods were used to develop a deep and holistic understanding of an emerging problem—the stigmatization of cervical cancer patients and survivors. Women who are impacted personally by this issue were involved in the research development process as key informants, and helped shape the research questions and instruments. Given the evolving nature of this issue and cervical cancers' changing "reputation," applied anthropology is

particularly suited to clarifying its dimensions and complexities through the application of its theory and methods. Perhaps most importantly, this research will be put back into the hands of those who might be able to utilize it more widely through an executive report.

It would be beneficial for further anthropological research into cervical cancer-related stigma to focus on the structural and economic forces that give it shape and in which the condition is embedded. This type of approach is exemplified by McMullin's (in press) recent analysis of social inequalities and cervical cancer disparities among Latinas: in it, she examines how their "status in society and epidemiological risk factors [sex at a young age, multiple sexual partners] are used to stigmatize them" (McMullin in press:115) in the context of the current political discourse surrounding Latinos in the U.S. This task would benefit greatly from the expertise of anthropologists, who are uniquely situated to examine both large-scale forces and local experiences of a particular issue—in this case, the ways in which cultural beliefs about cancer and political, economic and social policies are actualized in an individual's everyday life. Combining this particular research project (which focuses strongly on individual-level experiences with stigma) with a broad cultural and social analysis will provide rich data with which to contextualize cervical cancer survivors' experiences with stigma.

Not only is this topic highly relevant for anthropologists. The field of public health has a critical interest, first, because of stigma's role in disease development and perpetuation, and second, because of the field's major focus on the elimination of health disparities. Numerous public health scholars have written about the significant role that stigma plays in shaping and exacerbating rates of disease in the population because it

mediates access to healthcare—both preventive and treatment (Bayer 2008). On an individual level, for example, stigmatization can hinder an individual's willingness to seek out screening services because she is embarrassed or because she experiences degrading treatment from healthcare professionals when she does. Or, on a structural level, stigma may decrease policy-makers empathy for certain diseases and make them less likely to commit dollars for outreach programs. Accordingly, the argument that disease incidence, prevalence, and mortality are directly linked to stigmatization places the issue squarely in the domain of public health. Attention to stigma in the design and implementation of population-wide health programs may help to mitigate stigma's effects on care-seeking and provision among certain populations.

As addressed in Chapter Two, a number of stigma scholars have argued that the same structural and economic forces that create social inequalities and give rise to health disparities also influence who and what is stigmatized within a given culture (Castro and Farmer 2005; Jones et al. 2004; McMullin in press). The relationship between disparities and stigma is thus bi-directional in that stigma both contributes to creating disparities within a particular disease and is perpetuated by existing disparities. According to this argument, public health—because of its attention to health disparities—would have a large stake in further research on the subject if there is ever hope of creating a just healthcare system. Public health's expertise in program development, evaluation and social marketing could greatly benefit from an increased focus on stigma and its role in mediating access to healthcare.

In sum, the combined understandings of micro- and macro-level causes and consequences of stigma will have great value for both applied anthropology and public

health. The information and recommendations generated by this study can be put to several uses, ideally in a collaborative setting. First, this study is premised on the idea that a fuller understanding of the dimensions of patients' and survivors' experiences with cervical cancer and disease-related stigma will help to inform future educational messages tailored to reduce its impact. Second, the finding that differential application of the HPV vaccine has generated and fostered negative stereotypes and incorrect perceptions about women and sexually transmitted infections can be taken into consideration in the design of vaccine programs and educational materials. These findings, along with a more detailed understanding of the consequential stigmatization of the HPV vaccine, could help to inform future vaccine policy and prevention messages. Third, participants' grievances regarding current breast and cervical cancer funding patterns exposes a major need to analyze the utility of agency and governmental policies that have historically combined these funding streams. Fourth, a great gap has been exposed related to cervical cancer-specific support and financial resources, and this report serves as a call for more action and attention to these issues. A more thorough understanding of stigma related to this disease is a first step in designing more effective and relevant cervical cancer-specific support programs. And finally, healthcare providers who deal with survivors on a day-to-day basis can use this information to generate more positive and candid interactions with their clients regarding the social impact of cervical cancer.

RECOMMENDATIONS

As "stigma occurs as a result of social processes that can be potentially challenged by social action" (Newton and McCabe 2005:68), I would like to offer several

recommendations based upon the insights of this analysis and those coming directly from the participants' themselves. These fall into the general categories of de-stigmatization, interactions with healthcare providers, funding policy, and future research directions.

De-Stigmatization

A consistent point to emerge from all phases of research concerns the prevalence of HPV. It is the most common sexually transmitted infection, such that between 70 to 80 percent of sexually active adults will contract HPV at some point in their lifetime (Burk et al. 1996; Koutsky 1997; Lorincz 1996). In a recent report, the National Institutes of Health discovered that 26.8 percent of sexually active females between the ages of 14 and 59 tested positive for one or more strains of HPV in a point prevalence (one-time) study (National Institutes of Health 2008). It was found through the website content analysis that non-profit advocacy organizations emphasized these statistics above many others, which could be interpreted as an attempt to normalize, and thus de-stigmatize, the infection. Further, participants in the interview and survey phases consistently argued that if the public *knew* how common the infection is, then it would cease to carry such a heavy moral weight. Women with cervical cancer who later learned about the high prevalence of the infection felt comforted by this knowledge, and reported that they felt less embarrassed and guilty. These findings closely parallel those of other studies and reports on STIs (IOM 1997), and the idea of “normalizing” HPV infection because of its high prevalence has precedent in the literature (Perrin, Daley, Naom, Packing-Ebuen, Rayko, McFarlane, and McDermott 2006; Waller 2004).

Another frequently-mentioned idea was a dual emphasis on men and HPV. The website content analysis revealed a disproportionate emphasis on women, creating an

appearance that HPV is chiefly a woman's disease. Developing and marketing the vaccine exclusively to girls and women bolsters this perception. Aside from the fact that most websites failed to report the fact that men too can contract HPV and that it can have serious health consequences for them, it also leaves the burden of vaccination, prevention and stigma on women's shoulders. Giving equal focus to men in educational messages and eventually offering the HPV vaccine to them will remove some of the stigma associated with women as the "carriers" of sexually transmitted infection, an enduring stereotype.

Interactions with Healthcare Providers

The ability to have an honest and candid conversation with their doctor was a prized asset among study participants. Many reported the frustration, bitterness, and ensuing resentment created when they felt that they did not receive timely information about the connection between HPV and cervical cancer by their healthcare providers. This was a serious omission in many respondents' eyes, no matter what the underlying intention of the provider. It appears as though a number of providers do not like to raise the issue, either because they feel it is a moot point (given that the participants had already developed cervical cancer), or because they assume the information will make the patients feel badly about themselves. Nevertheless, participants seemed to highly value information about HPV when it was received, and longed for a candid conversation with their physician about its role in their own cervical cancer as well as future implications for their lives—including an acknowledgement and open discussion of the issue of stigmatization.

Funding Policy

A comparison to breast cancer and its disproportionate funding levels was a topic raised so often that I believe it is important to include a recommendation to address it. It is not clear why funding streams for breast cancer and cervical cancer are combined—this is especially confusing in the case of low-cost breast and cervical cancer screening programs where eligibility guidelines for both are based on the ages where breast cancer incidence is the highest, between ages 50 and 64 (Daley 2008, personal communication). In contrast, cervical cancer incidence is highest in a woman’s reproductive years, and peaks in her 30s. Thus, these programs are inherently missing a large portion of the women at highest risk for cervical cancer. In addition, socioeconomically these cancers tend to affect, on the whole, completely different populations: breast cancer incidence is highest among those in the upper income brackets, while cervical cancer incidence peaks among lower-income populations. A policy evaluation that assesses the effectiveness of combining these funding streams, and its relative benefits and drawbacks, would be extremely useful in addressing some of the disparities in resources for the two cancers (Daley 2008, personal communication).

Future Research Directions

Based on the fact that the survey’s stigma items and qualitative comments were frequently stronger amongst the dysplasia and carcinoma-in-situ participants than in the invasive cancer sample, this remains a critical area for future research. I have found little in the way of research on this population and the uncertainties of living with a possible cancer diagnosis at any time. Additionally, numerous comments in the survey revolved around HPV and dysplasia’s “invisibility” among researchers, and how these conditions

are not seen as worthy of research dollars because they are considered preventable by sexual behavior, screening, and now the vaccine. An important discussion ensued on a non-profit's discussion board about this very topic, and one woman's comment summarizes this point succinctly:

“We need some visibility for women with cancer ‘precursors’ since this is a huge group of women that are completely missing from any statistics and any usual discussion of cervical cancer. It is said that cervical cancer is almost 100% preventable through routine screening, and that it only impacts about 10,000 women per year. Yet no one talks about the hundreds of thousands of women who are diagnosed with cancer precursors (that are not preventable, short of abstinence) and how these women’s fertility, sexuality, relationships, finances and emotional health are impacted...I don’t mean to diminish the experience of those with cancer, I just want to say that we can’t have a realistic and meaningful discussion of the impact of HPV without addressing the women (often very young women) who risk losing their fertility and other things to HPV even though they aren’t counted in the numbers because they don’t have cancer.”

Additionally, an investigation of what we consider the boundaries of “cancer,” “pre-cancer”, and healthy cells—or what Martinez (2005) might term the ambiguous “borderlands of health, disease and illness”—would shed much light on our cultural beliefs about this illness. Future study would speak to what it means to *have* cancer, and the motivation behind why some people might identify with it in certain instances and not in others.

This relates somewhat to another potential research direction: survivor identity and survivorship. An interesting finding of this study revealed that survivors often pick and choose the most appropriate and strategic occasions to use this terminology, and the point at which they begin to identify at all with the label is highly individualized. Additional explorations into survivor identity would shed light on the complexities of living with a stigmatized and life-threatening condition that is not admittedly well-understood or explained by the biomedical community.

A final important theme emerged in the interview data whose importance was reinforced by findings from the survey. The potential loss of fertility was one of the most distressing aspects of the whole experience for many of these women, and on that very basis it merits in-depth further study. Cervical cancer incidence peaks in a woman's reproductive years, and thus these two life-changing medical diagnoses—cancer and infertility—tend to frequently co-exist. Post-treatment quality of life is also a relatively new concern for cancer research and treatment, usually undertaken by researchers in the psychosocial realm. An anthropological perspective on this issue, incorporating our society's genetic and biological constructions of parenthood and a differentially applied "right to reproduce," would lend considerable, important and innovative insight.

On the whole, anthropology has much to contribute in the future research needs identified above. Holistic ethnographic accounts are few and far between in both the cancer and sexually transmitted infection realm, and would add considerable depth and breadth to our understanding of what it means to have these afflictions in an era of rapidly-evolving medical technologies and advancing scientific discovery. Research on the cultural and social impact must keep pace with these modern developments; meanwhile, many of the seminal anthropological works in these areas are decades old.

STUDY LIMITATIONS

This study was limited by several factors. First, as discussed in detail in Chapter Three, I experienced difficulties with recruitment that resulted in an inability to establish a long-term rapport and relationship with a community of women. There was no in-person "community" to be found. Although I am not sure that this is a clear-cut "limitation" as it revealed much about the local context of cervical cancer resources and

support services, in an anthropological study many might consider it a limitation given the fact that I am researching a topic with sensitive roots—sexual behavior. Second, this scenario perhaps resulted in a skewed inclusion of women who are particularly outspoken and who have involved themselves in advocacy circles, and thus would be the people with whom I was able to make contact. This certainly creates the possibility that the issues here might be under-reported, and overall merits consideration in terms of any future studies undertaken on this topic. This reflects the difficulties involved in researching any stigmatized condition, and it is clearly possible that the women who are feeling the impact of stigmatization most acutely are the ones least likely to volunteer for a research project of this nature.

Methodologically, the use of telephone interviews in an anthropological study is certainly less-than-ideal and may have resulted in interviews that were not as candid or in-depth as they might have been if conducted in-person; however, this was a last-resort option that was necessitated by recruitment difficulties. Further, because of financial constraints and the self-funded nature of the study, women participated strictly on a volunteer basis and were offered no compensation, which arguably might have had an impact on the participation rate.

Finally, women varied greatly with regards to when they were diagnosed, ranging from just one week to 33 years prior to the interview or survey. While this approach allowed for a great range of experiences along the continuum of cancer diagnosis, treatment, and long-term “survivorship,” it would be helpful—perhaps in future studies—to investigate how a person’s location in the process of coping or managing a cancer diagnosis might interplay with their experiences of stigma and perceptions about the

disease. Certainly, a woman diagnosed one week ago is dealing with greatly different issues than one who has had 33 years to reflect on and process the experience.

CONCLUSION

This study has detailed numerous underlying factors and intricacies regarding the nature and source of cervical cancer-related stigma—its connection to sexual behavior, its perception as a disease that is caused by individual lifestyle choices and behaviors, and its new recognition as a preventable condition. Beliefs about all of these characteristics have combined to generate untold consequences from the perspective of the survivors—guilt, shame, and embarrassment, fear of others’ beliefs and perceptions, lack of services and cutting-edge treatment, and structural discrimination in funding and research policy. All of these find reflection in the ways in which survivors live their daily lives, from the healthcare that they receive, from the types of treatment that are available to them, to the financial assistance and support resources that they are able to locate and access, and to the people they choose (or not choose) to confide in. These are the ways in which stigma, in both micro- and macro-level expressions, come to affect and shape the lives of those who must confront cervical cancer even as a possibility—individuals in the screening system, women who have been diagnosed, loved ones, and those who have chosen to resist, either individually or collectively, the labels that this disease begets. The more that we can explain the ways in which stigma operates on both of these levels, and its role in cervical cancer’s demographic label as a disease of disparity, the better able we will be to design programs and health messages aimed at mitigating stigma and its vast consequences. This holds true not only for cervical cancer but for any disease that is tied in the public consciousness to poverty and individual responsibility.

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Appendix A: In-Depth Interview Guide

INTERVIEW GUIDE: Cervical Cancer and Stigma

- 1. How would you describe yourself?**
- 2. What are the three most important things in your life? Why?**
- 3. There are many problems that we face every day. What are the biggest problems facing you now?**
- 4. When you think about cancer, what are the first three things that come to your mind?**
- 5. Could you tell me a little bit about your experience with cervical cancer?**
- 6. What are some of your ideas about how you may have gotten cancer?**
- 7. Who have you told about your cancer experience?**
- 8. Where have you been able to get support during this experience?**
- 9. Have there been any situations where you had to tell someone about it, even if you did not want to?**
- 10. How do you feel about having had cervical cancer?**
- 11. A lot of people talk about the words ‘cancer survivor,’ and it has many different meanings. What do the words ‘cancer survivor’ mean to you?**
- 12. Are there positive aspects of having cervical cancer? Tell me about them ...**
- 13. What have the hardest aspects of having had cervical cancer been?**
- 14. What kinds of things could have made it easier?**
- 15. Who do you think gets cervical cancer?**
- 16. What did you think about people with cancer before you were diagnosed?**

17. **How do you think the general public views cervical cancer?**
18. **Do you think that people treat you or look at you differently because you have had cervical cancer?**
19. **Have you heard anything recently in the media on cervical cancer? (If yes) What have you heard about the new HPV vaccine that came out?**
20. **What kind of effect, if any, do you think the media attention on HPV and the vaccine is having on cervical cancer patients and survivors?**
21. **Do you seek out information about HPV? (If yes) Where do you get your information from?**
22. **Do you seek out information about cervical cancer? (If yes) Where do you get your information from?**
23. **Is there anything else you would like to add to this that we have not already covered today?**

Demographics:

Age:

How would you identify yourself in relation to ethnicity or race?

Place of residence:

What do you do for a living?

Appendix B: Online Survey

ONLINE SURVEY: Women's Experiences with Cervical Cancer

Thank you for taking the time to complete this online survey! This is part of a study at the University of South Florida that explores women's experiences with cervical cancer. We are interested in your personal opinions, feelings, and beliefs, and we will use this information to help women like you in similar situations. Please answer these questions to the best of your ability.

This survey will take about 15 minutes to complete. It is completely confidential and anonymous, and you are not required to use your name. You do not have to answer any questions that make you feel uncomfortable and you can stop taking this survey at any time. If you have any questions or concerns, please contact Karen Dyer, the study's Principal Investigator, at (813) 974-8379 or kdyer@health.usf.edu.

Consent to Participate in Survey: Please read the following statement and check the box below if you would like to fill out the survey.

You have been invited to participate in a study through the University of South Florida's College of Public Health and Department of Anthropology. The study is entitled "Women's Experiences with Cervical Cancer" and is being conducted by Karen Dyer, a graduate student, and Dr. Roberta Baer in the Department of Anthropology. The purpose of this research project is to explore the experiences of women who have been diagnosed with cervical cancer. If you agree to voluntarily participate in this research, your participation will include the completion of a short online survey that asks questions about your experiences with cervical cancer. If you choose to volunteer, you will not be compensated for your time. There are no known risks to participants taking part in this research project. If you do decide to participate, you may withdraw at any time without consequences and there is no need to offer an explanation. Everything that you answer in this survey will be kept completely confidential. For the purposes of analysis and to ensure confidentiality, you will be assigned a numerical code that will be used in place of your first and last name. The only people allowed to see the study records are the Principal Investigator Karen Dyer, Faculty Advisor Dr. Roberta Baer, the University of South Florida Institutional Review Board, and the Florida Department of Health. We may publish what we learn from this study, but no personally identifying information about you will be used. If you have any questions, concerns or complaints about this study, please call Karen Dyer at (813) 974-8379, or the USF Division of Research Integrity and Compliance at (813) 974-9343.

- Checking this box indicates that you have read the above consent form and are giving your consent to participate in our survey.**

I. DEMOGRAPHICS

1. **What is your current age?**
2. **What is your state of residence?**
3. **What is your ethnicity? (for example, Caucasian, African American, etc.)**
4. **What is your occupation?**
5. **What is the highest degree that you received in school?**
 - Some high school
 - High school diploma
 - Bachelor's degree
 - Master's degree
 - Doctorate or professional degree
 - Other
 - Decline to answer
6. **How many children do you have, if any?**
7. **What type of health insurance do you currently have?**
 - I do not have health insurance
 - Private
 - Medicaid
 - Medicare
 - Student
 - Military
 - Other
 - Decline to answer
8. **What type of health insurance did you have when you learned you had cervical cancer?**
 - I did not have health insurance
 - Private
 - Medicaid
 - Medicare
 - Student
 - Military
 - Other
 - Decline to answer
9. **What is your current relationship status?**
 - Single
 - Boyfriend/girlfriend, not living together
 - Boyfriend/girlfriend, living together

Married/engaged
Divorced
Widowed
Decline to answer

II. ILLNESS HISTORY

10. **When were you first diagnosed with cervical cancer? Please give the approximate month and year, if possible.**
11. **What was the stage of your cancer when you were diagnosed?**
Stage 0
Stage 1
Stage 2
Stage 3
Stage 4
I don't know
Decline to answer
Please add any comments _____
12. **Who diagnosed you?**
Primary care physician
Gynecologist
Oncologist
Other _____ (please list)
Decline to answer
13. **How did you first know that there was a problem?**
Experiencing symptoms (please list below)
Routine Pap smear
Other _____ (please list)
Decline to answer
Please add any comments _____
14. **If you were treated for cervical cancer, how long did (or will) your treatment last?**
15. **What type(s) of treatment have you had, or will you have? Please check all that apply.**
- | | |
|----------------------|---------------------|
| No Treatment | Pelvic Exenteration |
| Conization | Trachelectomy |
| Cryotherapy | Internal Radiation |
| LEEP | External Radiation |
| Laser Surgery | Chemotherapy |
| Radical Hysterectomy | Other |

Total Hysterectomy Decline to answer
 Please list any other treatments: _____

16. **What side effects have you experienced during your treatment? Please check all that apply.**

- | | |
|---|---|
| No side effects | Diarrhea |
| Nausea/vomiting | Fatigue |
| Loss of appetite | Dry, itchy or irritated skin |
| Hair loss | Painful intercourse/difficulty having sex |
| Pain | Frequent sickness or infection |
| Cramping | Mouth sores |
| Vaginal bleeding | I don't remember |
| Vaginal discharge | Others (please list) _____ |
| Difficulty urinating or having a bowel movement | Decline to answer _____ |

17. **Do you identify yourself as a cancer survivor? Why or why not?**

- Yes
 No
 Please explain your answer: _____

18. **Please list any OTHER cancer diagnoses that you have had, including recurrences. Please include the approximate dates that you received them.**

19. **What are the first three words or things that come to mind when you hear the word "cancer"?** _____, _____, _____

20. **What do you think caused your cervical cancer? Please explain.**

21. **Who do you think is more at risk of getting cervical cancer?**

III. EXPERIENCES

22. **Since your first diagnosis, please rate how troubling the following have been for you:**

	Not at all troubling	A little bit troubling	Somewhat troubling	Extremely troubling	N/A
Physical symptoms before diagnosis (for ex., bleeding, painful intercourse)					
Physical side effects of treatment (for ex., pain, nausea/vomiting, hair loss)					

Loss of fertility or compromised fertility					
Other long-term side effects of treatment					
Fear of recurrence					
Effect on ability to perform job					
Financial effects					
Problems with health insurance					
Difficulties in marriage or relationship with significant other					
Difficulties in relationships with friends or family members					

Please list any other effects you may have had: _____

23. **How often do you feel that people look at you differently because you had/have cancer?**

- Always
- Frequently
- Sometimes
- Rarely
- Never
- I don't know
- Decline to answer
- Please add any comments: _____

24. **How often do you feel that people treat you differently because you had/have cancer?**

- Always
- Frequently
- Sometimes
- Rarely
- Never
- I don't know
- Decline to answer
- Please add any comments: _____

25. **Specifically, how often do you feel that people look at you differently because you had/have CERVICAL cancer?**

- Always
- Frequently
- Sometimes
- Rarely
- Never
- I don't know
- Decline to answer
- Please add any comments: _____

26. **Specifically, how often do you feel that people treat you differently because you had/have CERVICAL cancer?**

- Always
- Frequently
- Sometimes
- Rarely
- Never
- I don't know
- Decline to answer
- Please add any comments: _____

27. **Are you afraid that other people would have less respect for you if they knew about your diagnosis?**

- Yes
- No
- Decline to answer
- Please add any comments: _____

28. **Since your first diagnosis, please rate how often you agree with the following:**

	Never	Rarely	Sometimes	Frequently	Always	N/A
I blame myself for my condition.						
I think that others blame me for my condition.						
I think that this condition could have been prevented.						
I am angry at myself.						
I feel embarrassed or ashamed.						

I am too embarrassed or ashamed to tell someone about it.						
I think less of myself because of my condition.						
My family thinks less of me because of my condition.						
I think that others pity me.						
I think that others judge me negatively because of my condition.						

Please add any comments _____

29. **In your experience, do you feel that women with cervical cancer are stigmatized (in other words, looked down upon and negatively stereotyped because of their diagnosis)?**

Yes

No

Decline to answer

Please explain your answer _____

IV. RELATIONSHIPS

30. **Whom have you told about your diagnosis? Please check all that apply.**

Significant other/spouse/partner

Parent(s)

Sibling(s)

Other family

Friends

Co-workers

Members of my religious group (ex., church, temple, etc.)

Neighbors/community members

Others _____ (please list)

No one

Decline to answer

31. **If you did not tell your family members and friends, why not?**

32. **If possible, would you prefer to keep people from knowing about your diagnosis?**

Yes

Sometimes

No

Decline to answer
 Please explain your answer _____

33. How would you characterize the support of these people during your experience?

	No support at all	Not enough support	Some support	Good enough support	Exceeded my expectations	N/A
Significant other/spouse/partner						
Parent(s)						
Sibling(s)						
Other family members						
Friends						
Co-workers						
Members of my religious group (ex., church, temple, etc.)						
Neighbors/community members						
Others (please list)						

V. INFORMATION & RESOURCES

34. For each type of information, please select where you received that information. Check all that apply.

Information on CERVICAL CANCER:

	Didn't receive info on this topic	Doctors	Other health-care workers	Family and friends	Internet	T.V.	Other media (ex., radio)	Organizations (ex., ACS)
Causes								
Treatment and side effects								
Long-term side effects of treatment								

Support groups								
Advocacy organizations								

Information on HPV (HUMAN PAPILLOMAVIRUS):

	Didn't receive info on this topic	Doctors	Other health-care workers	Family and friends	Internet	T.V.	Other media (ex., radio)	Organizations (ex., ACS)
Causes								
Treatment and side effects								
HPV vaccine								
Support groups								

VI. THANK YOU!

Thank you very much for taking the time to participate in this survey! Your efforts have made this study possible, and have helped us to learn as much as we can about women's experiences with cervical cancer.

Please add any additional comments about your experiences with cervical cancer:
