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“A Wound That Never Heals”: Health-Seeking Behaviors and Attitudes Towards Breast Cancer and Cancer in General Among Women in Nakirebe, Uganda

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“A Wound That Never Heals”: Health-Seeking Behaviors and Attitudes Towards Breast Cancer and Cancer in General Among Women in Nakirebe, Uganda

by

Ann Louise Tezak

A thesis submitted in partial fulfillment of the requirements for the degree of Master of Arts with a concentration in Biocultural Medical Anthropology
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Keywords: medical decision-making, access, prevention, screening, treatment, applied anthropology

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DEDICATION

I would like to dedicate this manuscript to some influential people in my life who have helped me through this journey: To my husband, Martin Muganga, who has stood by my side through every step of this journey showing me the mightiest love, support, and kindness. To my mother, Paula McKenzie, who has worked tirelessly to provide for my future, always encouraged me, and continues to demonstrate admirable strength. To my sister, Michelle (Bell) Tezak, who has always showed me love and provided me tender laughs when moments became too overwhelming. To my Gramzie, Marjean Tezak, who passed away just before she could read my work, but had always blessed me with her love and pride in my growth.
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ABSTRACT

The scale and severity of cancer, specifically breast cancer, remains significantly different across the spectrum of low-income to high-income countries. This study explores women’s beliefs about breast cancer and associated prevention and health-seeking behaviors in a rural area of Uganda. Through a critical medical anthropological perspective, the study examines the social, cultural, and economic factors that shape women’s understanding of cancer, and breast cancer specifically, and that influence their use of biomedical services. Data were collected over a three-month period through 35 in-depth interviews and two focus groups with 10 women older than 18 years in the rural setting of Nakirebe within Mpigi District, and through five interviews with health care personnel from a private and a government health care facility in Mpigi District. Quantitative and Qualitative data were analyzed using SPSS version 23 and MAXQDA 12.0.2, respectively. Findings suggest that women in this rural setting have limited access to screening and incomplete knowledge about breast cancer, and cancer in general, and internalize fears of a cancer diagnosis. No women were diagnosed with any type of cancer at the time of this study. Common attitudes towards cancer from the women include inevitable death, cancer is caused by contact with artificial substances and/or germs, and cancer causes pain, wounds that never heal, and the removal of body parts. Recommendations for improving cancer control and management in rural Uganda through awareness initiatives and community health outreach programs are presented.
CHAPTER ONE: INTRODUCTION

Across the world, breast cancer has become one of the most common cancer diagnoses for women. Such diagnoses, however, remain significantly different in scale and severity across the spectrum of low-income to high-income countries. In high-income countries, such as the United States, breast cancer has received major support from private and public institutions bringing awareness to the disease and to preventive measures (BREASTCANCER.ORG 2016). As a result, over the past few decades, breast cancer has become one of the best managed cancers with advanced screening and treatment options (WHO 2016a). On the other hand, low-income countries have experienced a rise in breast cancer over the years, with those women younger than 50 years of age being the group at highest risk (BREASTCANCER.ORG 2016, Youlden et al. 2012). Although developing countries, such as those in Sub-Saharan Africa, have lower overall rates of breast cancer diagnoses among women, their rates of incidence are increasing rapidly and are coupled with much higher rates of mortality compared to high-income countries (UICC 2016a, WHO 2016a). This higher mortality is primarily due to late or no diagnosis, lack of screening services, and inadequate treatment options for women with cancer, in particular women in rural areas of low-income countries (Sankaranarayanan et al. 2010, WHO 2016a, Youlden et al. 2012). Furthermore, when minimal services are available, they may be difficult, if not impossible, to access due to social, political, economic, and cultural barriers, including poverty, political unrest, social pressures, and cultural beliefs (Furnham, Akande, and Baguma 1999, Gondos et al. 2005, Mensah 2014, Youlden et al. 2012).
In Eastern Africa, the incidence of breast cancer is estimated at about 25 per 100,000, with mortality estimated at about 18 per 100,000 (GLOBOCAN 2016a). In comparison to other developing regions such as South Central Asia where the incidence rate of breast cancer is about 27 per 100,000, while the mortality rate is about 14 per 100,000, or even South Eastern Asia where the incidence rate is about 32 per 100,000, while the mortality rate is about 14 per 100,000, Eastern Africa has one of the highest mortality rates compared to incidence rates of breast cancer in less developed areas of the world (GLOBOCAN 2016a). In Uganda specifically, cancer is among the top 10 leading causes of death for women, with breast cancer among the top two leading cancer deaths for this group (CDC 2016b). Most recent data estimate that breast cancer incidence in Uganda is at about 28 per 100,000 with mortality at about 15 per 100,000 for women (GLOBOCAN 2016b). It is important to note that cancer incidence and mortality in less developed countries, in particular Uganda, can be gravely underreported. In Uganda there exists one voluntary cancer registry system, the Kampala Cancer Registry, covering only Kyadondo County (IACR 2016). Kyadondo County includes the capital city of Kampala, and neighboring suburbs of the city, where the majority of cancer care centers are located, in particular the Uganda Cancer Institute (IACR 2016, Wabinga et al. 2014). This is particularly important when understanding cancer in the rural setting of Uganda, where access to cancer care and cancer information is limited.

Multiple studies suggest that female patients suffering from breast cancer in Uganda are particularly disadvantaged in regards to stages of diagnosis, aggressiveness of the disease, accessibility to proper treatment centers, knowledge about screening options, and overall cancer management (Gakwaya et al. 2008, Gondos et al. 2005, Kiguli-Malwadde et al. 2010, Sankaranarayanan et al. 2010). In Uganda, women are being diagnosed with breast cancer at
younger ages and during more advanced aggressive stages of the disease compared to women in high-income countries, such as the United States and Canada (Gakwaya et al. 2008, Roy and Othieno 2011). Socio-cultural stigma towards cancer and high rates of poverty are potential factors creating barriers for women in primarily rural areas of Uganda to acquire knowledge about the disease, seek annual screenings, or receive adequate treatment (Furnham, Akande, and Baguma 1999, Gondos et al. 2005). In order to better explain the high rates of late diagnosis of breast cancer in Uganda, it is necessary to assess basic knowledge and attitudes towards the disease, as well as awareness about and access to cancer screening and treatment services; all within the context of social, cultural, and economic factors that shape women’s health-seeking behaviors and medical decision-making patterns.

The goal of this research study is to understand women’s beliefs about breast cancer, and cancer in general, in rural Uganda, where the disease is on the rise. Over a 20 year period, breast cancer, in particular, has rapidly increased at 3.7% annually according to the Kampala Cancer Registry (Wabinga et al. 2014). As stated previously, the Kampala Cancer Registry is voluntary and covers only one county in Uganda, likely causing information and reporting to be underestimated. In this regard, it is important to explore cancer knowledge and health behaviors not only among women who are directly affected by the disease but also among women in general, and especially among those who reside in rural areas where access to cancer care is limited. The aim is to investigate the cultural, social, and economic factors that impact rural Ugandan women’s knowledge about health care and attitudes towards breast cancer, and cancer in general, in regards to prevention, screening, and treatment.

Applied anthropology is well suited to examine the context of cancer, and more specifically breast cancer, in rural Uganda. Through this lens a description of the social, cultural,
and economic outcomes of chronic diseases can unfold. Merrill Singer and Pamela Erickson (2013) note that the “social consequences” of chronic diagnoses “may also convey cultural understandings about the character of the sufferer, the nature of his or her social group, the will of supernatural beings, and much more” (56). In the end, anthropology has the power to highlight the “biological consequences of social experiences and social consequences of biological experiences” (Singer and Erickson 2013, 56). Breast cancer, and cancer in general, cannot be understood without investigating how this disease interacts with society and cultural norms, and how it shapes experiences of both biological and social outcomes of lived realities.

**Research Setting**

The research setting of this study was strategically chosen based on previous personal experience in Uganda and with the help and guidance of research staff at International Health Sciences University (IHSU). This study took place in the rural setting of Nakirebe Village in Kikondo Parish which is located in Kiringente Sub-county within Mpigi District, about 25 kilometers (15 miles) Southwest outside of Kampala, the country’s capital. See Figure 1 on the following page, depicting a Google map highlighting the route from Kampala to Nakirebe (Google Maps 2016). The area consists of lush green open land and farmland with rolling hills. The most common crops harvested near Kikondo Parish and within all of Mpigi District are sweet potato, maize, and cassava. Running through the middle of Kikondo Parish and all of Mpigi District is Masaka highway which functions as the primary route into Kampala from the Southern border of Uganda connecting to Rwanda.
Prior to data collection, a meeting with Nakirebe Village’s Local Chairman (LC) was scheduled in order to gather detailed information about the community. During the meeting, the LC explained that Kikondo Parish consists of three zones, also called villages: Nakirebe Zone A, Kataba Zone B, and Nantuwala Zone C. In total, all three zones have a population of about 3,500 people. More than half of this population is female, at about 2,000. The specific site of this study was located within Nakirebe Zone A, also referred to as Nakirebe Village or simply Nakirebe, which includes about 600 people, with women making up half of the population. The average age of women in Nakirebe is about 40 years with the majority of women working in the nearby flower company, Fiduga, which manages a large distribution of flower export. Most of these women are not native born to Nakirebe, but instead resettled in the community for work after traveling from distant villages, mostly from within Masaka District. The average household size in Nakirebe is about five, however, many households could have up to about 13 individuals residing in one house. The source of this information comes directly from the LC of Nakirebe.

Figure 1: Map of the location and distance from Mulago Hospital in Kampala city center to Fiduga Flower Company nearby Nakirebe Village. Image taken from Google Maps at www.google.com/maps/.
No written data is available detailing the specific demographics of Nakirebe. See Figure 2, showing a landscape view of Nakirebe Village.

![Figure 2: Image of the landscape overlooking Nakirebe Village. Fiduga Flower Company sits in the background. Photo taken by Ann Louise Tezak.](image)

Nearby Nakirebe there are three health care facilities, both private and government. Most residents of the area seek health care from either the local government health centers or the nearby private health center, but no longer seek health care from traditional health care practitioners. According to the LC, the local churches became a beacon of support for this community within the past 10 years and discouraged seeking health care services from traditional healers. Residents were encouraged to seek health care services from biomedical professionals at either nearby government or private health care facilities. Gradually over this
time, the lack of support shown towards traditional health care practices caused traditional practitioners to leave the area or be discouraged from using their traditional practices. According to the LC, local use of traditional healers still takes place at times in the area, however, is much less recurrent, especially in regards to major health issues in this particular village due to the influence of the local churches of primarily Catholic and Protestant denominations. See Figure 3, detailing a map of Mpigi District.

![Figure 3: Image of a map of Mpigi District taken from the office of a health care provider at Mpigi Health Center IV. Photo taken by Ann Louise Tezak. *Health care provider gave permission to take and use this photo.](image)

Overall, Nakirebe includes an underserved population who faces limited access to biomedical health care resources, specifically in regards to cancer care. The majority of health centers in the area, whether private or public, are either understaffed or lack necessary medical
equipment. The nearest cancer ward with comprehensive cancer screening and treatment is located in Kampala at the Uganda Cancer Institute connected to the major referral health center, Mulago Hospital. Women, in particular, face challenges to travel the extensive journey, up to 25 miles by a combination of foot, taxi-van, and boda boda, which is a local motor-bike taxi. The journey can take anywhere from one to three hours one-way depending on traffic flow outside and within the city of Kampala to reach Mulago Hospital in order to receive any type of comprehensive cancer care, whether it be screening or treatment. It is important, therefore, to assess the services which are available to these women within their rural setting, along with their general beliefs about and attitudes towards breast cancer, and cancer in general.

**Study Overview**

This study utilized an exploratory approach to gather qualitative and quantitative data through in-depth and semi-structured interviews and focus groups. In particular, the study looked at knowledge about cancer causation and general health-seeking behaviors among women in Nakirebe. In addition, health care personnel from two widely utilized health care centers near Nakirebe were also interviewed to assess services available for cancer care, knowledge about local women’s use of services, and areas for improvement. The study was conducted over the course of three months (from June through August, 2015) in collaboration with International Health Sciences University (IHSU).

The in-depth interviews with 35 women in Nakirebe sought to gather demographic information, to assess a collective level of knowledge about cancer including causation and treatment, and to explore personal beliefs of breast cancer and health-seeking behaviors. The two focus group discussions (n=10) aimed to elicit suggestions from the women participants for
community-based breast cancer awareness initiatives and development of screening programs, as well as to assess beliefs about cancer and breast cancer specifically. Furthermore, five health care personnel from both public and private health care centers near Nakirebe were interviewed to gather a collective understanding of cancer and areas for improvement in rural cancer control, as well as their interpretation of patients’ health-seeking behaviors in relation to breast cancer screening and treatment.

This research sheds light on the perspectives of breast cancer, and cancer in general, from a rural setting in Uganda that is underserved in health care and situated outside the Kampala city center, where cancer control and management are mostly available. The findings from this study contribute to further research in rural cancer care and guide community-based advocacy and program development in regards to reproductive cancer care in rural Uganda. Overall, this research builds on current work that highlights the increase of cancer incidence and mortality in low-income countries and demonstrates implications for health outcomes in the rural setting of Uganda.

**Research Aims**

This research focuses on the attitudes of women towards cancer, with particular attention to breast cancer, within the rural and medically underserved setting of Nakirebe, where health care services are less accessible, available, and affordable. In addition, it captures a better understanding of basic health-seeking behaviors of women in this rural setting, as well as health care personnel’s knowledge about cancer and suggestions for stronger cancer control and management in rural Uganda. The overall research aims to:

1. Understand women’s basic health-seeking behaviors in regards to general health care,
2. Explore women’s attitudes towards cancer, with specific attention to breast cancer,
3. Understand women’s health-seeking behaviors in regards to breast cancer screening,
4. Explore health care providers’ knowledge of and attitudes towards breast cancer, as well as services provided at their health care facilities,
5. Gather suggestions for improvements in cancer control and management from both women and health care personnel, and
6. Inform community-based advocacy and program development in regards to cancer care in rural Uganda.

**Thesis Outline**

*Chapter Two* will present the background of existing research on breast cancer in Uganda. This chapter will focus on the significance of breast cancer morbidity and mortality in Uganda, existing qualitative research on breast cancer in Uganda, and an anthropology of cancer. It will frame the research within a critical medical anthropological perspective and the Health Belief Model framework.

*Chapter Three* will present the research methodology used for this study. The description will include an overview of this study’s collaboration with International Health Sciences University (IHSU), recruitment processes, data collection activities, data analysis, ethical considerations, and a reflection on my positionality within the wider context of the research.

*Chapter Four* presents qualitative and quantitative results of the research study. Findings are broken down into sections based on data analyzed from the in-depth interviews with women, focus groups with women, and semi-structured interviews with health care providers. The
sections include both demographic information and ethnographic descriptions. Each section is broken down further into sub-sections based on grouped findings and major themes.

Chapter Five presents a critical discussion of the results presented in the previous chapter, contextualizing them in the current literature. Themes pulled from the findings are triangulated and explored in detail and considered within the broader context of social, cultural, and economic factors which influence health-seeking behaviors and cancer management. Specifically, health equity and health efficacy are explored within the context of the findings and initiate a discussion on empowerment.

Chapter Six, the final chapter, presents the conclusion of this thesis and provides recommendations for cancer awareness initiatives, advocacy at the community level, policy changes within the health care sectors, and the strengthening of support groups in rural Uganda. Areas for future research are then discussed with specific regard to cancer care capacity building and culturally appropriate investigations of cancer-related health care services. Lastly, the contributions this research makes to applied anthropology and public health are highlighted, and limitations of the research are approached.
CHAPTER TWO: BACKGROUND AND SIGNIFICANCE

In this chapter, cancer is examined through the lens of critical medical anthropology and global health. Breast cancer specifically is discussed within the context of incidence and mortality and access to biomedical health care services. Furthermore, factors relating to currently known perceptions of the disease in Uganda are thoroughly reviewed. The chapter also describes the theoretical models used to guide this research in both practice and analysis: Critical Medical Anthropology, with specific regard to socio-cultural theory and a political economy of health, and public health’s renowned Health Belief Model which places this research within the context of perceived health.

Cancer and Breast Cancer on a Global Scale

Cancer is a global concern and can no longer be considered simply a disease uniquely associated with high-income countries. Although this chronic condition does appear to be more prevalent in high-income countries than in low-income ones (GLOBOCAN 2016a), it still places a rising burden on the health of populations in less developed countries where access to cancer-related health care services might be scarce. In fact, in low-income countries the burden of cancer disease is often underreported due to lack of screening services (Ma and Yu 2006). This poses a threat to the control and management of cancer in low-income countries, as their health systems are often ill-suited to manage cancer on the comprehensive and expensive scale needed to tackle this complex chronic disease (Global Burden of Disease Cancer et al. 2015).
According to Cancer Research UK (2015), the global burden of all cancers in 2012 was nearly 14.1 million new cases worldwide, with female breast cancer among the top four most common type of cancer occurring worldwide. New cases of cancer across the globe are expected to increase due to better screening and more diagnoses by 2035 to nearly 24 million (WCRFI 2016b). It is important to note that more than four out of every ten cases of cancers across the globe occur in low- to middle-income countries; furthermore, in 2012 the estimated mortality of cancer worldwide was 8.2 million people (Cancer Research UK 2015). The etiology of cancer is still debated and mostly unknown to this day; especially with regard to causes that lie outside genetic components of inheritable cancer. According to the National Cancer Institute (2016b), age, alcohol use, carcinogens, chronic inflammation, diet, hormones, immunosuppression, infectious agents, obesity, radiation, sunlight, and tobacco use are the most common and identifiable risk factors related to most cancer diagnoses. Cancer often co-exists with additional health problems, such as obesity, chronic inflammation, and carcinogen poisoning (NCI 2016b). Prevention of the disease, therefore, often needs to manifest through behavioral change on different habitual levels. For instance, the most effective behavioral changes recommended to prevent breast cancer, and even cancer in general, are lessening alcohol consumption, becoming more physically active, and eating a balanced diet to maintain a healthy weight (WCRFI 2016b). This means avoiding or controlling the use of or contact with substances that cause cancer, altering one’s diet and physical lifestyle, and taking steps to detect precancerous conditions early in order to take the right treatment measures (NCI 2016a). The feasibility of such changes in behaviors, however, can be difficult to manage and are largely based on available resources and one’s perceived efficacy.
When shifting into a discussion of breast cancer worldwide, it is important to also review incidence and mortality alongside foreseeable causes and screening practices. Again, breast cancer must also be seen as a disease no longer confined to high-income countries, but more importantly as a disease rapidly burdening low-income countries. Breast cancer worldwide affected nearly 1.7 million women in 2012 and exists as the most common cancer in women across the globe and second most common cancer overall (WCRFI 2016a). In 2012 about 522,000 women died due to breast cancer, causing an increase in mortality by about 14% (UICC 2016a). In low-income countries, such as those in the Sub-Saharan African region, it is believed that the rapid change of social norms, structural entities, and economic stability towards that of more industrialized countries is leading to a rise in the burden of reproductive cancers, such as breast cancer (UICC 2016a). Overall, research points towards much later diagnoses and poorer overall outcomes and survival rates in low-income countries regarding breast cancer; for instance in Eastern Africa, about 25 to 30 per 100,000 new cases of breast cancer have recently been reported compared to 90 per 100,000 new cases in western Europe, however, the mortality for both regions remains the same at about 15 to 18 per 100,000 (GLOBOCAN 2016a, UICC 2016a). This is coupled with the alarming fact that breast cancer survival rates for women in high-income countries are between 60 to 80%, whereas, in low-income countries survival rates are below 40% (Coleman et al. 2008).

Screening practices for breast cancer include clinical breast exams as well as breast self-exams (CDC 2016a). Mammograms are considered the gold standard for breast cancer screening across the globe and are seen as the best way to ensure early detection (CDC 2016a). This might remain true in high-income countries where routine screening is available, but in low-income countries mammography services might not be available, accessible, or affordable, especially on
a routine basis and for rural residents. This means, breast self-examinations remain a first-line defense for most women. Breast self-examinations provide a unique self-awareness tool encouraging women to know the shape and texture of their breasts and feel regularly for any abnormalities (NBCF 2016). In fact, 40% of breast cancer cases are first detected through breast self-examinations, which then encourages women to seek further screening from a clinician (NBCF 2016).

The above facts highlight the lived reality of cancer in low-income countries and suggest the need for a deeper look at current research on cancer in such settings. Theories in anthropology and public health can shed light on why these discrepancies exist and where further research needs to unfold. These major discrepancies in cancer incidence and mortality worldwide point towards a need to examine cancer, and breast cancer specifically, at the local level in an area where the burden of disease is being overwhelmed by mortality due to a variety of reasons which will be explored in the following section.

**Cancer Care and Breast Cancer in Uganda**

Uganda currently has a population of nearly 38 million, with the majority living in rural areas (WHO 2016b). The country’s total expenditure on health accounts for less than 10% of the national GDP, while life expectancy is 57 and 61 for males and females, respectively (WHO 2016b). The top ten causes of death in Uganda are HIV/AIDS, malaria, low-respiratory infection, tuberculosis, meningitis, cardiovascular disease, cancer, diarrheal disease, road injuries, and ischemic heart disease; with cancer accounting for about 4% of all deaths (CDC 2016b). More specifically, cancer overall in Uganda accounts for about 140 per 100,000 deaths among women
across the country, with the probability of dying due to cancer being just below 10% (WHO 2016b).

Uganda’s health care sector is divided into two systems; the private health sector and the public health sector (Kavuma 2009). These two systems are then broken down further in regards to services offered, facilities established, and types of practitioners. The private health sector includes private health care practitioners, privately funded non-government organizations delivering health care services, and traditional health care practitioners dealing in natural medicine, such as herbalism and spiritualism (Kavuma 2009). The public health sector consists of government-run health care services and facilities, ranked as Village Health Teams, Health Centers II for outpatient care, Health Centers III for outpatient care and maternity wards, Health Centers IV for outpatient and inpatient care, and Referral Hospitals, that are all overseen by the Uganda Ministry of Health (Kavuma 2009, Konde-Lule et al. 2010). Referrals between and within the private and public health sectors occur on a regular basis, as each level of health care provides a certain degree of services based on location, personnel, and medicinal stock (Kavuma 2009). One of the major differences between health sectors is the cost of services; the public health sector often times being less expensive or even free of cost compared to the private health sector which always charges for their health care services (Konde-Lule et al. 2010). One major issue here, however, is that government-run health care facilities face regular shortages in medical supplies, medical personnel, and staff due to limited government funding allotted to public health care; this is especially the case in rural settings difficult to access, given that—as mentioned previously—less than 10% of the country’s total GDP is spent on health care (Konde-Lule et al. 2010, WHO 2016b).
Cancer care in Uganda is based primarily on services offered through the only specialist cancer institute located in the capital city of Kampala. The Uganda Cancer Institute (UCI), founded and supported by the Fred Hutchinson Cancer Centre, is an oncology institute attached to the National Referral Mulago Hospital, providing primarily screening services and chemotherapy and radiotherapy treatment and surgery (Ojambo 2016). One day a week, the screening and prevention clinic at UCI offers free cancer screening to all patients, as well as a free educational workshop on the definition of cancer, types of cancer, potential causes of cancer, and different treatment options available (Ojambo 2016). It is important to note that during the writing of this thesis manuscript, UCI’s only radiotherapy machine, and the only machine of this kind in all of Uganda, broke beyond repair in early April, 2016 (BBCWorld 2016). This impacts many patients’ lives, including those who were currently receiving radiotherapy and those needing radiotherapy in the near future. To date, there is still no news of replacement for the machine, which was previously donated to UCI in 1995 (BBCWorld 2016). It is further important to note that Uganda currently does not have a population-based mandatory cancer registry system; rather it has a voluntary Kampala Cancer Registry located in Kampala city center attached to Makerere University’s Department of Pathology (IACR 2016). The Kampala Cancer Registry is infrequently utilized due to cancer not being a reportable disease in Uganda and because the registry covers only Kyadondo County which includes the capital city of Kampala and certain suburbs within about 30 kilometers of the city (IACR 2016).

During a personal visit to UCI on July 10, 2015 during my field research in Uganda, I was able to speak with various UCI employees, including a clinician, health educator, and public affairs officer in order to learn most details about UCI and services offered. I learned that the screening services and cancer education workshops are provided on Wednesdays and Fridays;
with a cost of 50,000 Ugandan Shillings (equating to about 15 to 20 US Dollars) on Wednesdays, whereas Fridays’ screening is provided free of charge. People are asked to stand around the health educator while the health education sessions are completed in Luganda with interpretation in English where needed. Additionally, screening services are completed on a first-come, first-serve basis with most patients being referred from external health centers and others referring themselves based on suspicious personal health conditions. Furthermore, my visit to UCI also informed my knowledge of cancer research taking place in Uganda. Most research focuses specifically on cancer outcomes and effects of treatments from within the cancer institute rather than including external research on awareness and knowledge about the disease. Beyond UCI, cancer care and treatment are scarce across Uganda, particularly in the rural areas, according to providers at UCI. While screening services are available elsewhere, upon suspicion of a cancer diagnosis, most patients are referred to UCI for further diagnostics and treatment.

**Morbidity and Mortality of Breast Cancer in Uganda**

Current data on breast cancer in Uganda indicate that most women are diagnosed between 30 and 39 years and usually not until the disease has reached stage III (Gakwaya et al. 2008, Galukande and Kiguli-Malwadde 2010). Over the past decade, research highlights various factors contributing to the rise of breast cancer in Uganda. Late diagnosis of breast cancer is believed to be the most common factor responsible for high rates of morbidity and mortality (Gondos et al. 2005, Jemal et al. 2011, Porter 2008, Sankaranarayanan et al. 2010, Uganda Breast Cancer Working Group 2003). Late diagnosis is associated with a wide range of structural issues such as cultural, social, and economic factors that hinder a woman’s ability to seek screening, preventive, and treatment services (Porter 2008). In fact, higher rates of death due to
breast cancer in Uganda are thought to be associated with marginal health care, lack of knowledge about breast cancer, and socio-cultural barriers relating to fear or mistrust in the biomedical systems (Mwaka, Okello, and Orach 2015, Porter 2008).

Furthermore, there exists some stigma in Uganda surrounding cancer, primarily due to ignorance about the disease (Mwaka, Okello, and Orach 2015). There is also a stronger emphasis on the part of the health care sector on the provision of preventive and curative services to address other diseases such as malaria and HIV/AIDS (Furnham, Akande, and Baguma 1999, Grady 2013). Research suggests that lack of awareness about breast cancer is common among women and even health care practitioners in Uganda, therefore, contributing to limited screening and inconsistent treatment (Kiguli-Malwadde et al. 2010). Research has highlighted the need to promote screening options for breast cancer in Uganda, such as breast self-examinations, through stronger awareness campaigns by cancer support organizations and health care facilities (Galukande and Kiguli-Malwadde 2010, Uganda Breast Cancer Working Group 2003). Little research, however, has examined the existence and overall efficiency of such initiatives in Uganda (Galukande and Kiguli-Malwadde 2010, Kwesiga et al. 2015).

Limited resources exist in Uganda in regards to cancer care, especially in the rural setting. For example, in 1998 only 5% of the total cancer patients had access to the only one radiotherapy and one chemotherapy unit available in all of Uganda; this number has remained about the same throughout the past decade (Abdel-Wahab et al. 2013, Gondos et al. 2005). A study conducted by Konde-Lule and colleagues (2010) looking at health care facilities in three rural districts of Uganda, one being Mpigi District where this study took place, found that private for-profit facilities were more common throughout the three districts. They further found through household surveys that private for-profit facilities, though most common, were the least often
utilized health care centers due to high cost of medical services (Konde-Lule et al. 2010). Though their research does not look specifically at cancer care in the health care facilities they assessed, their findings demonstrate an observed structural barrier to accessing primary health care in the rural setting of Uganda. Personal observations in Uganda in 2010 further suggest that many women live long distances from any type of affordable biomedical establishment, making it difficult to travel at their own expense in order to seek preventive screening or receive biomedical treatment.

It is further important to note that over the past 25 years, more developed countries have greatly improved on their treatment methods for breast cancer due to early detection of the disease, appropriate care available, and access to such care (Jemal et al. 2011). An interesting paradox is that in low-income countries the adoption of a more “westernized” lifestyle is taking place, however, that lifestyle is not coupled with an adoption of the same development in biomedical quality and access that is found in developed countries (Parkin et al. 2010, Qian et al. 2014, Wabinga et al. 2000, Wabinga et al. 2014). Women are becoming less active, joining a sedentary workforce, delaying childbearing, and eating more “westernized” diets, all of which is hypothesized to potentially increase their risk for developing breast cancer (Porter 2008). Obesity, physical inactivity, alcohol consumption, and changes in reproductive patterns are becoming more prevalent in low-income countries, such as Uganda, but are not coinciding with “westernized” advancements in breast cancer control (Porter 2008, Qian et al. 2014, Wabinga et al. 2000, Wabinga et al. 2014, Youlden et al. 2012).

As the literature demonstrates, minimal to moderate cancer care available in Uganda is paired with structural issues such as socio-economic factors relating to late diagnosis, stigma, and lack of knowledge about breast cancer. This highlights the essential need to investigate
women’s knowledge and health-seeking behaviors before generating sufficient recommendations in cancer control and management. An on the ground assessment of women’s attitudes and behaviors related to breast cancer beyond the clinical setting can help to shed light on the reasons contributing to high breast cancer mortality and subsequently demonstrate backdrops for adequate breast cancer control in low-income resource-poor settings, such as in rural Uganda.

**Existing Qualitative Research on Breast Cancer in Uganda**

Few studies in Uganda have looked qualitatively at beliefs towards breast cancer and cancer in general. Studies that have investigated attitudes towards breast cancer routinely include only women diagnosed with the disease and are overall less robust and theoretical in nature. One study by Koon and colleagues (2013) looks specifically at outreach attempts by cancer support organizations and breast cancer survivors to assess the role of supportive partnerships in breast cancer awareness and treatment advocacy. Researchers gathered information from women about their knowledge of breast cancer through focus group discussions with women between the ages of 25 and 59, all of whom were breast cancer survivors. Qualitative results reveal that women had all heard of breast cancer before their diagnoses and had many preconceptions about the disease, including that it was painful and deadly and caused by diet, certain breastfeeding practices, familial linkages, artificial substances entering the body, and/or trauma to the breasts. Furthermore, the majority of women in this study were unaware of early detection techniques for breast cancer, such as ultrasounds, mammograms, or even breast self-examinations. Their results demonstrate that women have very little knowledge about breast cancer prior to any breast cancer diagnosis. The authors, therefore, highlight the importance of advocacy organizations and education initiatives to provide adequate culturally sensitive medical information about cancer to
women. Furthermore, they recognize the unique position of women’s cancer support groups in providing this knowledge about cancer, and breast cancer specifically, to women across Uganda through outreach and capacity building (Koon, Lehman, and Gralow 2013).

Another small-scale study conducted by Gonzaga (2013) qualitatively examines cancer experiences for women currently receiving treatment. This exploratory study recruited 12 women diagnosed with breast cancer and seeking services from the radiology department at Mulago Hospital. Gonzaga found four major themes that were prominent for the female participants: death, living, female identity, and coping. The results demonstrate that women experience challenges in relation to coping and seeking treatment, and therefore are in need of health care that goes beyond the basic biomedical cancer treatment and more towards a personalized psychosocial care. From this study, women diagnosed with breast cancer were found to experience a wide variety of psychosocial challenges, such as fearing death, trying to find the strength to live, losing their female identity if breasts were removed, and searching for coping mechanisms that would help them face their diagnoses. Qualitative data reveal that many sought religious support to help cope with their cancer outcomes and find the strength in “fighting for their life and living on” (Gonzaga 2013, 3).

A third study by Kiguli-Malwadde and colleagues (2010) investigates women’s attitudes towards mammography, the common breast cancer screening technique at Mulago Hospital. This study was cross-sectional and recruited 100 women who actively reported to the radiology department for screening services. The cross-sectional study found that women did not have adequate knowledge about breast cancer screening techniques, for 71% of women were unaware of mammograms and 75% of women believed that ultrasounds posed as a risk factor for cancer. The authors suggest that awareness campaigns demonstrate the importance of screening as a
preventive technique and, furthermore, suggest that the inclusion of men could play an integral role in disseminating this information, since men are key players in household decision-making status. In fact, they suggest that beyond the clinical realm, breast self-examinations are necessary for women in a resource-limited country, such as Uganda, and that more knowledge should be shared among women about clinical breast examinations and their use in further screening for breast cancer (Kiguli-Malwadde et al. 2010).

These three studies demonstrate the use of exploratory small-scale qualitative techniques in researching breast cancer in Uganda and provide vital information to a better understanding of breast cancer experience and knowledge in particular. However, all three studies lack a pre-clinical approach to research. The studies predominantly focus on women confirmed with a breast cancer diagnosis and those in close proximity to cancer treatment. Furthermore, their presentation of the research is not adequately supported by the qualitative information they gathered. For example, in their article, Koon and colleagues fail to provide first-hand accounts from the women they interviewed. On the other hand, although Gonzaga did provide such anecdotal evidence, the sample size was so small (12 participants), that the results cannot be generalized to the larger population. Finally, while Kiguli-Malwadde and colleagues conduct a significantly larger-scale research, they limit their study to women already within the medical setting and actively seeking preventive services. This creates a bias in the data excluding women who have had little to no association with the clinical setting in regards to breast cancer screening methods. Overall, these three studies lack a thorough description of the data gathered and do not account for women who have not been diagnosed with the disease.

In the end, their studies offer important contributions to breast cancer research, but at the same time highlight the desperate need to further investigate beliefs about or attitudes towards
breast cancer among women in general (both those who have been diagnosed and those without
cancer) before making recommendations for breast cancer control in low-income countries.
Overall, breast cancer research in Uganda lacks in rigorous qualitative frameworks and analysis
or fails to look beyond the clinical setting. More commonly, research in Uganda looks
quantitatively at occurrence of breast cancer and overall morbidity and mortality (Kingham et al.
2013). This presents a challenge in efficient breast cancer control, when women outside the
realm of cancer diagnoses and the clinical setting are not being included. Research trends remain
focused on the number of women accessing screening and treatment services and on survival
rates for women diagnosed with cancer (Coleman et al. 2008, Coleman 2009). As discussed
above, those studies conducted in clinical settings are biased towards women previously
diagnosed with breast cancer and those women actively seeking screening and treatment services

Some literature recognizes this gap in cancer research and highlights the need to examine
behaviors of women on the ground in resource-poor settings in order to better understand access
to health care and the medical decision-making patterns constrained by structural pressures
(Galukande and Kiguli-Malwadde 2010, Galukande et al. 2013, Galukande, Mirembe, and
Wabinga 2014). More specifically, a deeper look at cultural and structural barriers for women in
Uganda is pertinent to understanding current issues with breast cancer incidence, and how future
programs can be culturally appropriate and sound within the confines of social structures.
Galukande and colleagues in their study on patient delay in breast cancer management
emphasize, “Identification of underlying modifiable factors and the appropriate interventions to
mitigate prolonged delay are needed urgently” (2014, 6). Recommendations for breast cancer
care, such as screening, in low-income countries have been provided, including accurate
registries, promoting breast cancer awareness, adequate treatment centers, policy change in cancer health care, teaching breast self-examinations, and providing access to screening options (Al-Foheidi, Al-Mansour, and Ibrahim 2013). However, a rigorous examination of beliefs about breast cancer is needed to guide the design and implementation of such programs. Health-seeking behaviors in breast cancer control are key to survival and a significant step in the health care of a woman's life. Before defining suggestions for cancer control in low-income resource-poor settings, rigorous on the ground research must take place. This can best be examined through a closer look at how culture shapes individual behavior and beliefs, and how social and economic influences guide health-seeking behaviors in rural Uganda.

**Anthropology of Cancer**

Cancer is a disease not only of the person, but equally a disease of the community and society, for it places an individual at risk of losing active membership in their community, it pulls from the financial pockets of society, and it can leave a person disabled from economic and personal growth and development from within in their community. This places cancer at the forefront of anthropology and a critical examination within biocultural medical anthropology. Cancer remains “a metaphor for lack of control and degeneration as well as signifier of difference, something that is part of our body and world and yet an unacceptable occurrence” (McMullin and Weiner 2009, 3). In fact, the study of cancer sheds light on extreme cases of inequality in health care, including prevention, screening, and treatment measures across the globe, but specifically in resource-poor settings. Furthermore, as McMullin and Weiner state, this “documentation of the unequal distribution of cancer is matched by a multitude of voices engaged in exploring and understanding cancer knowledge, experience, and resources” (2009, 4).
This is where the anthropology of cancer lies; in an examination of voices and the profound cancer experience which shapes present beliefs about and attitudes towards the disease and self-awareness of the body through self-examination, as well as screening, health care access, and health-seeking behaviors. With the use of a critical medical anthropological perspective, we can better understand attitudes towards this disease, specifically breast cancer, in resource-poor settings, such as rural Uganda.

In the remainder of this section, I discuss the theoretical approaches guiding this research study. It is important to note that as a medical anthropologist looking at cancer, I approached the selection of theory throughout the building and implementation of this research study. In fact, the theoretical structure in this research is more eclectic, bridging perspectives, theories, and models which helped to shape the context of this study. With critical medical anthropology at the forefront of this research, other theoretical frameworks have helped guide the milieu and backbone of data collection and analysis. They are discussed in detail below.

**Critical Medical Anthropology**

There are multiple theories in anthropology and public health that stress the importance of understanding an individual and their health within the bounds of their structural society and culture (Potvin et al. 2005). This study adopts a theoretical framework within the context of critical medical anthropology where illness and health are situated within the confines of economic and political forces that shape meanings, beliefs, and behaviors (Baer, Singer, and Susser 2013). Health-seeking behaviors, in particular, are often defined based on an individual’s personal and collective knowledge about the world around them (Dressler 2005). In fact, Baer and colleagues note that “health is not some absolute state of being but an elastic concept that
must be evaluated in a large sociocultural context” (2013, 5). Socio-cultural theory and political economy of health recognize the human as an agent of both change and response to the structural entities such as social, political, cultural, and economic systems in place surrounding them (Baer, Singer, and Johnsen 1986, Dressler 2001, Dressler 2012, Kagawa Singer 2012, Potvin et al. 2005). Humans remain active within their cultural system, yet are equally shaped by the constant power struggles and structural barriers they face on day-to-day endeavors.

William Dressler (2005) argues that health and behavior must be deconstructed within an understanding of local culture and a definition of cultural consensus. Dressler postulates that the social and economic transformations that take place on the ground under the structural forces of these socio-economic and political factors have numerous effects on the health of people, both individually and collectively (2001, 456). For instance, he and others (Baer, Singer, and Johnsen 1986, Kagawa Singer 2012) argue that low socio-economic status plays a detrimental role in the health of an individual; and that researchers should examine why social inequality, and even structural inequality, lead to ill health. More importantly how does the structure of society which places hierarchical control over resources and access to the health care shape health outcomes of an individual? How does structure in society dictate an individual’s health-seeking behaviors and accessibility, affordability, and availability to health care? These questions are answered through a critical examination of on-the-ground beliefs and behaviors in relation to health and culture that manifest within the larger socio-economic structural components of society.

Dressler’s observations relate well with earlier assertions by Hans Baer, Merrill Singer, and John Johnsen, who stress that a critical examination of health and illness among individuals must be contextualized within power differentials and “access to and control over the basic material and non-material resources that sustain and promote life at a high level of satisfaction”
(1986, 95). Their explanation of a political economy of health involves a deeper look at control of the health care delivery system, who has that power, and how it shapes behaviors within the medical systems, such as patient decision-making patterns, doctor-patient relationships, and access to medical care (Baer, Singer, and Johnsen 1986). Singer (1989) stresses that both a macro and micro level examination of individual experience and behavior and unequal social relations are critical to understanding the social processes that exist within plural medical systems. Individual behaviors and struggles must be analyzed within and outside the health arena in order to comprehend social relationships, expressions of illness, mobilization in plural medical systems, and the capacity of control over personal health (Singer 1989). Overall, culture and health are interlocking components in the life of every individual. Such components are further constructed by socio-economic and socio-political pressures.

In fact, control is a central construct in the examination of health through the lens of critical medical anthropology. Medical anthropologists are interested in behavioral patterns related to health and illness, which in turn are “mediated by a sufferer’s subjective interpretations of the meaning of experienced symptoms” (Singer and Baer 2011, 25). This interpretation of illness experiences can be portrayed by those individuals’ first-hand experiences of a disease or also by those by-standers observing an illness or simply learning of an illness from a distance. In the end, “these interpretations are not solely idiosyncratic;” instead they demonstrate a connection to the larger society and cultural influences which shape our meaning and understanding of disease (Singer and Baer 2011, 25).

Socio-cultural theory and a political economy of health are central to the study of breast cancer within rural Uganda and also have important implications for cancer in general. This is in large part due to increasing research, as discussed earlier, which highlights that the growing rate
of breast cancer diagnoses is in direct relation to factors such as obesity, physical inactivity, alcohol consumption, and changes in reproductive patterns (Fregene and Newman 2005, Jemal et al. 2011, Parkin et al. 2010, Qian et al. 2014, Youlden et al. 2012). These factors are thought to be more evident in present day Uganda because of the adoption of more “westernized” lifestyles (Parkin et al. 2010, Porter 2008, Qian et al. 2014, Wabinga et al. 2014, Youlden et al. 2012).

Beyond personal behaviors, further research points towards the role of equity in health care in Uganda and that lack of health equity in Uganda “revolves around addressing the socio-economic differences that limit health care access for interest groups within populations” (Wooding, Nagaddya, and Nakaggwa 2012, 228). More specifically, this entails a closer look at vulnerable groups’ quality of, access to, and health financing for health care needs, especially in relation to chronic health care (Wooding, Nagaddya, and Nakaggwa 2012). A systematic review by Kiwanuka and colleagues (2008) demonstrated that poor and vulnerable groups in Uganda experience greater disease burden yet have limited access to health care services. For instance, the authors found that geographical access to health care played a major role in health outcomes as the western, eastern, and northern regions of Uganda with the poorest access to health care also have over 50% of their populations living below the poverty line (Kiwanuka et al. 2008). A more recent study looking at health equity in Uganda, found that “the distribution of health service benefits is generally to the advantage of the rich and the less needy;” showing that public hospitals are a third more likely to demonstrate adequate health benefits to patients of higher socio-economic status (Kwesiga et al. 2015, 8). In the end, socio-cultural theory and a political economy of health are necessary to examine breast cancer incidence, beliefs about cancer, and access to cancer screening and treatment services in order to better understand potential structural vulnerabilities and power differentials that cause detriments to health.
It is not enough to simply say that breast cancer incidence is on the rise due to the adoption of “westernized” lifestyles, but rather a rigorous look at power differentials, behavioral patterns, medical decision-making, and access to health care can help to critically highlight the experiences of women who adopt changes in lifestyle and behaviors. A critical component of this examination is also the study of ethnic identity and its influence on local culture, health beliefs, and behaviors in Uganda. Recent studies looking at staple foods, urinary tract infections, and cervical cancer have highlighted the important roles played by ethnic identity throughout Uganda in beliefs about health, decision-making, and behaviors (Amone 2014, Bing et al. 2014, Mwaka et al. 2014). For instance, Amone found that ethnic identities in Uganda emerge and are maintained by various staple foods throughout the country, such as the choice to regularly cook matooke, which is cooked and smashed plantain, among the Buganda Kingdom (2014). Another example is from Mwaka’s and colleagues’ study, where they found that local naming of illnesses and diseases was shaped in large part by regional ethnic identities in the eastern region of Uganda, such as the belief that tuberculosis in adults and fever and pneumonia in children were similar diseases due to their comparable symptoms, or that cervical cancer is caused by lubricants from condoms (2014). Ethnic identity and a strong connection with one’s kingdom in Uganda is thought to influence health-seeking behaviors and the transfer of knowledge about health and illness within a community (Mwaka et al. 2014). More specifically, cultural ties to one’s kingdom, also referred to as a tribe, often dictate or influence behaviors on daily accounts; from language and communication, to interpersonal relations with family and friends, to types of foods prepared and consumed, to beliefs about the spiritual world and attitudes towards one’s own health (Uganda Consulate 2011). In regards to breast cancer, it is equally as important to
acknowledge all factors of influence on a woman’s beliefs and behaviors, including both structural pressures and ethnic identity.

The use of socio-cultural theory and political economy of health model to examine beliefs about breast cancer, and cancer in general, in Uganda helps to contextualize the social, cultural, and economical control of health-seeking behaviors. In order to do this, research must adapt to a critical exploration of what Singer (1990) terms as political economy of health; where relationships between health, beliefs, and behaviors are contingent upon the political and economic structures in place within and around medical systems. Furthermore, culture and ethnic identity at the individual and group level is central to health outcomes due to individual and collective experiences with illness and disease (Dressler 2005). This is best defined through an examination of cultural domains and themes where cancer can be understood based on personal beliefs of causation and treatment.

No relevant studies have taken such a theoretical approach into account when critically examining the growing incidence of breast cancer in Uganda. This is particularly alarming since human behavior and health-seeking practices are not constructed purely by personal insight, but are consciously or sub-consciously shaped by extraneous forces from the systematic environment. In this regard, the foundation of this research study is tailored to capture cultural beliefs about cancer and breast cancer specifically for women in rural Uganda under the influence of ethnic identity and within the social, cultural, and economic pressures present in their lives. An anthropology of cancer is needed in order to elaborate on women’s health-seeking behaviors and attitudes towards cancerous diseases, such as breast cancer, amid cultural and structural contexts that dictate behaviors and beliefs. Furthermore, an exploratory look at breast cancer beliefs and attitudes held not only by women diagnosed with the disease but also by all
women potentially vulnerable to the disease is necessary in order to holistically understand the effects of breast cancer, and cancer in general, in low-income resource-poor settings.

**Health Belief Model**

In addition to a critical medical anthropological perspective, there is need to tap into a well-renowned theoretical model in public health; the Health Belief Model. This model poses a framework for the overall development of research looking at health-seeking behaviors and attitudes towards disease. In fact, the Health Belief Model situates exploratory research within the psychosocial context of one’s lived experience and health realities by examining perceived susceptibility and severity of a disease, as well as perceived barriers to health care and one’s self-efficacy (Coreil 2009, NCI 2005). In its totality, the Health Belief Model recognizes an individual’s “decision to take action to protect one’s health;” a decision that is based on perceptions of susceptibility, severity, benefits, and barriers (Coreil 2009, 76-77). Perceptions of health and ill health dictate actions planned and implemented by an individual and therefore shape health outcomes.

The utilization of health care services is key in regards to the Health Belief Model. “Patient characteristics and behavior, provider characteristics and behavior, and health system factors” build the context within which health outcomes are shaped (Coreil 2009, 97). Furthermore, these factors that define one’s health also mold and are molded by external issues related to health, such as economic stability or socio-economic status. In fact, there is a linear relationship between socio-economic status and health outcomes which governs access to health care, both physically and emotionally (Coreil 2009, NCI 2005). Medical anthropology acknowledges the direct connection between disparities in health and health behaviors, and
recognizes that individual behavior is held in connection with the larger overarching structure of society; this includes social and economic inequality, environmental risk, and political power (Singer and Baer 2011). How an individual perceives their susceptibility to illness, shaped by an understanding of the body and the surrounding environment, and barriers to access health care in turn produces behaviors and health outcomes.

One recent study looking at Korean American immigrant women’s breast cancer screening practices utilized the Health Belief Model focusing on access to screening (Lee, Stange, and Ahluwalia 2015). This study demonstrated that women’s perceived barriers to accessing clinical breast examinations hindered their actual access to or adherence to such screening services; that alternately “having a mammogram increased when women had lower barriers to screening and greater confidence in screening” (Lee, Stange, and Ahluwalia 2015, 455). In fact, the study highlights that perceived control over one’s ability to take action in screening measures and perceived beliefs about cancer weighted heavily on a woman’s access to health care (Lee, Stange, and Ahluwalia 2015). Another recent study by Wang and colleagues (2014) used the Health Belief Model to look at factors affecting regular mammography screening among Eastern Taiwan women. The results indicate that delayed or no clinical breast cancer screening was not due to a lack in knowledge about breast cancer, but rather was shaped by perceived susceptibility and seriousness of the disease. This study demonstrated the barriers to screening resided in perception of the disease and benefits of such screening, as well as available time and emotional distress (Wang et al. 2014). Overall, these studies demonstrate the critical role the Health Belief Model plays in better understanding women’s perceptions towards cancer and how those attitudes define behavior and barriers to accessing health care.
Again the construct of control is prevalent in this context and the use of the Health Belief Model. Control over one’s bodily actions and health outcomes is dictated by external forces from society, but equally by perceived risk, benefits, and barriers. In fact, the molding of critical medical anthropology with the Health Belief Model can recognize that “individual and group decision-making and action, are ‘constructed and reconstructed in the action arena between socially constituted categories of meaning and the political-economic forces that shape the context of daily life’” (Baer, Singer, and Susser 2013, 44, Singer and Baer 2011, 40).

These two theoretical frameworks and the plethora of sub-frameworks that make up critical medical anthropology are paramount in the study of cancer, specifically breast cancer, in resource-poor settings. Examining perception towards disease and how that perception is dually shaped by structural issues such as social constructs and economic stability, which in turn dictate behavior, is key in better understanding health outcomes, health-seeking behaviors, and medical decision-making patterns. This is especially important in regards to a chronic disease, such as cancer, on the rise in low-income countries. What are attitudes towards the disease, and how are such perceptions shaped by external forces in society? Only through the lens of critical medical anthropology, taking into account the “bio-socio-cultural interactions that impact health” (Singer & Erickson 2013:25) and the use of the Health Belief Model can a clearer understanding of cancer, specifically breast cancer, unfold within a rural setting of Uganda.
CHAPTER THREE: METHODS

Current research on cancer, specifically breast cancer, in Uganda focuses primarily on quantitative data or captures perspectives of the disease mostly from a clinical setting with participation of individuals already diagnosed with breast cancer and readily accessing treatment services. A qualitative applied anthropological approach to data collection is especially useful when looking at attitudes towards a chronic disease, general health-seeking behaviors, and access to screening and treatment services in rural settings. In this study, beliefs about cancer, with specific attention to breast cancer, and access to basic health care services and cancer screening are brought to light through in-depth interviews and focus groups with women and semi-structured interviews with health care personnel from both a government and private health care facility, all within the setting of rural Nakirebe, Uganda.

Participants included 45 women (18 years of age and older), as well as five health care personnel, all from or nearby Nakirebe within Mpigi District of Uganda. This rural area offered a unique setting to capture the perspectives of breast cancer from women who face challenges to acquire adequate health care. Nakirebe is situated about 25 kilometers from Kampala where the Uganda Cancer Institute is located. Based on preliminary observations, the general population is underserved in regards to biomedical health care services, as the majority of health centers are either understaffed or undersupplied with necessary medical equipment. Women face challenges traveling the long distance to Kampala in order to receive any type of comprehensive cancer care, whether it be screening or treatment services. This study demonstrates the importance of
assessing the services which are available to these women in their rural setting, along with their general beliefs about and attitudes towards cancer, specifically breast cancer.

**Partnership with International Health Sciences University (IHSU)**

This research was proposed and implemented through collaboration with International Health Sciences University (IHSU). IHSU is located in the capital city of Kampala and was established in 2008. The University is fully licensed by the Uganda National Council for Higher Education and Serves as a leader in training health care professionals and health care researchers. I first came in contact with IHSU through two mentors from my undergraduate education at The University of Montana in Missoula, Montana. After learning about the work IHSU has done in health care service throughout Uganda over the past seven years, I knew this institution would serve as an essential stakeholder in the conduct of my research.

My partnership with IHSU was established through the collaboration with their research unit lead, Teddy Nagaddya, MA. This research received approval through both the University of South Florida’s Institutional Review Board and IHSU’s Institutional Review Board. My partnership with IHSU was established under the terms of being an international researcher in need of local oversight. Additional research staff from IHSU were recruited to assist with entry into the rural community of Nakirebe, as well as translation purposes during the collection of data. Four research personnel from IHSU assisted with building the interview guides and conducting the interviews and focus groups. Each research personnel was compensated for their time through IHSU based on an international research fee I paid to the University for rendering their services.
Recruitment

The 35 women who participated in the in-depth interviews and focus groups were recruited through the Local Chairman (LC) and Vice LC within Nakirebe. Prior to conducting interviews, I, along with research staff from IHSU, visited Nakirebe to meet with the LC, the head chairman in-charge acting as the gatekeeper into the community. Upon meeting with the LC, we were able to engage in conversations about the community and learn of specific demographics unique to the area (detailed in Chapter One). After concluding our meeting, the LC gave us permission to enter the community at later dates in order to meet with women to conduct interviews and focus groups. He also connected us with the Vice LC, who became integral to the recruitment process on each day of the interviews and focus groups. When returning to Nakirebe on the days of the interviews, the Vice LC assisted IHSU research staff and me in connecting with women in the village and asking their permission to be interviewed. The Vice LC knew of women who were currently available to be interviewed during the day and time we were in Nakirebe and lead IHSU staff and me to each woman and provided an introduction that allowed us to proceed with explaining the study and their position as a potential participant. The Vice LC acted as gatekeeper for this study and played a central role in gaining trust from the community members, as well as identifying community members who would potentially participate in the study. Regarding specifically the 10 women who participated in the two focus groups, the Vice LC helped to inform women, who had not previously completed in-depth interviews, of the opportunity to participate in a focus group and assessed their interest in taking part in the study. On these occasions, the Vice LC asked 10 women he previously found to be interested in participating in the focus groups to meet me and IHSU research staff on the day of conducting the focus groups.
After completion of the 35 in-depth interviews and two focus groups with 10 women from Nakirebe, data were initially analyzed in order to determine the most frequently preferred health care facilities for basic health care within the area by the women interviewed. Preliminary findings revealed that the majority of women visited either a local government-run health center or a local private health center within Mpigi District for their basic health care needs. Names of these two facilities will not be revealed in order to protect the identity of health care personnel interviewed at these locations. Based on this information, contact was made with an administrator at the Ministry of Health in Mpigi District to obtain permission to visit these two local health care facilities nearby Nakirebe in order to identify health care personnel to be interviewed. The administrator subsequently agreed to participate in an interview regarding cancer-related health care services offered in Mpigi District.

Data Collection

In-depth interviews were conducted in both English and Luganda with 35 women from Nakirebe. I conducted all interviews lead in English, while interviews lead in Luganda were conducted by a research staff member from IHSU. The in-depth interviews were outlined to measure personal beliefs of breast cancer including causation, screening, diagnosis, biomedical treatment, alternative treatment, risk reduction, support, and stigma, and access to screening and treatment services, and overall health-seeking behaviors (See Appendix A and B for the in-depth interview instruments in English and Luganda). Prior to each interview, participants were provided an informed consent document in their preferred language and given the opportunity to ask questions about the study before consenting. After completing the interviews, each woman was provided with 5,000 Ugandan Shillings, equivalent to two to three US Dollars, for
compensation of their time. Each interview lasted between 30 to 60 minutes and took place in Nakirebe at a location convenient for the participant, most commonly outside her home or workspace on an open veranda. During each interview, detailed notes were taken by the interviewer. Interviews specifically conducted in Luganda were translated into English at the time of the interview by the research staff member from IHSU who conducted the interview. One-on-one interviews with female participants were not able to be tape-recorded due to limited resources of tape-recorder equipment at the time of the interviews.

Two focus groups were subsequently conducted in both English and Luganda with 10 women from Nakirebe who did not complete a semi-structured interview (n= 5 each). I conducted and lead both focus groups in English and was assisted by research staff from IHSU for translation into and out of Luganda throughout discussion. Most of the women in the focus groups could only speak minimal English, therefore, needed frequent translation into Luganda. Both focus groups took place in the house of one of the female participants who volunteered her living space for the day. Women recruited to participate in the focus groups were provided with an informed consent document in their preferred language and given the opportunity to ask questions about the study prior to consenting. Upon receiving signed informed consent, the women were asked to engage in discussion on various questions. The focus groups were outlined to further explore beliefs about breast cancer and suggestions for community-based breast cancer awareness initiatives and development programs for breast cancer screening and treatment (See Appendix C for the focus group instrument). The first focus group took place in the morning and lasted about 45 minutes. After a 20 minute break, the second focus group took place in the same location and lasted about 30 minutes. Both focus groups were tape-recorded and
transcribed in English. After completing the focus groups, each woman was offered 5,000 Ugandan Shillings, equivalent to two to three US Dollars, for compensation of their time.

Lastly, semi-structured interviews were conducted with five health care providers working at a government health care facility and a private health care facility nearby Nakirebe to explore their perceptions of health-seeking behaviors among women in the cancer screening and treatment setting, as well as of general perceptions of breast cancer and health care services offered to women in the area (See Appendix D for the semi-structured interview instrument). Health care personnel were provided the opportunity to ask questions about the study and given an informed consent document to review and sign prior to completing each interview. I conducted four interviews in English, while one interview was conducted in English by an IHSU research staff member. Each interview was tape-recorded and lasted between 20 to 30 minutes and was conducted in or nearby the office of the health care provider at their respective health care facility.

Upon completion of all data collection, IHSU research staff and I returned to Nakirebe at a later date to conduct a workshop on cancer. This workshop was organized and implemented after hearing from the majority of female participants that they would like to receive more information about cancer; information to which IHSU research staff and I had access to through internet and libraries on campus in Kampala. Further details of the workshop and results are explained thoroughly in the following chapter presenting the results from this study.

**Data Analysis**

Data from interviews and focus groups originally gathered in Luganda were translated into English at the time of the interviews and focus groups by IHSU research staff. I further
transcribed that data into Microsoft Word for preliminary analysis. Data were then analyzed using two software programs specializing in qualitative and quantitative research analysis. SPSS version 23 was used to analyze data from the in-depth interviews with the 35 women. Though the majority of information gathered during these interviews was more qualitative in nature, certain questions, primarily those regarding demographics, presented important quantitative findings. Demographic questions and “yes” or “no” response questions were coded in SPSS based on the grouping of answers. Frequencies were then pulled to determine occurrence and percentages of responses.

MAXQDA 12.0.2 was subsequently used to code for themes from all three groups of interviews conducted in this study. Data from the in-depth interviews and two focus groups with women, along with the five semi-structured interviews with health care providers were uploaded to MAXQDA. Themes were coded from each interview based on redundancy, consistency, and saturation. A plethora of themes were revealed which were then condensed based on overarching ideas. These findings were then exported to excel format in order to cluster themes for write-up.

Final analysis of the data, both qualitative and quantitative, is based on connections back to the current literature. A critical discussion of these connections is presented in Chapter Five. Finally, in Chapter Six recommendations related to cancer control and management are made based on the overall analysis of the study’s findings.

Ethical Considerations

Potential risks of this study relate to protection of confidentiality and perceived coercion. Female participants were selected through direct contact with the Vice Local Chairman (LC), as discussed in the previous section on recruitment. This process entailed the Vice LC approaching
women in the community and introducing me and IHSU research staff. Though women were
given the opportunity to resist participation in the study, the possibility for perceived coercion
from the Vice LC could have influenced their decisions to accept participation. Furthermore, this
poses lack of confidentiality, where the participant is no longer anonymous by way of the
community. Though her information remains anonymous, her position as a participant in a
research study is known by leaders within the community.

Several measures were put in place to protect the privacy of all participants, as well as the
right to choose participation for all participants. In order to abide by ethical conduct, three
primary principles were taken into account at every stage of the research: respect for persons,
beneficence, and justice (Whiteford and Trotter II 2008). Specifically, respect for persons
entailed the assurance that participation was voluntary, that participants’ information was kept
confidential, and that participants were provided with an informed consent document in their
preferred language for their review and approval prior to participating in the study.

The overall objectives of this research, seek to provide adequate information to key
stakeholders in cancer care, and specifically breast cancer care, in rural Uganda in order to
improve the livelihoods of women seeking screening or treatment for cancer. The intentions of
this research abided by the guidelines of beneficence and do no harm to the participants
throughout all stages of data collection by respecting participants’ decisions. For example, when
a participant chose to skip a question during an interview, their decision to do so was respected
in order to ensure their well-being. Though this did not take place, if a participant had chosen to
withdraw from the study, his or her decision to do so would have been respected, also to ensure
their autonomy and right to choose. Lastly, the research was conducted in a manner that was fair
and equitable to all participants in the study. For instance, each participant received equal incentive compensation for their time.

In order to abide by the above ethical conduct, if issues were to arise, guidelines set forth by Whiteford and Trotter (2008) in *Ethics for Anthropological Research and Practice* were followed to ensure supported ethical problem-solving. Such problem solving techniques include six steps: determining the facts of the research case, identifying values at risk, describing primary ethical dilemmas, determining possible courses of action, choosing one specific course of action, and defending that course of action (Whiteford and Trotter II 2008, 98). Throughout the course of this research, all measures were taken into account to ensure ethical conduct and the protection of all participants who provided key insight into the important subject matter of cancer in rural Uganda.

**Positionality**

Prior to this field research, I lived in Uganda, specifically within the Buganda Kingdom, during the year 2010. During this time, I engaged in local community research and outreach programs throughout Mpigi District in partnership with a non-government organization, PROMETRA Uganda. At that time I was a young single woman from the United States who was new to the country and willing to learn about and engage in a variety of cultural norms and traditions. I was an aspiring anthropologist, having just completed my bachelor’s degree at the University of Montana. During this time in Uganda, I learned a great deal about the Buganda Kingdom, including standard greetings and important cultural values.

My position as a young white woman in a low-income Eastern African country presented with it some intriguing intersections of reflexivity and cultural relativism. I was challenged to
adapt to and adopt a set of customs that were unfamiliar to me having grown up in the United States. As a freshly trained anthropologist, I was placed in a position to demonstrate reflexivity in my personal values and beliefs, as well as actions. It was time for me to reflect upon my previous teachings. One book in particular which shaped much of how I see the interactions of two cultures, Anne Fadiman’s book (2012) *The Spirit Catches You and You Fall Down*, remained with me during my first trip to Uganda and guided my approach in cross-cultural interactions and understandings.

When returning to Uganda for three months in 2015 to conduct my thesis research, presented in this manuscript, I was a slightly older woman, now married to a Ugandan man from the Buganda Kingdom. This position shaped my experience and the way I was perceived by the women and men I worked with and interviewed. I had spent the previous four years married to a Ugandan man learning, as well as experiencing in-depth, values, customs, and traditions of the Buganda Kingdom. My cultural relativism was now partially from the eyes of an insider in closer proximity to the local traditions and beliefs of a Ugandan culture. Even my language skills in Luganda, the main dialect of the Buganda Kingdom, advanced to some degree beyond standard greetings; still not to the fluency I desired, but I could capture certain words and phrases in written and spoken Luganda. My own spoken Luganda, however, was still broken and to this day remains in need of dire practice.

Overall, my history with Uganda, specifically the Buganda Kingdom, provided me an unforeseen higher position of respect from local women and men whom I encountered in this study, for they often saw me as an insider of a Ugandan culture and more accepting of the information they were providing me. For instance, the Buganda Kingdom values customs and norms, humility, pride, kindness, and respect; these values I demonstrated throughout my time in
Uganda while conducting my research. It is important to note, however, that my closer relativity to Ugandan culture and the Buganda Kingdom brought with it some frustrations. Since I had been married to a Ugandan man years prior, I was expected to be fluent in Luganda by the standards of most people I encountered. Other times, I was expected to have already bore children, as that is part of the responsibility of a Buganda woman. The frustration came when the knowledge of my marriage to a Ugandan man surfaced, people were both elated of the news, but then equally filled with assumptions that my position meant I was both fluent in Luganda and a mother of a “mixed-up” baby. Participants who learned of my true history—that I am married to a Ugandan man, but am not fluent in Luganda nor have children at this time—were quick to show excitement at my marital status, but equally quick to question what the future holds for myself and my husband and our unborn children. In the end, my lack of fluency in Luganda played the most limiting role in the amount of data I could collect from participants. On the other hand, my history with Uganda and relativity to the Buganda Kingdom mitigated women’s hesitancy to inform me of their knowledge of cancer during interviews. Overall, women could trust me by recognizing I was not just another outsider conducting research, never to return again.

Not only was my position as a married woman to a Ugandan man and as a veteran of previous research in Uganda part of what shaped this study and its overall success, but also I was trained in medical anthropology and public/global health. I still carried with me the teachings from Fadiman on cross-cultural understanding; but this time I was also well-versed in global health practice and a critical understanding of health and disease at the intersections of both biological and socio-cultural phenomena. I was able to demonstrate an understanding of local
cultural perspectives interacting with broader social, cultural, and economic frameworks in society which make-up the lens of critical medical anthropology (Singer and Erickson 2013).
CHAPTER FOUR: RESULTS

This research study explored women’s attitudes towards and beliefs about cancer, with specific attention to breast cancer, in a rural setting of Uganda called Nakirebe. This study also examined these same women’s basic health-seeking behaviors and health care decision-making patterns within their community. Subsequently, health care providers from two health care facilities nearby Nakirebe were interviewed to learn about cancer care services provided to this community and suggestions for strengthening cancer awareness and cancer control. This chapter presents the comprehensive findings of the study, including the in-depth interviews and focus groups with women and semi-structured interviews with health care providers. This chapter is divided into five overarching sections: one section, with seven sub-sections highlighting major themes, reports on findings from the in-depth interviews, one section presents on data from the focus groups, another section focuses on the semi-structured interviews with health care providers, one section draws upon conclusions of the overall results, and a final section details the workshop on cancer that was conducted post data collection.

In-Depth Interview Results

Demographics

A total of 35 women participated in in-depth interviews that explored basic health-seeking behaviors and attitudes towards breast cancer. Most (n=30) of the participating women were between the ages of 18 and 34 years, ranging in age from between 18 to 70 years. The
average age of all 35 female participants in this study was 28 years. A little over half of the women (n=19) lived in Nakirebe between one to five years. About half the participants (n=18) self-identified as Catholics and over half of the women (n=21) were from the Buganda Kingdom in Uganda. About half the women (n=18) were either married to or cohabitating with a male partner, while six women were in a relationship but not living with their male partner. Over a quarter of the women (n=11) had only one biological child, while nearly half of the women (n=16) had between two to four biological children. Ten women total were caring for at least one child less than one year old, while 12 women were caring for at least one child between the ages of one to three years old. A little less than half of the women (n=14) were breastfeeding at the time of this study. (See Table 1 on page 51).

In regards to education levels of the participants, over half of the women (n=20) reached secondary school, which is the equivalent of high school in the United States; though many of these women did not graduate from secondary school but only completed senior four, which is equivalent to sophomore year in high school. A total of 24 women were working for financial gain at the time of this study, with half of these women (n=12) managing self-employment, such as selling crops from their gardens, tailoring clothes, or styling hair. The second most common form of employment for these women (n=6) was school teaching. A little over half of the women (n=19) who were working earned a monthly income of between 1,000 and 300,000 Ugandan Shillings. This is equivalent to an average of about 50 to 60 US Dollars per month, depending on the current exchange rate which fluctuates often between 2,500 and 3,000 Ugandan Shillings for every one US Dollar. Only one working woman was making more than 500,000 Ugandan Shillings per month, equivalent to an average of greater than about 165 US Dollars. (See Table 2 on page 52).
Of all the participants, 24 women mentioned that their male partner makes a steady income every month. A variety of occupations were reported, including self-employment, mechanic and carpentry work, full-time driving, security guard, teaching, engineering, and real estate. When women were asked how many Ugandan Shillings their partners earned in one month, a third of the women (n=11) did not know their male partners’ income. Most women attributed this to the fact that their partner does not share that information with them or further does not share tangible monetary benefits with them. Of the women who were able to relay their partners’ monthly income, only five said it was greater than 500,000 Ugandan Shillings and six women said it was between 1,000 and 300,000 Ugandan Shillings each month. This equates to an average of over 165 US Dollars monthly and an average of about 50 to 60 US Dollars per month, respectively. Overall, most women who had a working male partner, whether or not they lived with them, were unable to relay their partners’ monthly income or were not provided tangible access to their partners’ monthly monetary benefits. (See Table 2 on page 52).

When women were asked about estimated household income per month, a wide range of earnings between 1,000 to 500,000 Ugandan Shillings (an average of about 80 to 100 US Dollars) were mentioned, with some women (n=6) mentioning above 500,000 Ugandan Shillings (an average of no less than 165 US Dollars) each month. Of all the participants, 14 women could not estimate the average income of their household. This mostly included women with male partners who were unwilling to communicate and/or share their monetary benefits with them. Six women noted that their average household income was between 1,000 to 200,000 Ugandan Shillings monthly (an average of about 30 to 40 US Dollars monthly), while nine women said their average household income was between 201,000 to 500,000 Ugandan Shillings every month (an average of about 115 to 140 US Dollars). Finally, when women were asked about the
average monthly finances spent on health care for their household, a quarter of the women (n=9) said they spend more than 50,000 Ugandan Shillings each month (an average of more than 15 US Dollars each month). Over half of the women (n=22) estimated they spend between 1,000 to 50,000 Ugandan Shillings each month (an average of about eight to 10 US Dollars each month) on health care expenses whether for themselves or for their children. (See Table 2 on page 52).

One participant, 21 years of age with a four month old baby, addressed the financial burden of health care and the consistent spending of about 20,000 Ugandan Shillings (an average of at least six US Dollars) each month on health care “because we always get sick.” She was most commonly referring to becoming ill with malaria and high fevers. Some women even went as far as briefly highlighting further expenses that pull from their monthly and household incomes, such as food expenses, educational bills for the children, and transportation fees.

Only four women were unable to recall their monthly health care expenses. This was partially attributed again to the fact that the male partners did not disclose their personal income, yet maintained the majority of control over household finances. One participant, 30 years old with four biological children, explained after being asked how much was the estimated household income and how much they spend on health care services each month:

*I don’t know because in most cases I get treatment on loan and my partner pays at a later date, so I don’t know how much is spent per month.*

Similarly, another married participant in her early 30s also with four children addressed the issue of not knowing her estimated household income or not being able to indicate how much money was spent on health care each month:

*My husband buys everything in the house. It is hard for him to give me hard cash. When the children fall sick, he goes with me to the hospital and clears the bill without giving me any money. I don’t know [how much money is spent on health care] because whenever I fall sick or the children [fall sick], he takes us to the clinic himself or he directs us to go to the clinic, and he settles the bill later.*
Table 1: Socio-Demographic Characteristics of the Study Sample (n=35)

<table>
<thead>
<tr>
<th>VARIABLE</th>
<th>FREQUENCY</th>
<th>PERCENTAGE (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-24</td>
<td>14</td>
<td>40.0</td>
</tr>
<tr>
<td>25-34</td>
<td>16</td>
<td>45.7</td>
</tr>
<tr>
<td>35-44</td>
<td>4</td>
<td>11.4</td>
</tr>
<tr>
<td>≥ 45</td>
<td>1</td>
<td>2.9</td>
</tr>
<tr>
<td><strong>Time Living in Nakirebe</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤ 12 months</td>
<td>10</td>
<td>28.6</td>
</tr>
<tr>
<td>13 months to 5 years</td>
<td>19</td>
<td>54.3</td>
</tr>
<tr>
<td>61 months to 10 years</td>
<td>3</td>
<td>8.6</td>
</tr>
<tr>
<td>≥ 11 years</td>
<td>3</td>
<td>8.6</td>
</tr>
<tr>
<td><strong>Religion</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Catholic</td>
<td>18</td>
<td>51.4</td>
</tr>
<tr>
<td>Protestant</td>
<td>8</td>
<td>22.9</td>
</tr>
<tr>
<td>Muslim</td>
<td>3</td>
<td>8.6</td>
</tr>
<tr>
<td>Pentecostal</td>
<td>5</td>
<td>14.3</td>
</tr>
<tr>
<td>SDA/Others</td>
<td>1</td>
<td>2.9</td>
</tr>
<tr>
<td><strong>Tribal Affiliation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Buganda</td>
<td>21</td>
<td>60.0</td>
</tr>
<tr>
<td>Minyankoli</td>
<td>3</td>
<td>8.9</td>
</tr>
<tr>
<td>Minyarwanda</td>
<td>4</td>
<td>11.4</td>
</tr>
<tr>
<td>Busega</td>
<td>2</td>
<td>5.7</td>
</tr>
<tr>
<td>Mugishu</td>
<td>2</td>
<td>5.7</td>
</tr>
<tr>
<td>Atole</td>
<td>1</td>
<td>2.9</td>
</tr>
<tr>
<td>Mugwere</td>
<td>1</td>
<td>2.9</td>
</tr>
<tr>
<td>Meso</td>
<td>1</td>
<td>2.9</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>5</td>
<td>14.3</td>
</tr>
<tr>
<td>Married/Cohabiting</td>
<td>18</td>
<td>51.4</td>
</tr>
<tr>
<td>Divorced/Separated</td>
<td>4</td>
<td>11.4</td>
</tr>
<tr>
<td>Widowed</td>
<td>2</td>
<td>5.7</td>
</tr>
<tr>
<td>In a Relationship</td>
<td>6</td>
<td>17.1</td>
</tr>
<tr>
<td><strong># of Biological Children</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>One child</td>
<td>11</td>
<td>31.4</td>
</tr>
<tr>
<td>Two children</td>
<td>9</td>
<td>25.7</td>
</tr>
<tr>
<td>Three children</td>
<td>2</td>
<td>5.7</td>
</tr>
<tr>
<td>Four children</td>
<td>5</td>
<td>14.3</td>
</tr>
<tr>
<td>Six children</td>
<td>1</td>
<td>2.9</td>
</tr>
<tr>
<td>Nine children</td>
<td>1</td>
<td>2.9</td>
</tr>
<tr>
<td>No biological children</td>
<td>6</td>
<td>17.1</td>
</tr>
<tr>
<td><strong>Currently Breastfeeding</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>14</td>
<td>40.0</td>
</tr>
<tr>
<td>No</td>
<td>21</td>
<td>60.0</td>
</tr>
</tbody>
</table>
### Table 2: Socio-Economic Characteristics of the Study Sample (n=35)

<table>
<thead>
<tr>
<th>VARIABLE</th>
<th>FREQUENCY</th>
<th>PERCENTAGE (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Highest Level of Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No schooling</td>
<td>1</td>
<td>2.9</td>
</tr>
<tr>
<td>Primary school</td>
<td>9</td>
<td>25.7</td>
</tr>
<tr>
<td>Secondary school</td>
<td>20</td>
<td>57.1</td>
</tr>
<tr>
<td>Tertiary (University)</td>
<td>2</td>
<td>5.7</td>
</tr>
<tr>
<td>Vocational</td>
<td>3</td>
<td>8.6</td>
</tr>
<tr>
<td><strong>Women’s Monthly Financial Earnings</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1,000-100,000 UGX</td>
<td>7</td>
<td>20.0</td>
</tr>
<tr>
<td>101,000-200,000 UGX</td>
<td>8</td>
<td>22.9</td>
</tr>
<tr>
<td>201,000-300,000 UGX</td>
<td>4</td>
<td>11.4</td>
</tr>
<tr>
<td>301,000-400,000 UGX</td>
<td>2</td>
<td>5.7</td>
</tr>
<tr>
<td>401,000-500,000 UGX</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>≥ 501,000 UGX</td>
<td>1</td>
<td>2.9</td>
</tr>
<tr>
<td>Cannot estimate due to inconsistent income</td>
<td>2</td>
<td>5.7</td>
</tr>
<tr>
<td>No personal monthly income</td>
<td>11</td>
<td>31.4</td>
</tr>
<tr>
<td><strong>Male Partners’ Monthly Financial Earnings</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1,000-100,000 UGX</td>
<td>1</td>
<td>2.9</td>
</tr>
<tr>
<td>101,000-200,000 UGX</td>
<td>4</td>
<td>11.4</td>
</tr>
<tr>
<td>201,000-300,000 UGX</td>
<td>1</td>
<td>2.9</td>
</tr>
<tr>
<td>301,000-400,000 UGX</td>
<td>1</td>
<td>2.9</td>
</tr>
<tr>
<td>401,000-500,000 UGX</td>
<td>1</td>
<td>2.9</td>
</tr>
<tr>
<td>≥ 501,000 UGX</td>
<td>5</td>
<td>14.3</td>
</tr>
<tr>
<td>Does not know partner’s monthly income</td>
<td>11</td>
<td>31.4</td>
</tr>
<tr>
<td>Does not have a steady partner (i.e., single or in a relationship)</td>
<td>11</td>
<td>31.4</td>
</tr>
<tr>
<td><strong>Overall Estimated Household Income per Month</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1,000-100,000 UGX</td>
<td>2</td>
<td>5.7</td>
</tr>
<tr>
<td>101,000-200,000 UGX</td>
<td>4</td>
<td>11.4</td>
</tr>
<tr>
<td>201,000-300,000 UGX</td>
<td>5</td>
<td>14.3</td>
</tr>
<tr>
<td>301,000-400,000 UGX</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>401,000-500,000 UGX</td>
<td>4</td>
<td>11.4</td>
</tr>
<tr>
<td>≥ 501,000 UGX</td>
<td>6</td>
<td>17.1</td>
</tr>
<tr>
<td>Cannot estimate monthly household income</td>
<td>14</td>
<td>40.0</td>
</tr>
<tr>
<td><strong>Household Expenditure on Health Care per Month</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1,000-10,000 UGX</td>
<td>3</td>
<td>8.6</td>
</tr>
<tr>
<td>11,000-20,000 UGX</td>
<td>4</td>
<td>11.4</td>
</tr>
<tr>
<td>21,000-30,000 UGX</td>
<td>6</td>
<td>17.1</td>
</tr>
<tr>
<td>31,000-40,000 UGX</td>
<td>4</td>
<td>11.4</td>
</tr>
<tr>
<td>41,000-50,000 UGX</td>
<td>5</td>
<td>14.3</td>
</tr>
<tr>
<td>≥ 51,000 UGX</td>
<td>9</td>
<td>25.7</td>
</tr>
<tr>
<td>Cannot estimate household expenditure on health care</td>
<td>4</td>
<td>11.4</td>
</tr>
</tbody>
</table>
Health-Seeking Behaviors

Information was further gathered on basic health-seeking behaviors. The same 35 women were asked a variety of questions about the most common health care facility they visit, looking at issues of transportation, reasons for selecting such facility, number of visits over the previous six months, and whether she has ever been screened for breast cancer at this health care facility.

When asked which type of health care facility the women prefer to receive basic health care services for common illnesses, nearly half of the women (n=17) said they prefer to visit a private health care facility nearby Nakirebe. The second most commonly preferred type of health care facility by the women was government-run health care facilities (n=15). Only a couple women said they prefer to only go to a pharmacy or local drug shop, while one woman said she prefers to self-medicate. When asked for the specific health care facility the women tend to choose first for managing their basic health care needs, two facilities were more commonly mentioned by the women, one was a private health care facility that has about 5 regular health care staff on site who commonly provide outpatient care but also administer prenatal and delivery services, and the other was a government-run health care facility consisting of more than 10 regular health care staff members and provides both outpatient and inpatient care, as well as is equipped with a large maternity ward. Of these two facilities, the private health center is closer to Nakirebe, yet has higher rates for medical fees. The third most commonly mentioned health care facility was another government-run health care center, a smaller health care clinic with about 4 regular health care staff members and is located in the center of Nakirebe providing only outpatient care primarily for HIV/AIDS and malaria treatment, though is also equipped with a small delivery room.
When the women were asked why they chose their respective health care facility for managing their basic health care, a majority of the women (n=15) responded that patient care is good, meaning the medical staff treat them with respect and care for their well-being. A 32 year old woman explained:

*My doctor is very good because he is patient with me, as I always have so many questions to ask. He talks nicely to me and will always give me good advice about my condition, and if I follow his advice, I get better.*

Equally important were the less expensive health care services offered at their chosen facilities; this being a determining factor for many women (n=9) in deciding where to seek basic health care. Not surprising, most of the women who mentioned the government-run health care facility as their commonly utilized facility for basic health care needs, subsequently mentioned this was because of the cheaper expenses involved. Other reasons for choosing their preferred health care facility included the nearby accessibility of the health care facility (n=7), the trustworthiness of the facility (n=1), and the fact that the particular facility was the only health care center with which they were familiar with in the area (n=2). A 30 year old woman with two children below nine years stated:

*It’s close to where I live, the health workers are warm and the cost of treatment is affordable. At times if you do not have ready cash, they can loan you the medicine.*

On average the majority of women (n=19) traveled between two to five kilometers to reach their preferred health care facility. Most of the women said they utilize public transportation, such as a taxi-van, to reach their preferred health care facility. Sometimes women even had to use both a taxi-van and a boda boda in order to reach the facility. Boda bodas are privately run taxi motorcycles commonly used throughout Uganda and vary in cost based on negotiations made with the driver before transit, though an average cost for a one to three kilometer ride would be about 3,000 to 5,000 Ugandan Shillings. They typically cost more than
the taxi-van, since taxi-vans tend to have consistent fares depending on the distance, averaging anywhere from 500 to maybe 3,000 Ugandan Shillings when traveling about one to three kilometers. Boda bodas are able to reach destinations faster, yet can be much riskier modes of transportation. Walking was also addressed as a common form of transportation for most of these women. Often times women will still need to walk a certain distance in order to reach a taxi-van and/or boda boda station or reach the health care facility from the point at which the taxi-van or boda boda drops them off. Overall, the women said it often takes between 30 to 60 minutes to reach their preferred health care facility from their home; again traveling at least some distance on foot, then paying for either a taxi-van or boda boda.

When asked how often the women had visited their preferred health care facility within the six months prior to the time they completed their interview, about a third of the women (n=10) said they had to visit the health center three times during that period. This was commonly due to feeling ill with a fever, stomach pains, or diarrhea. Thirteen women said they had to visit their health care facility one or two times, while only three women said they visited their health center four times in the past six months. Again reasons for such often visits was brought on by feeling ill or needing certain medications for common ailments, such as malaria. Less than a quarter of the women (n=6) said they had not visited their preferred health care facility within the past six months. (See Table 3 on page 56).

Finally, in order to segue into a discussion on cancer and breast cancer specifically, the women were asked whether they knew if breast cancer screening was available at their preferred health care facility. Overall, the women presented mixed knowledge about this topic. A little less than half of the women (n=14) believed they could be screened for breast cancer at their preferred health care facility, whereas 10 women said they could not, and 11 women said they
did not know whether breast cancer screening was offered at their preferred facility. It is important to note that many of the women answering “yes” or “no” or “I don’t know” were speaking about the same health care facility at times, demonstrating inconsistencies in adequate knowledge about services offered at their respective health centers.

**Table 3: Health-Seeking Behavioral Characteristics of the Study Sample (n=35)**

<table>
<thead>
<tr>
<th>VARIABLE</th>
<th>FREQUENCY</th>
<th>PERCENTAGE (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Preferred Local Health Care</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Public/Government Health Care Facility</td>
<td>15</td>
<td>42.9</td>
</tr>
<tr>
<td>Private Health Care Facility</td>
<td>17</td>
<td>48.6</td>
</tr>
<tr>
<td>Drug Shop/Pharmacy</td>
<td>2</td>
<td>5.7</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>2.9</td>
</tr>
<tr>
<td><strong>“Why did you choose this health care facility?”</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient care</td>
<td>15</td>
<td>42.9</td>
</tr>
<tr>
<td>Cheap</td>
<td>9</td>
<td>25.7</td>
</tr>
<tr>
<td>Trust facility</td>
<td>1</td>
<td>2.9</td>
</tr>
<tr>
<td>Nearby</td>
<td>7</td>
<td>20.0</td>
</tr>
<tr>
<td>Only place known</td>
<td>2</td>
<td>5.7</td>
</tr>
<tr>
<td>No response</td>
<td>1</td>
<td>2.9</td>
</tr>
<tr>
<td><strong>“How far from your home do you travel to reach this health care facility?”</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤ 1km</td>
<td>8</td>
<td>22.9</td>
</tr>
<tr>
<td>2-5km</td>
<td>19</td>
<td>54.3</td>
</tr>
<tr>
<td>6-10km</td>
<td>5</td>
<td>14.3</td>
</tr>
<tr>
<td>≥ 11km</td>
<td>3</td>
<td>8.6</td>
</tr>
<tr>
<td><strong>“How often have you visited this health care facility within the past 6 months?”</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>One time</td>
<td>5</td>
<td>14.3</td>
</tr>
<tr>
<td>Two times</td>
<td>8</td>
<td>22.9</td>
</tr>
<tr>
<td>Three times</td>
<td>10</td>
<td>28.6</td>
</tr>
<tr>
<td>Four times</td>
<td>3</td>
<td>8.6</td>
</tr>
<tr>
<td>Five times</td>
<td>1</td>
<td>2.9</td>
</tr>
<tr>
<td>≥ Six times</td>
<td>2</td>
<td>5.7</td>
</tr>
<tr>
<td>Never</td>
<td>6</td>
<td>17.1</td>
</tr>
</tbody>
</table>

**Beliefs, Knowledge, and Attitudes Towards Cancer**

After asking women about basic health-seeking behaviors, discussion moved towards a detailed account of women’s beliefs about cancer, including questions asking about common types of cancer throughout Uganda, causes of these cancers, how their community perceives
cancer, and how she would handle a hypothetical cancer diagnosis. Themes emerged surrounding women’s perceptions of the disease, which will be discussed in detail throughout this section, but most commonly highlight assumptions that cancer will always result in death. Secondly, cancer was thought to be most commonly caused by contact with artificial substances and/or germs in the environment. A third common theme surfaced around pain and the loss of body parts; that cancer is an extremely painful disease and inevitably will result in the loss of body parts in order to save one’s life or only to extend one’s life. Furthermore, cancer was believed to be a wound that never heals on the body, resulting in the outcomes previously mentioned. Additional themes, which will be discussed in detail below, surfaced throughout the interviews regarding common reproductive cancers, such as breast, cervical, or uterine cancers and a belief that varying breastfeeding practices can lead to breast cancer. Finally, discussions of family support manifested throughout the interviews, as women spoke of who they would inform about a hypothetical cancer diagnosis and the types of support they would seek (this topic will be discussed within its own subsequent section).

When looking further into data that highlights cancer as a death sentence, often times women would reiterate that cancer is purely “a disease that kills.” Some women would further highlight that “it is a disease that affects people with no treatment” or that it “spreads [throughout the] whole body and becomes incurable.” One woman aged 35 with six children noted, “[It is a] disease that cause death; spreads [throughout the] whole body and becomes incurable. Sometimes you die before knowing what is wrong with you. [Cancer] kills if no fast treatment.”

Women would further compare cancer to other common diseases they see throughout Uganda. A 20 year old woman compared a cancer diagnosis to that of a malarial diagnosis,
emphasizing the fatal nature of cancer. She stated, “This is a disease that kills. Once it is advanced in stage, one has to die, which is different, [unlike] other diseases like malaria.” She highlights that malaria is a common disease in Uganda which many people are capable of surviving, whereas cancer is too often a fatal disease. Some women also compared cancer to HIV/AIDS, noting the severity of cancer versus HIV throughout Uganda today. A 27 year old woman who has lived in Nakirebe for the past four years relayed an anecdote of her discussions with other people in the community:

Some people say ‘If I know I have cancer then I can kill myself. I’d rather have HIV than having cancer.’ Because people with HIV can now live for 30 to 40 years just fine with medicine.

She addressed the belief by many people that individuals infected with HIV commonly live longer because of their ability to access life-saving drugs, whereas cancer is seen to be more expensive and often times less treatable. Another woman in her 30s with four children spoke about the communities’ perception that “The community perceives cancer as a disease that does not cure and is more painful compared to HIV/AIDS.” Similarly, another woman in her early 30s noted that “[The community] talk about it that it’s a serious disease, and it can’t get cured and is more serious now than HIV.” The undertone throughout these comments being that HIV/AIDS is more prevalent and treatable within this community, compared to cancer which remains a more serious less common disease.

Other ideas about why cancer is a “killer disease” regarded the belief that it “occurs on its own and has no cure.” Some women spoke about the mystery of cancer and pondered during their responses about what actually causes cancer. In fact, when women were asked what they believe causes cancer, they would often times reverse the question to the interviewer after
providing their response as a way to gain reassurance. The unknown nature of cancer’s cause presented a proponent of death, as one 40 year old woman with nine children notes:

That cancer is a deadly disease and when a person gets cancer, it does not cure. A person’s body parts that have been affected with cancer is cut off often, like every time.

This woman, among many others, recognized the severity of cancer and even its harsh treatment of the body with the removal of infected body parts, which will be discussed in more detail later on in this section.

In further regard to the mysterious nature of cancer, women would often speak about the longevity of a cancer diagnosis. An 18 year old woman noted that cancer is “a disease that attacks specific body parts causing wounds that don’t heal.” The idea of wounds that never heal resulting from cancer was commonly addressed by many women throughout the interviews. Since women often mentioned the high likelihood of death associated with a cancer diagnosis, they also attributed this to “being a wound that does not heal despite the treatment and keeps spreading.” Cancer was commonly seen as a never-ending spiral like disease that will inevitably end in death.

This brings attention to the idea of pain and cancer as a common dyad. Because the disease was thought to be “a wound that never heals,” it was also noted for its common association with pain. A 29 year old woman explained, “Cancer is painful...makes some people lame and kills.” In fact, when women spoke about cancer as a death sentence, they would equally define it as a very painful disease, the two outcomes going hand-in-hand. A 30 year old woman who has lived in Nakirebe her entire life noted, when talking about how she understands cancer and what she has heard people in her community talk about the disease:

Cancer is an incurable disease, very painful and brings wounds on one’s body...There are no taboos I know, but people in this community perceive cancer as an incurable disease because most people who get it die.
It is important to address women’s beliefs about the causes of cancer. A general theme that emerged during the in-depth interviews was the belief that cancer is commonly caused by artificial substances that come in contact with the body or germs that enter the body. A 22 year old woman with a two year old baby explained, “I believe [cancer] can attack someone if you don’t protect the body. For example if you are pricked by a short nail and don’t treat yourself early.” Women also often spoke of contact with feminine products such as “hair chemicals and skin lotions” or the use of “lip-shiner” or “eye pencil decorations” or “wearing a bra which are holding breasts so tight.” A 43 year old woman who has lived in Nakirebe her entire life, discussed her beliefs about the disease:

I think sometimes people like us who are HIV positive get skin cancer or may get skin cancer because of the medication we take [ARVs]. And also using cosmetics used for bleaching the skin that has expired.

These artificial substances entering or coming in contact with the body were seen as risk factors for developing cancer. Furthermore, a few women mentioned the ingestion of “too much tablets [aspirin or birth control pills]” or “steel wool [from] cleaning saucepans” was thought to be a cause of cancer. A 30 year old woman with a primary level education noted, “I think family planning [depot or pills] causes wounds on the intestines and breasts which turn cancerous.” The ingestion of bad substances was even referred to in regards to the intake of certain foods. A 32 year old woman who is a caretaker for children talked about “The way we eat maybe causes these cancers, because most [foods] are sprayed with chemicals.” Furthermore, the use of cell phones was even identified as a cause of cancer, specifically brain cancer, and the high intake of alcohol or smoking was thought to cause lung cancer. Other than one woman noting the connection between cell phone use and brain cancer and another connecting alcohol and smoking
with lung cancer, most women spoke in general about cancers and contact with various types of artificial substances and carcinogens remaining the major risks for developing cancer.

Aside from mentioning artificial substances, the majority of women in this study also spoke about germs that enter the body and cause cancer. A 21 year old woman with a secondary level education noted that cancer is actually a “disease that moves in the blood. If you use another person’s razorblade or nail file with blood, you can get cancer...probably painful.” She believed that cancer was spread through contact with infected blood. Other women associated cancer specifically with poor hygiene practices, specifically “poor menstrual hygiene.” A woman in her late 20s explained that “Some women don’t clean well her private parts. Women can get infections that can cause cancer, especially if a woman is always getting infections.” A few times this reality of poor hygiene was attributed specifically to the development of cervical cancer, but more often than not, germs anywhere in the body where thought to cause cancer at any site. “Being dirty and bathing in a dirty bathroom” was suggested by a 19 year old woman as a major risk factor for developing cancer. Furthermore, another common association with the cause of cancer by germs was the spread of sexually transmitted infections. A 29 year old woman with a primary level education explained that a person can get cancer “because there are so many diseases which cause them [‘cause’ cancer], like AIDS and syphilis.” This participant believed that by being diagnosed with a sexually transmitted infection, one could also then become infected with cancer by way of that infection. Similarly, a 27 year old woman spoke about cancer actually being a sexually transmitted disease. When asked what she believes causes cancer, she said “[you can get cancer] when you or one that’s involved with a person who had cancer has sexual intercourse.” Overall, cancer was often times attributed to a blood-borne disease acquired through contact with germs that enter the blood stream.
In addition to speaking about cancer as a deadly disease that is painful and is acquired by contact with artificial substances or germs, women also spoke often about the more immediate outcomes of a cancer diagnosis. A 27 year old woman with four children explained, “Cancer is a disease that destroys a given part on the body and if not diagnosed in its early stages [cancer] may be incurable and may cause death.” If an individual is not treated at the earliest possible stage, they will likely die from the disease. In this regard, women often mentioned the only treatment for cancer or the only “cure” is to have that affected body part removed. A woman in her early 30s with no children mentioned:

I hear it’s a disease that it can be in someone and can affect someone, maybe in the bone, and can move all over the body. So if you go to the hospital early then you can cut away the body part to treat.

The majority of women believed that because cancer is a chronic disease, it has no cure, other than surgery where the infected body part can be removed. A 21 year old woman with a four year old boy relayed, “It’s one of the feared diseases here...they remove breasts and amputate lower limbs, yet there is no ability [or] funds for early diagnosis.” This participant highlights the reality of the expensive nature of a cancer diagnosis and even cancer screening; that treatment and even early screening services are difficult to receive due to high cost, so the affected body part is simply removed. This theme pertaining to lack of funds and even early diagnosis is further discussed when women talk about how they would handle a hypothetical cancer diagnosis in the following section and even by the women who participated in the focus groups, which will also be discussed in a later section. Another woman of 21 years noted, “Cancer is a deadly disease. If you get breast cancer and you don’t go for immediate treatment, they cut off your breasts.” In the end, in order to help save your life or extend your years when facing cancer, removing the affected body part was the solution, because “[cancer] has no medicine.”
When discussing removal of body parts and death, a few women mentioned how stages of cancer diagnoses are relevant to prolonged life or early death. After being asked why cancer is believed to be the so threatening, one woman in her early 30s said, “I think it’s because people are not knowledgeable about the different cancers in terms of threat and therefore seek treatment late.” This participant was speaking in regards to breast and cervical cancer being the most common cancers in Uganda and those with the highest risk factors. Another woman in her late 20s noted that “most people are getting [cancer] because they don’t get early treatment.” This notion of early treatment versus late treatment appeared in many different conversations with the women during interviews. When asked why she feels this community and herself fear cancer, a woman in her early 40s who has lived in Nakirebe her entire life answered that it is “because in most cases cancer is diagnosed during its late stage when nothing can be done to reverse it.” A late stage diagnosis of cancer, which is often times inevitable due to lack of early screening services, was perceived as a prevalent cancer outcome.

Throughout the interviews, women were asked what they believed were the most common types of cancer affecting people in Uganda. Responses varied, as participants spoke about cancers commonly affecting women or cancers they have personally experienced through a family member or friend or cancers they have simply heard about through random discussion within the community. Overall, the most frequently cited was breast cancer (n=30), followed by cervical cancer (n=18). It is important to note, however, that cervical cancer was simultaneously referred to as uterine cancer. The native language of Luganda spoken by all of the participants—though some women spoke a mixture of Luganda and English—refers to cervical and uterine cancers as nabana, thus, leading most women to believe they were the same type of cancer. All
other cancers were mentioned at most eight times or at least one time. These cancers were bone, colon, blood, skin, throat, stomach, brain, neck, and lung. (See Table 4 on page 65).

Most women in this study believed breast or cervical cancer to be the most common cancers affecting women in Uganda. Even without directly stating breast or cervical cancer, most women mentioned a reference towards reproductive cancers when speaking about attitudes towards the disease and causes of the disease. When asked what she believes cancer is, a 40 year old woman with nine children, responded, “Cancer is a swelling that affects the uterus and spreads to other parts of the body like the breasts.” In fact, this woman was unaware of any other types of cancer, besides breast and uterine cancer. A 26 year old woman explained after being asked about her perception of cancer that “Women are the easiest people who get cancer, because in every year a woman delivers [a baby] and it is easy for her to get cancer.” This participant was specifically referring to breast cancer, which she believed to be the most common type of cancer due to frequent breastfeeding practices. Subsequently, cervical cancer and breast cancer were described by a 20 year old woman with no children as the most prevalent:

*For cervical cancer, I have heard it is common among women who have ever given birth. It is caused when a woman gives birth to very many children. For breast cancer I have heard that when a woman breast feeds a baby for a period of one year, they are likely to get [cancer], but I am not sure.*

A 30 year old woman further explained:

*Breast cancer is the most common because it is rooted in the family. If one family member gets cancer of the breasts it means the next generation will also have it.*

This idea of cancer being inherited from one generation to the next, was only mentioned by this one participant during the discussion of cancer in general, however, the theme of hereditary cancer arose again later on in the interviews when women were asked more in-depth questions about breast cancer specifically, which will be discussed in a later section.
Lastly, this section cannot go without observing the few participants who simply did not know about cancer. Out of the 35 participants, eight were unable to describe anything related to their knowledge or perceptions about cancer. They simply stated in various ways, “I cannot confidently explain what it is.” Other women would begin their description with a simple “I don’t know,” but then would often times lead into a brief or sometimes detailed explanation of their best guess in describing cancer. Other times, when women were asked to explain why they believed certain cancers such as breast, cervical, colon, or skin were the most common cancers in Uganda, they simply said, “I don’t know.” These women had only heard of these cancers, but were not confident in describing them or explaining why they affected people so severely in Uganda. Only a couple of these women who did not identify any common cancers in Uganda were the same women who were unable to describe cancer in their own words. For those women who did describe their perceptions of cancer, overall, they were often times hesitant or weary to express self-assurance in their explanations.

Table 4: “What do you think are the most common types of cancer in Uganda?” (n=35)

<table>
<thead>
<tr>
<th>Most common types of cancer</th>
<th>Number of times cancer type was mentioned</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast</td>
<td>30</td>
</tr>
<tr>
<td>Cervix (also referred to as uterus)*</td>
<td>18 (13 cervix &amp; 5 uterus)</td>
</tr>
<tr>
<td>Bone (also referred to as cancer of the leg)</td>
<td>8</td>
</tr>
<tr>
<td>Skin</td>
<td>3</td>
</tr>
<tr>
<td>Throat</td>
<td>2</td>
</tr>
<tr>
<td>Colon (also referred to as intestine/abdomen)</td>
<td>6</td>
</tr>
<tr>
<td>Blood</td>
<td>4</td>
</tr>
<tr>
<td>Brain</td>
<td>2</td>
</tr>
<tr>
<td>Lung</td>
<td>1</td>
</tr>
<tr>
<td>Stomach</td>
<td>2</td>
</tr>
<tr>
<td>Neck</td>
<td>1</td>
</tr>
</tbody>
</table>

*Cervix and uterus were interchangeable in conversation, as the local term for both in Luganda (the native language) is *nabana*, which relates to the general area where the baby develops and is birthed from. Women often times did not differentiate the two anatomical body parts.
Handling a Hypothetical Cancer Diagnosis

When women were asked how they might handle a hypothetical cancer diagnosis, certain responses were recurrent. Often women spoke of seeking family support or immediate medical attention. The majority of women discussed their ability and overwhelming need to inform family if they were to ever experience a cancer diagnosis. A woman in her mid-20s living on her own mentioned that she would “tell my parents to consult with them.” Another woman of 30 years with two children and living with her parents, siblings, and nieces and nephews relayed, “I would discuss it with my mom because she is my confidant, and then I would request her to provide me with some money for treatment.” Informing immediate family members and further requesting financial assistance were two major themes of which are discussed in detail throughout the remainder of this section.

Some women spoke about their desire to inform their family in order to guide them in pursuing healthy lives. One woman above 50 years with four children said:

*I would tell my family that I have been diagnosed with cancer; tell the family to take good care of themselves and learn more about the things that cause cancer.*

Similarly, a woman in her mid-20s with three children presented a comparable explanation:

*I would tell my family members that I have been diagnosed with cancer, a disease that does not cure. I would also advise my sisters to lead a life that will prevent them from getting cancer. I would request my family to support me financially to enable me access [to] some medication.*

Overall, most of the woman spoke about being able to “freely talk about [a cancer diagnosis]” with a close relative. Most often the husband was mentioned along with parents or siblings as those family members to confide in. One married woman of 21 years with a four year old son made an observation in regards to comparing cancer with other diseases. She relayed that if she were to ever find out she was diagnosed with cancer:
I openly tell my husband that I have cancer because it’s an issue of life and death, because I know he is a supportive husband. Unlike for HIV, where you cannot just talk.

The comparison of cancer to HIV was again brought to light briefly by this one participant when discussing hypothetical cancer diagnoses; that cancer is a new and very deadly disease, whereas HIV has been seen throughout the community for years and carries with it many taboos. In the end, the discussion of a hypothetical cancer diagnosis brought with it expressive dialogue from the women. A few women mentioned feelings of anxiety when thinking about a cancer diagnosis; that “I will be filled with fear” or “fear and scared because I think cancer has no cure.” Internal fear was paired with the need to plan for death. A 30 year old woman with four children said, “I would tell my family members especially my mother and husband, and I would ask them to take good care of my children when I die.” Only one participant, who was 28 years old with two children below six years of age, noted that she would not be able to inform her husband due to fear:

I would tell my mom and tell her that I am going to die. I cannot tell my husband because he will divorce me, saying I have brought him problems.

Overall, the majority of women spoke about confiding in their family members, commonly blood-related kin or one’s spouse, for moral support if ever found to be diagnosed with cancer.

Along with being able to freely inform family members of a hypothetical cancer diagnosis, many women mentioned the need to tell family due to a request for financial support. A 40 year old woman with nine children spoke about telling her children about her cancer diagnosis:

I would open up and tell my family most especially my children that I have cancer, so that they can find possible ways of providing me with the necessary treatments.

The need for financial support brought with it a discussion of gathering funds through familial connections. It was not always that a woman would directly ask one person for funds when faced
with a hypothetical cancer diagnosis, but rather informing a family member would ensure her that that one person could “organize funds for me to get treatment.” Organizing funds meant that relatives to the woman would work together in requesting sponsorship from other family members or even community members in order to help with treatment costs. Overall, women recognized the high expenses involved in cancer treatment and the need to inform multiple relatives in order to request financial assistance. A 27 year old woman with four children explained, “I would tell my family that I have cancer so that they can help me to meet the treatment costs since I heard that cancer treatment is very expensive.”

In addition to seeking support from family in regards to both financial relief and emotional support, some women spoke about the desire to seek additional medical help immediately after learning of a cancer diagnosis. A 23 year old woman with a newborn baby expressed “First tell parents, then go to counselors about how it pains and hurts you and go for tablets [painkillers].” She further expressed how some people feel strong emotions about cancer to the point of wanting to kill themselves in order to stop the suffering. She explained that for herself “Can you really kill yourself? No, you take tablets.” Though the pain of cancer was seen as a frequent severe outcome of the disease, as discussed in the previous section on beliefs about cancer, this participant recognized that medicine could help to control that pain and enable an individual to continue living. Lastly, two women talked about seeking further medical advice from experts in cancer at a larger health care facility in the capital city of Kampala. A woman in her early 20s mentioned going to a “bigger hospital like Mulago for further cancer screening and check-ups.” Another woman in her early 20s expressed that women should “first make sure you are informed about [cancer] from health workers at Mulago.” Finally, a 27 year old woman recognized that with a cancer diagnosis she would not stand alone:
I can handle that problem because I’m not the only one that has had [cancer before]. It can be cured if you go early for treatment. If cancer is young than [it] can heal. So I take care of self and get help fast by doctor.

Her belief was that since she is not the only person who would have experienced cancer before and lived with the disease, she could likely survive the experience, as long as treatment is received promptly. Overall, woman in this study recognized the need for early treatment in order to have better chances of surviving the disease, as well as understood the severity of the disease and financial burden of treatment. Familial support became a major factor in discussing outcomes of cancer and management of the disease.

**Beliefs, Knowledge, and Attitudes Towards Breast Cancer**

After discussing women’s beliefs about cancer in general, focus moved towards a discussion on breast cancer specifically and women’s beliefs and attitudes towards this type of cancer. When asking the women what they knew about breast cancer, a plethora of themes were unveiled, which are discussed in detail throughout this section. Similar results to beliefs about cancer in general emerged from this section of the interviews. Women spoke overwhelmingly of death, fear to lose breasts, pain associated with the disease that never heals, specific signs of the disease, and the cause of breast cancer again to be associated with contact to artificial substances and/or poor hygiene practices. A specific discussion of breast feeding practices emerged in regards to how breast cancer is caused. Occasionally women spoke about linkages to a family history of cancer, certain foods causing breast cancer, early diagnosis and treatment is necessary to survive breast cancer, and the discouraging expense of a breast cancer diagnosis.

Of all the women interviewed, none had been diagnosed with breast cancer, however, the majority of women were able to demonstrate a sense of understanding for breast cancer and its
implications to one’s health. Only five women had experienced the reality of a close relative being diagnosed with breast cancer, specifically a cousin, an aunt, or a grandmother. This experience weighed in on their attitudes towards breast cancer, specifically the belief that breast cancer is a painful disease which never heals and will make a woman lose one or both of her breasts. Even though the majority of women did not have a close relative diagnosed with breast cancer, their attitudes were similarly expressed in relation to the few women who had witnessed first-hand a breast cancer diagnosis.

An overwhelming theme which emerged again when discussing breast cancer specifically was the attention to death. Women made it clear that an individual’s biggest fear in regards to a breast cancer diagnosis will always be death. Women regularly used terminology such as “fatal disease” or “deadly” or “bad disease that kills” or “a killing disease” or “breast cancer is incurable” or “fear of death.” Additionally, women knew that death brought with it the abandonment of their children. A 26 year old woman with three children between four and nine years of age expressed her concerns of “dying and leaving my children at a young tender age” when thinking about breast cancer as a fatal outcome. Another woman 20 years of age with no children thought more about her future and how breast cancer would be a tragedy:

Dying when I have not given birth to any kid. I need to leave behind a child who will take care of my property that I may acquire. Secondly the child can make your dreams come true in terms of any plans you had earlier.

According to this respondent, the grave loss of life would bare misfortune not only on the woman herself but also on her future lineage. This was similarly expressed by another woman in her early 30s who had one child nine years of age when she spoke that her fear of cancer is “death and having to leave any son behind before I plan of his future.” Overall, death was paramount in acknowledging attitudes towards breast cancer among the participants interviewed.
Upon discussing death as a common outcome of a breast cancer diagnosis, women also talked about the reality of losing one or both breast(s). This theme was addressed as both a fear, for a woman would lose part of her femininity, but also as a best practice for treatment. The reality of losing one’s breast(s) after a diagnosis of breast cancer was commonly seen as the best way to treat the disease in order to elongate life; that removal of the breast(s) is simply expected because it is the only form of treatment since medicine is either not available or too expensive. A 32 year old woman expressed, “I heard that if you have breast cancer they cut off your breasts to avoid the spread of cancer to other parts.” Some of the women spoke about how they “fear cutting off breasts.” In fact, a 27 year old woman expressed, “I worry that I won’t produce any babies and worry that you will cut off my breasts;” the undertone being that by losing the breasts, they would lose their womanhood or could no longer bear children. Some women also admitted to their fear of major surgery, and that a fear of breast cancer arose because the only way to treat it was through surgery. A 32 year old woman expressed, “The major thing they fear is cutting off breasts and it’s risky to do with infection. This is the major fear because the breast is very delicate.”

Another major theme addressed by the women was pain associated with breast cancer. Pain was not only associated with signs of potential breast cancer diagnoses, but was also, maybe even more strongly, associated with the outcome of breast cancer because cancer was believed to be a wound that never heals. Though none of the woman had ever experienced a breast cancer diagnosis, their assumption of the experience of living with breast cancer was strongly associated with pain. An 18 year old participant with a relative who was diagnosed with breast cancer mentioned that her grandmother expressed, “It’s a painful disease that kills.” Other women associated the pain of breast cancer with the idea that the disease “destroys women’s breasts and
makes the breasts painful;” that “the breast also swell and are painful.” A 24 year old woman explained how “it’s a wound on the breast that cannot heal at all and it’s painful.” When addressing treatment for breast cancer, some women who felt strongly that breast cancer will ultimately lead to death subsequently addressed the need to manage the pain; that this was the only option for women diagnosed with breast cancer. In fact, when asked if breast cancer can be treated, two women believed that the disease cannot be healed. A 32 year old woman noted that “doctors just manage the pain, but it’s incurable.”

As previously stated, pain was also seen as a sign or symptom of the disease along with feeling hard nodules in the breast tissue. A 32 year old woman mentioned, “I hear that if you feel pain in the breast and when you touch [the breast], you feel something hard inside and you go for a check-up.” Similarly a 26 year old woman explained:

It’s the type of disease that affects [the] breast, and you feel pain in breast and feel hard things in breast and sometimes feel like water. So you need to seek a doctor for help.

The mention of a hard substances, like a tumor, within the breast was explained by most women as a clear sign of breast cancer; that you “develop a tumor inside the breast, and the tumor is always hard like a stone.” A woman over 50 years of age expressed, “We were told that whenever one feels hard tissues in the breasts, which is unusual, the person should see the health care provider with immediate effort.” The hard tissue was commonly spoken about in reference to a “rock” or “stone.” A woman in her early 20s expressed, “Breast cancer is a tumor which develops inside the breast, and when you touch it, it is like having a stone inside.”

In addition to pain and hard tumors in the breast, women noted further signs of breast cancer. Some woman mentioned the change in appearance of breasts can be an indicator of breast cancer. A 21 year old woman explained, “If breasts have texture of oranges, it may be cancer.” She had heard this from nurses during an educational talk many months prior; that if the
skin on your breasts became rough or dimpled like oranges, than it could be a sign of breast cancer. Another woman just 20 years old spoke of the enlargement of the breasts; that “I would say that if one develops abnormal swellings on the breasts, then it’s breast cancer, and this swelling is at times itchy.” Similarly, a 23 year old woman mentioned that, “When breasts start itching you, you go to the doctors to get checked for it…when breasts itch so much you are suffering from breast cancer.” Only one woman of 30 years shared the idea, “I have heard that when a woman has breast cancer, the breasts have hard lumps and when pressing it, blood may ooze out.” Overall, many of the women believed that a change in the feeling, look, or texture of the breasts meant concern should be raised regarding the development of breast cancer.

Some women spoke about the expenses related to a potential breast cancer diagnosis when they were asked what they had heard about breast cancer and what their biggest fears would be if faced with a breast cancer diagnosis. One woman in her early 20s talked about how because breast cancer spreads so quickly, “the result is death because it’s expensive to manage and [you] fail to raise the funds.” This same concept was strongly expressed among a few other women. “A lot of money spent on treatment” leads to women dying from the disease. Furthermore, a 26 year old woman expressed the immense stress involved with a breast cancer diagnosis, stating that “They will be stressed. If you don’t have money some women might commit suicide or some might burden family, so divorce from family.” This was recognized as an extreme outcome of a breast cancer diagnosis, but realistic nonetheless. Overall, women addressed the cost of treatment for a breast cancer diagnosis as overwhelming and stressful.

Finally, a discussion of the causes of breast cancer was addressed throughout the interviews. The overwhelming majority of women believed that contact with artificial substances or germs had a direct correlation with the development of breast cancer. A 26 year old woman
explained, “I heard that breast cancer is caused by poor hygiene practices.” Though poor hygiene was mentioned by some women, more women spoke about artificial substances coming in contact with the body as a direct cause of breast cancer. The “use of perfumes and chemicals on the body” along with “money near breasts” were mentioned as potential causes of breast cancer. The idea was that if artificial substances like chemicals or materials that would hold chemicals on their surface, such as money, came in contact with the skin, than these chemicals could enter the skin through the pores. A few women also mentioned “tight bras and metallic bras” as a link to breast cancer; that squeezing the breasts too tight or placing them in an unnatural position could be a risk for developing breast cancer. Even the ingestion of artificial substances, like metal particles, and medications, such as those that treat other diseases, family planning methods, or dietary supplements, were seen by some women as being a risk factor for developing breast cancer. A 26 year old woman with three children believed “Steel wire also causes breast cancer if one uses it to wash utensils and does not effectively rinse out the small particles that remain on the utensils.” A woman of 30 years with four children, when asked what she thinks causes breast cancer, answered “I think family planning methods, especially injectable [depo] and pills.” In fact, another woman of 19 years believed that family planned methods were such a risk factor for developing breast cancer that “There is no way to prevent breast cancer because so many women use family planning pills.” Lastly, only one woman made a connection between smoking and breast cancer.

A few other beliefs about breast cancer and its causes that were addressed by women related to foods, as well as familial linkages. One woman mentioned “poor diet,” while another woman spoke about the “western diet of food we now take” as potentially causing a breast cancer diagnosis. These few women who mentioned food in relation to breast cancer believed strongly
that a poor diet can lead to the disease; specifically a diet consisting of lots of sugar and sweets and even processed foods bought at major supermarkets, rather than garden grown foods. Other women mentioned a hereditary component to breast cancer. One woman 28 years old said:

*It’s not common to hear people talk about it but I have heard that if any member of your family has it then other family members can get it too.*

Similarly, a 26 year old woman noted, “*It can be inherited if [a] family member had it before.*” Though inheritance was expressed among only a few women as a primary cause of breast cancer, it still presented a significant fear for one woman in her late 20s who believed that if she were pregnant at the time of having cancer, it could spread to her child.

Lastly, a significant findings from this portion of the interviews was that many of the women associated breast cancer with varying breastfeeding practices; from breastfeeding for too long, never breastfeeding at all, or the inability to exclusively breastfeed for a long period of time. A 26 year old woman with three children believed that breast cancer can be caused when, “*failure to breastfeed till term [two years];*” when a woman does not breastfeed long enough. On a similar note, a 28 year old woman with two children mentioned, “*I heard that if you don’t breastfeed your baby, breast milk clogs your breasts and it causes breast cancer.*” The delay in breastfeeding was a common theme presented by the women, in particular, delays in breastfeeding immediately after birth and periodic delays throughout the first year or two of a baby’s life. Another woman of 23 years with a new born baby who was currently breastfeeding, when asked what causes breast cancer, expressed:

*Poor breastfeeding, such as breastfeeding early in the morning then waiting like five to 10 hours before breastfeeding again, or when a woman delays in breastfeeding a child after two years by not breastfeeding right away.*

This participant stressed the consistency that should be involved in breastfeeding, such that milk does not stay in breasts for too long a period before being fed to the baby and allowing more
milk to be produced. Another woman in her early 20s who had lived in Nakirebe for two years further discussed the idea of careless breastfeeding:

*If you are careless when you are breastfeeding because the nipple is so delicate, this is mostly in village ladies after breastfeeding and they have left the breast out, it gets infected.*

She believed that older women from deep within the village who had never left the area were often times more careless with their breastfeeding practices and lacked cleanliness post breastfeeding. Lastly, a few women spoke about over breastfeeding and its relation to breast cancer. One woman just 20 years old with no children noted, “*When a woman over breastfeeds a baby, say for a period of one year, it causes cancer.*”

After addressing causes of breast cancer, women initiated a discussion on the fact that early treatment would need to be sought in order to help extend one’s life. When asked what women should do once they suspect a problem, one 19 year old woman expressed, “*Go to the hospital for treatment as early as you can!*” In fact, early treatment was again seen as the most important first step in a breast cancer diagnosis. The majority of women mentioned early treatment as the best way to manage the disease. Out of the 35 participants, 26 believed breast cancer could be treated, whereas only 19 participants believed breast cancer could be prevented. When asked how breast cancer can be treated, many women referenced a similar statement to “*it can only be treated if the person is diagnosed at an early stage and treatments [are] given on time.*” A few other women believed breast cancer could not treated at all; only the pain could be managed, as mentioned earlier in this section. These women addressed the reality of only seeing death as an outcome for those individuals they had witnessed with cancer. Furthermore, two women referred to breast cancer as a blood-borne disease that cannot be treated. A 21 year old woman explained, “*I heard there is no cure because once it gets to body it goes into blood and*
once the disease gets to blood it is hard to get cured.” Overall, early treatment for breast cancer was seen as essential to the longevity of life by most women interviewed.

In regards to prevention, the women who believed breast cancer could be prevented explained prevention in regards to avoiding the main causes that were discussed above. For those women who believed breast cancer could not prevented, they reached this conclusion from witnessing family members or friends dying from the disease or from lack of confidence in knowing the true causes of breast cancer and risk factors to avoid. On the other hand, women who did believe breast cancer could be prevented, thought that one must simply avoid the main risk factors for breast cancer, such as contact with artificial substances and/or germs or irregular breastfeeding practices. Two women, in particular, when asked what they believe can prevent breast cancer, guessed that vaccines might be able stop the disease since they had seen how vaccines could prevent other known diseases, such as measles.

Clinical Breast Cancer Screening Practices

Of the 35 female participants who completed the in-depth interviews, only nine women had ever experienced a clinical breast examination by a certified health care practitioner. Subsequently, the majority of women had never been screened for breast cancer through a health care facility. Most of these women attributed their lack of clinical breast screening practices to expenses, lack of availability of such services at local clinics, and no referral to seek such screening. One participant 21 years of age explained that she has never been screened by a health care provider for breast cancer because, “I didn’t think it was important. I think I have to wait for painful breasts before screening.” Another of the youngest participants 18 years old explained why she has never received clinical breast cancer screening, “The services are not here, and
“besides I feel no desire to check since I am not well informed.” She believed that since the services for breast cancer screening were not available within her community and since she is ill-informed on the importance of screening, there is no need for her to seek such health care.

Similarly, another woman 30 years of age and who has lived in Nakirebe her entire life stressed, “The services have not been extended to our area;” this being her main reason for never seeking clinical breast cancer screening. A couple women further mentioned their self-realization that they are healthy and their breasts feel fine, therefore, they feel no need to go to a health care provider for screening. A 32 year old woman with a strong Catholic faith proclaimed, “I’ve not had any sign on me, and I know I don’t have it in the name of Jesus!” Overall, screening services were mostly unavailable to this population of women within Nakirebe or seen as not urgent to access since signs of breast cancer were not present. Only one woman, 35 years old, explained her change in perception after her latest visit with a health care provider, “I did not think it was important [to be screened] but doctors told us it was important, so [I’m] going to be screened on next visit.”

Of the 26 women who had never been screened for breast cancer, 19 women knew where they could go if they wanted to be checked by a clinical health care provider. Only seven of the 26 women were unsure of any location that provides clinical breast cancer screening services nearby Nakirebe. For the women who had never been screened for breast cancer and mentioned locations that they think offer such screenings, the majority spoke of Mulago Hospital which is located in the Kampala city center and is the major government referral hospital throughout the region and is also connected to the Uganda Cancer Institute. The second most common facility mentioned was Mpigi Health Center IV, also known as Mpigi Hospital, located in Mpigi Town just a few kilometers down the main highway from Nakirebe. This government health center is
Mpigi District’s main hospital providing inpatient and outpatient services and is located next to Mpigi District’s Ministry of Health offices. Mulago Hospital and Mpigi Health Center IV are both accessible by taxis or boda bodas, though the cost to reach Mulago Hospital would be twice that compared to reaching Mpigi Health Center IV due to distance of travel. In fact many women noted that fees to reach Mulago Hospital would cost anywhere from 6,000 to 10,000 Ugandan Shillings (an average of about two to four US Dollars) compared to Mpigi Health Center IV which would cost about 3,000 Ugandan Shillings (an average about one US Dollar). A 30 year old woman with two children working as a store manager described her accessibility in reaching Mulago Hospital, which she believed was the only location to receive clinical breast screenings:

*It’s easy to access because I think the health workers are there, though the waiting hours are long. I would use a taxi which costs about 10,000 [Ugandan Shillings]. It’s quite a lot of money, but I may not have a choice.*

Walking to these facilities is not feasible due to the distance and the travel along the major Masaka highway. Another woman of 43 years with one child who was currently unemployed explained how she would travel to Mpigi Health Center IV to receive a clinical breast exam:

*I use a taxi. Since I have never been screened for breast cancer, I would not know what happens in that department. However, I am free to travel to Mpigi Hospital if I wanted at no cost apart from transport cost.*

Since Mulago Hospital and Mpigi Hospital are government-run health care institutes, the fees for services are cheaper, if not free, when compared to private health care facilities. Instead of medical service fees, the women discussed that the primary cost attributed to visiting either of these facilities would entail travel expenses, food, hours waiting, and hours spent away from home and work. Only a few women mentioned health care facilities which are much closer to Nakirebe, however, one of these facilities is privately-run and charges higher medical fees while the other is a much smaller government health care facility that is often times understaffed.
Of the nine women who had been clinically screened for breast cancer in their lifetimes, two had been screened more than once, while the remaining seven women had only been screened once for breast cancer. The earliest a woman had been screened was in 2012, while only one woman had been screened the same year her interview was completed, in 2015. Four women had been screened for breast cancer in the year 2014, and three women had been screened in 2013. Most of these women had been screened during clinical examinations by a health care provider through manual palpating and massaging of the breasts. A 26 year old woman explained the screening procedure she encountered:

*The health worker first puts a gadget [blood pressure wrap] on my upper arm to find out if I have the temperature that would expose one to breast cancer, then proceeded to touching my breasts, and later she said I did not have breast cancer.*

Only a few women described the screening process with the use of machines to examine the breasts; though none of the women could name the mechanical process involved in the screening, commonly stating that “they used a machine to check them.”

When asked why they chose to be clinically screened for breast cancer, most of the women mentioned that they wanted to know their breast cancer status and to make sure there are no issues with their breasts. A few other women discussed the nature of breast cancer screening which takes place when pregnant and after you deliver a baby; that women are often screened for breast cancer during pre- and post-natal care at the clinic. A 24 year old woman with two children stated, “*It was a hospital routine that after delivery you get screened for breast cancer.*” This theme of screening for breast cancer during post-natal care for woman was also addressed by the health care providers interviewed and will be discussed in a later section. Only one woman mentioned how she was screened for breast cancer through her work. Her company invited health workers to visit the facility and provide a standard check-up for all the female
employees, at which time her breasts were screened. None of the women referred to their clinical breast screenings as part of a yearly health care routine. Rather, most of the nine women who had been screened for breast cancer believed that by receiving the clinical breast exam just once, that was enough to determine they are free from breast cancer for life.

When asked about the experience of the screening process, a few women spoke about it being a positive experience and feeling more informed. A 22 year old woman, when asked about her clinical breast exam experience, noted, “[I am] no longer ignorant. It made me aware about breast cancer.” Similarly, another woman of 21 years explained, “It was a good experience because the health worker explained to me why I had to be screened for breast cancer.” Only a couple women mentioned the pain associated with the procedure or the overall discomfort of someone touching their breasts. The women who were screened, noted the accessibility of their procedure since it was at a health care facility close to their home or workplace. These women mentioned a variety of places where they were screened, such as Sekiwonga, a local government health care facility and Fiduga clinic and St. Monica Hospital, both private health care facilities nearby Nakirebe. Only two women mentioned Mpigi Hospital and Mulago Hospital as the locations where they received their clinical breast exams. Subsequently, these two locations were also the same facilities most often mentioned by the 19 women who had never received a clinical breast exam but believed they knew where to go if they wanted to be screened.

**Breast Self-Examination Behaviors**

Of the 35 women interviewed, 13 participants claimed that they knew how to conduct a breast self-examination. The remaining 22 women were unsure of the techniques involved in a breast self-examination. Of the 13 women who believed they knew what a breast self-
examination is, the majority explained that one simply presses down on the breasts and massages around to feel for anything hard inside the tissue. A 26 year old woman provided an elaborate description:

*If [you] raise [your] upper arm and use [your] opposite hand to touch [the] breast and you feel for hard things and pain. If you feel them you can suspect something is wrong.*

Another participant also 26 years of age stressed the importance of beginning near the armpit when massaging the breasts: *“I massage my breasts through my armpits or while moving towards my armpits to check for any foreign tissues, and I would do it on both breasts.”*

Furthermore, a 30 year old woman made note of swelling of the breasts and likely signs of a cancer diagnosis when she stated, *“It’s when you check for any abnormal swellings in your breasts and if you press the nipple and see blood, then you are likely to have cancer.”* In the end, these women were aware that breast self-examinations entail an observation of the breasts and the need to feel the breasts for anything that appears out of the ordinary.

These 13 women who knew of breast self-examinations were further asked where or how they learned to conduct the self-examinations. A few women mentioned that they were *“self-taught;”* no one in particular taught them the technique, they just knew one needed to feel the breasts for any abnormalities. On the other hand, the majority of women talked about lessons learned from nurses they met at health care facilities they visited over the years, including workshops put on by nurses regarding general health care. A few other women even mentioned friends who informed them of breast self-examinations. The same woman who explained that you must check for swelling and blood from the nipple noted that she learned about breast self-examinations from *“Women in my community...when I went for a burial for a woman who had died of breast cancer.”* Only one woman said she learned about breast self-examinations through a radio ad that explained the process involved in self-screening.
When all 35 women were asked if they ever think about having breast cancer in regards to fearing they might one day be diagnosed with the disease, 14 women admitted that they do think about the disease often. The majority of these women attributed this conscious awareness of breast cancer in their lives to the fact that often they will feel a change in their breasts, such as pain or irritation, which alarms them. Some women also acknowledged the fear of breast cancer resonating when they see a loved one suffering from the disease or a potential diagnosis. A 39 year old woman living with her parents and siblings expressed that she thinks often about having breast cancer:

*You never know whether it can catch you. When [my] sister was thinking [that] maybe [she has] breast cancer, I was worried about myself too and got so scared [that I might have breast cancer].*

A 32 year old woman with one child explained she constantly thinks about breast cancer:

*Because there is a time when my breasts, on pressing them, released water and they were abnormally big, so I got worried. And I head from the radio that this is a risk of cancer.*

Similarly, another woman of 30 years attributed her fear of breast cancer to the fact that “it was being talked about too much on [the] radio.” The abundance of radio announcements about breast cancer made her to worry about a personal diagnosis; as if the disease was wide-spread in the area and all women should be cautious. Another participant in her early 30s explained, “The disease does not discriminate, and I am a woman with breasts, so I think I can still get breast cancer.”

For the 21 women who said they do not think about breast cancer regularly, their responses varied from not feeling any abnormalities in the breasts, therefore, they do not fear the disease, to the fact that breast cancer is not common and has not affected someone close to them, so they do not think about it often. A 32 year old woman explained:
It’s not even in my brain. I don’t think about it because I know I don’t have, and if you think and worry then you could get [it], so don’t worry. And no family member [is] with it, so [I] don’t worry about it for myself.

Similarly, a 30 year old woman stressed, “People say it’s hereditary but there is no family member who has ever suffered from it, so I don’t think I can get it.” Another woman in her mid-30s explained why she does not think about breast cancer, “No such thoughts because my breasts have no problem or pain or itching.” One woman of 23 years of age talked briefly about her preference to remain in the dark about breast cancer by saying, “I don’t feel like knowing whether I have the cancer or not.” She simply did not want to face any potential reality of being diagnosed with cancer, therefore did not allow herself to think it. For these women, breast cancer was simply not on their minds; rather they were not worried about the disease or did not care to know about the disease, and therefore, believed the disease was outside their lived realities.

**Focus Group Discussion Results**

Upon conclusion of the in-depth interviews, two separate focus groups were conducted with women who did not complete the in-depth interviews but were still residing within the same community of Nakirebe. Each focus group consisted of five women of reproductive age. Discussions focused on beliefs about breast cancer, perceptions of breast cancer from within the community, how to learn about one’s own breast cancer status, support available within the community for women diagnosed with breast cancer, and changes or improvements they wished to see in regards to breast cancer awareness and health care access within the community. Focus group data reveals some new and some overlapping findings compared to the in-depth interview data. Throughout this section, the two focus groups will be referred to as FG1 (focus group 1) and FG2 (focus group 2).
Much of the conversations between FG1 and FG2 were similar in regards to certain topics. For instance, a discussion of breast cancer associated with death and being caused by contact with artificial substances and/or germs was present in both focus groups. Both groups of women saw breast cancer as a deadly disease or “bad disease that kills.” FG1, in particular, discussed in detail the mystery of breast cancer; that there is “fear of the unknown” because breast cancer is a fairly new disease to them. They mentioned how limited information causes lack of awareness regarding preventive measures and leads people to seek health care late. A woman from FG1 pointed out:

*The fact is [cancer] comes, like sometimes someone might be confused, they might be saying like it’s ulcer... they have no idea about that so called breast cancer...or they might be thinking it’s just the normal pain they feel every day....they find it’s too late and the treatment is too expensive for them.*

Overall, little awareness about breast cancer tends to cause confusion about the disease; even health workers in this rural setting “just assume [it is an] other disease and send you home.” This pushes individuals into later stage diagnoses which bring about more expensive treatments. In the end, “all money [for the household] has to go for medicine” and financial trouble becomes a reality for those infected. FG2 discussed this similar issue with the expense of breast cancer and that “even when people have money, they also lose relatives due to cancer, so there is no cure.” Women in FG1 further discussed the loss of breasts as a major outcome of breast cancer. The reality is “it’s traumatizing to lose the breast,” so women fear breast cancer and the impact it has on their ability to live a normal life and care for their children. The lack of awareness about breast cancer and expense of the disease was believed to ultimately lead to poor health outcomes resulting in death.

When discussing the causes of breast cancer, women in both FG1 and FG2 spoke about contact with artificial substances or carcinogens in the environment and germs being the leading
causes of this disease. In FG1, women talked about germs coming in contact with the breasts, such as sharing bras between women, especially among those already infected with the disease, or not cleaning the breasts after breastfeeding. Furthermore, women suggested that cosmetics like lipsticks, bath soaps, and bleaching detergents could cause breast cancer because “the more we apply, the more the chemicals can enter the body.” Even cigarette smoking was seen as a cause of breast cancer. Similarly, FG2 discussed how contact with cosmetics on the skin, such as lipstick or skin powder, could lead to breast cancer. Further discussions among this group led to a comparison between breast cancer and HIV/AIDS. In fact, the women in FG2 mentioned that within their community they have heard people speak about the “HIV virus and cancer bacteria...[having] the same cause...both don’t heal.” The belief that cancer was similar to HIV/AIDS was discussed briefly in the focus groups and even in the in-depth interviews from the previous sections; that both diseases were in fact similar and could be contracted through blood-borne viruses and bacteria and posed the same outcome of never healing. The women in FG2 also discussed the cause of breast cancer being attributed to breastfeeding practices. For some women, after giving birth, “breast milk can be a lot and overwhelming, leading to developing [a] lump.” This idea of too much breast milk in the breasts without enough release of the milk through breastfeeding was seen as a major issue among the women in FG2.

In both focus groups, women were asked what resources are available to them in order to learn of their breast cancer status should they choose to, and furthermore, what type of support would be available to a woman who is diagnosed with breast cancer within their community. These questions sparked similar responses in both FG1 and FG2. In fact, both groups mentioned breast self-examinations or simply going to a health care facility in search of clinical screening as options available to them in order to learn of their breast cancer status. Some women
mentioned being taught by midwives on how to self-examine the breast through massage or by “Do[ing] research on yourself.” In FG1, the women talked about “gain[ing] self-esteem” in order to visit a health care provider and allow them to look at and examine your breasts. Self-esteem was mentioned in the manner of encouragement for women to seek medical advice and not to fear health care workers or the biomedical system. Women specifically mentioned facilities such as the nearby Mpigi Health Center IV or Mulago Hospital in the capital city of Kampala as centers which might be able to provide the best breast cancer education. They also mentioned Sekiwonga Health Center III; a smaller clinic located in Nakirebe. The women in FG1 discussed this particular facility in regards to awareness initiatives; that Sekiwonga Health Center had previously participated in education initiatives by inviting women to an afternoon workshop. They further mentioned that in order to learn about breast cancer, they would wait for an awareness group from Sekiwonga to come and inform them of where free breast cancer screenings can be completed. Referrals were seen as a common form of gathering information about health care; that local health care facilities in Nakirebe do not necessarily screen for breast cancer, but rather will refer women to a bigger hospital such as the nearby St. Monica Health Center or Mpigi Health Center IV or the larger Mulago Hospital in Kampala.

Both FG1 and FG2 further discussed the lack of support available within their community in regards to demonstrating support for a woman who is recently diagnosed with breast cancer. In fact, both groups of women said there is no direct financial or group support for breast cancer patients in this area; there is simply “none at the moment at community level in this village.” Both focus groups went on to discuss the fact that family is the only support one can seek if found to have a breast cancer diagnosis. Though the women did say that if a family is not unified and willing to help one another, then support, mainly financial support, is completely
absent for that individual facing breast cancer. The only other route would be to seek support from fellow community members, though this also “depends on how one relates with their neighbors.” In the end, both focus groups recognized a lack of support within their rural community for any type of cancer.

A final discussion brought forward by both FG1 and FG2 was on what the women would like to see change or improve within their community in regards to breast cancer. Specifically, they were asked what resources they wished were available for women regarding breast cancer awareness. This sparked two major themes in both FG1 and FG2: accessing screening services and regular awareness initiatives. Women from both focus groups mentioned a desire for more options to access routine check-ups by health care providers within their local community. They then would prefer better referral services for those women found to potentially have breast cancer. In FG1 specifically, the women discussed the need for better incentives, such as food provided by the facility, in order for women to access health care services and be screened for cancer. In the end, “people need to be told of available facilities to go to for breast cancer services.” This also means “give[ing] people options of what to do next, which would motivate people of future support after screening.”

This brings the issue of lack of awareness that most women face in regards to breast cancer. Because breast cancer is still so new to this community, women from both FG1 and FG2 spoke of a dire need to provide educational sessions on breast cancer within the community. They specifically discussed how they want to know about the causes of breast cancer, the signs and symptoms, and what screening services are available. In FG1 specifically, participants talked about fears associated with screening and that there is a “need to be taught first about the benefits of early screening.” Overall, women discussed that people are scared of knowing their
status, similar to knowing an HIV status. One woman said, “People avoid such things. They fear the negative thing out of their life, so they need that counseling at least to have someone to encourage them.”

Educational sessions on breast cancer including preventive, screening, and treatments options would be beneficial to this community, according to the women in both focus groups. More importantly, educational awareness initiatives that are locally organized and implemented was desired by the women from both focus groups. In fact, one woman suggested, “Increase community awareness on breast cancer using local council individuals like the Chair persons.” The idea of utilizing local community members in outreach initiatives was an essential recommendation for it would establish a boundary of trust from individuals of whom the community has already elected to lead. One woman from FG2 emphasized, “People claim [that] white people come to teach people...[we] worry of English, so [we] need local people, as people think they can’t speak English.” This woman was addressing the reality of intimidation by white people who visit this community to relay information in a foreign language that many women have trouble understanding.

Women also mentioned that a stronger awareness of the signs and symptoms of breast cancer and cancer in general would allow for earlier diagnoses and treatment. As mentioned earlier, women from both focus groups discussed the fear aspect related to cancer and that since fear keeps women from taking action, they need to be first taught about the benefits of early screening for cancer, such that fear can subside and women will be proactive in knowing their status. Women in both focus groups discussed that the proactive component specifically entails educating women about the benefits of routine cancer screening. This also involves the provision of screening options for women. For example, women in FG1 and FG2 talked about providing
women the option to seek screening from those health care centers which offer such services and of which they prefer, as well as informing women about all the steps involved in a potential breast cancer diagnosis, such as options for treatment, cost involved, and how to plan for the future. Finally, a major recommendation provided by the women in both focus groups, however stressed more in FG2, was the overall need for better local health care services that are educated in cancer care. One woman noted, “…should provide us with health facilities that can perform breast cancer screening, like modern clinics and health workers who can check for cancer.” In the end, both FG1 and FG2 discussed the need for better access to cancer care services within their rural community and the introduction of educational initiatives that bring stronger awareness on breast cancer such that women are better prepared for a potential diagnosis or can become advocates of better health care. See Figure 4, for an image of participants in FG1.

Figure 4: Picture of women from Nakirebe who participated in Focus Group 1. Photo taken by Emma Robinson.
*Women provided verbal permission to take and use their photo.
Semi-Structured Health Care Provider Interview Results

Semi-structured interviews were conducted with five health care providers working near Nakirebe at two health care facilities; one a government owned center and the other privately owned. Three participants worked at the government health care facility, while two participants worked at the private health care facility. The two health care facilities were strategically chosen based on accessibility and frequent use by the female participants according to the in-depth interviews. In the remaining analysis, I will refer to the government health care facility as GHC and the private health care facility as PHC.

All five health care providers were asked how they would describe cancer, in general, to a patient. Responses among the participants varied, however, a consistent theme was addressed. Both the GHC and PHC providers referred to cancer through mostly scientific explanations of the disease such as “abnormal” cell growth in any one part of the body. When relating their descriptions of cancer to breast cancer specifically, all five health care providers noted similar explanations again. Abnormal cell growth and/or swelling of a lump or mass inside the breast was a common response given by all five providers. Subsequently, the providers mentioned either early treatment or detection as the best outcome for breast cancer or that when one feels a lump in the breast they should seek medical advice immediately. The following description from one of the GHC providers demonstrates an example of explanations given by all five providers:

...the breast cancer is when the cells will multiply abnormally and form, in the early cases they will form some kind of lump. So if any woman feels any small lump or mass in the breast then they should come to the hospital to have further checks.

Upon describing cancer, in general, and more specifically breast cancer, each health care provider summarized the fact that the causes of cancer are still unknown. A couple of health care providers ventured to discuss heritability of breast cancer and contact with carcinogens in the
environment, such as smoking. No provider was definite in their responses; instead they all addressed the causes of cancer as ultimately unknown. A PHC provider noted:

*Actually there is no clear cause of cancer...Some of those we think of are predisposing factors; factors that may increase your chances of developing cancer, but not the exact cause. So the factors that may increase your chances of developing breast cancer...genetic predisposition...or like chemicals or substances that may lead to the development of cancer, like smoke [and] maybe some poisons.*

When asked what type of cancers these health care providers think are the most common cancers in Uganda, similar responses evolved from each interview. Though breast cancer was seen by these health care providers as a cancer affecting primarily women, the most common cancer believed to be affecting women in Uganda was cervical cancer. A provider at the GHC facility summarized:

*I think I’m seeing more of the cancer of the cervix than any other cancer. I have seen cancer [of the] breast, I’ve seen cancer of the skin, cancer of the womb...But in my practice, I’ve think it’s cancer of the cervix.*

This response, paired with the other health care workers’ responses, highlights a commonality of reproductive cancers affecting women in Uganda.

After discussing common cancers in Uganda, their causes, and how they would describe the disease to patients, the five health care providers were asked more specifically about services provided at their health care facilities in regards to cancer care. When asked what type of breast cancer screening is available at their facility, the common technique discussed by all five health care providers was manual examination through massaging of the breasts. Simply palpating the breasts to feel for hard lumps under the tissue was a common practice at both the PHC and GHC facilities. In fact, at the PHC facility this was the only clinical breast exam they had available to offer patients. A health care provider at this facility explained that breast screening practices typically occur in the maternity ward during pre- and post-natal care. When asked about all other
women who present at the clinic for health care services aside from pre- and post-natal care, the health care provider noted that the examination is available to “those who request or those who have the complaints of breast cancer,” but exams are not routinely offered outside of the maternity ward.

At the GHC facility, two health care providers mentioned additional breast cancer screening techniques they have available, though their responses did not adequately match. One provider discussed the procedure he had often done for patients when he sees more extreme cases. For instance, this provider explained the process of conducting a needle biopsy to strengthen a diagnosis before referring the patient to Mulago Hospital in Kampala. Upon speaking with another health care provider at this same facility, they mentioned the use of an ultrasound machine which arrived at the facility recently. This provider explained that massaging the breasts is still the common screening technique, but the ultrasound machine can be used for further screenings. In the end, all five health care providers’ responses overlapped in regards the common use of physical exams for first-degree clinical breast screening.

This further sparked the question whether women who attend both these facilities are taught about breast self-examinations. Each health care provider explained that they provide lessons on breast self-examinations for women at their facility, only if the women request this information. One practitioner at the GHC facility noted, “Yes we teach them, especially how to massage and palpate the breast at discharge [from the maternity ward].” A similar theme emerged among the PHC health care providers’ responses. Commonly breast self-examinations were routinely taught in the maternity ward during pre- or post-natal care. A health care provider at the PHC facility explained, “For these other patients, they can do it [learn about breast self-examinations] when they come in for physical examinations.” In the end, at both facilities, the
option to learn about breast self-examinations is available, though it is not necessarily taught to all women attending the facility; most commonly it is provided to women in the maternity ward unless otherwise requested by the patient. This same theme was discussed earlier by women from the in-depth interviews who had ever received clinical breast cancer screening; that screening is only routine for pregnant women or women who have recently given birth. Subsequently, each health care provider mentioned the reality that only sometimes and quite infrequently do women come to their facilities complaining of signs and symptoms and suspecting to have breast cancer.

The health care providers were then asked what they would do for those women who end up at their facilities presenting with signs and symptoms of breast cancer, after providing a standard breast examination. All five respondents addressed the question similarly stating that referrals were the number one route after suspecting a breast cancer diagnosis for a patient. Specifically, all five health care providers mentioned referring patients to bigger health care facilities, such as Mulago Hospital in Kampala. Each health care provider further noted that even through referral is standard protocol, they will still commonly provide the patient with some counseling. A health care provider at the PHC facility explained, “Okay we first give counseling and we treat symptomatically. Like when they have pain, we give painkillers, then we refer to Mulago, Rubaga, [or] to where they prefer.” Care for the patient was still placed in high regard according to each of the health care providers from both facilities; referral was simply necessary in order for the patient to receive efficacious cancer treatment, since cancer screening services are all that are available at both the PHC and GHC facilities.

After discussing cancer care services provided through both facilities, the discussion turned to awareness programs about breast cancer, or cancer in general, that are offered to the
neighboring communities or patients who attend the clinics. A common thread throughout all five interviews was the inconsistent nature of cancer awareness programs. Each respondent mentioned health awareness activities that take place in the communities or at the health care facilities, but that topics on health often varied. In fact, there was never a guarantee that cancer or breast cancer specifically would be addressed at these talks or workshops. One provider at the GHC explained:

*Health education is supposed to be daily, but not that they are talking about cancer [of the] breast every time... The lady who comes today might hear about cancer [of the] breast, but the lady who comes tomorrow may not.*

A provider at the PHC facility also explained the irregularity of education on breast cancer and that more often than not breast cancer awareness was focused on during pre- and post-natal services. Overall, the topic of breast cancer is covered at times, whether it be during personal examinations or during health education sessions, but it is never consistent.

This segued into the conclusion of each interview by bringing a discussion of preferred breast cancer awareness initiatives they would like to see provided to neighboring communities. A health care provider from the PHC facility explained, *“Actually I would like to see sustainable funding to create more community awareness about breast cancer and then even breast cancer screening.”* The other provider at this same facility further mentioned the desire for stronger awareness and health education initiatives, *“Because for screening and treatment you refer them, but for awareness they first come here.”* This participant recognized the immediacy of their facility’s health care services because of its proximity and first-line treatment to community members. Other respondents at the GHC facility discussed the same reality and hope for stronger health education initiatives about cancer. When asked what they would like to see differently in regards to breast cancer awareness, one of the providers replied:
One is that [at] least people should be sensitized that breast cancer is here, that people can suffer from breast cancer. Then we should at least do every three months tell people, all people, to call to screen them, and I’m sure they would come, if we tell them.

This respondent approached the immediacy of needing regularly scheduled education sessions to cover the topic of cancer, specifically breast cancer, and furthermore, to provide routine screening services to all community members. Finally, a health care provider from the GHC facility explained:

*I think information should be given regarding early detection so that it can be properly managed in time so that we prevent dissemination of that cancer. And maybe we should also go to schools other than just communities around. Schools also need to be involved...And even men should know as well, because we know that some men control the budget in the home.*

This provider was the only one to mention the inclusion of family members beyond the individual woman in regards to awareness initiatives about breast cancer; that men specifically should be included because of their integral role in the household. In the end, each health care provider demonstrated a strong desire for more health care initiatives provided to nearby communities in order to strengthen awareness and sensitize individuals on cancer. A common theme was the need for regularity and sustainability in these sessions in order to best impact the community and provide adequate knowledge about health care and cancer care.

**Concluding Results**

Overall, the data presented in the preceding sections details information from all three groups of participants in this exploratory research study. In-depth interviews were conducted with 35 women within Nakirebe, two focus groups were conducted with women who did not complete the in-depth interviews within Nakirebe, and five semi-structured interviews were conducted with health care providers from health centers within Mpigi District that were most
commonly used by the female participants. In summary, the analyzed data presented above reflects demographic information, basic health-seeking behaviors, and attitudes towards cancer in general and breast cancer specifically. Various themes emerged from the in-depth interviews which overlapped with themes from the focus groups. The focus groups additionally provided insight into ways forward in efficacious cancer care within the rural setting of Uganda. Finally, the semi-structured interviews with health care personnel at both government and private health care facilities in the area also highlighted ways forward in the management of cancer screening and educational awareness initiatives. By triangulating this data, we can see where gaps exist in cancer care, management, and awareness in the rural setting of Uganda and how best to strengthen recommendations for sensitive and sustainable change; all of which will be discussed in detail in Chapter Five. The final section in this chapter details a workshop that was conducted in Nakirebe following the completion of data collection. This workshop brought information about cancer, and breast cancer specifically, back to the women who participated in the study as well as other women from within the community.

**Workshop on Cancer**

After data collection was completed, a team of researchers from International Health Sciences University (IHSU) and I returned to Nakirebe for the purposes of hosting a workshop discussing the basics of cancer and informing women about breast self-examinations. The workshop was open to all women who had previously participated in the in-depth interviews and the focus groups, as well as to any other women from within the community. The Vice LC, mentioned earlier in Chapter Three, helped to gather all the women at a convenient location in
Nakirebe; a woman’s compound which she offered for us to use for the purposes of our workshop.

The workshop consisted of a community health presentation defining cancer and providing information about causes, screenings, and treatments. It also included a presentation on how to conduct a breast self-examination. I presented all information in English, which was then translated into the native language of Luganda by my research associate, an employee of IHSU at the time. All women were provided a three-fold brochure in English and Luganda which detailed basic information about cancer and the step-by-step procedure for conducting a breast self-examination (see Appendix E for the brochures in English and Luganda). My research associate and I then demonstrated to the women through body movements how to conduct a breast self-examination. Information on cancer and breast self-examinations was gathered and synthesized from www.cancer.org. We further explained what should be done if anyone notices any abnormalities on or within their breasts, and provided the women with information on local health centers which can provide counseling and refer them to tertiary hospitals, likely Mulago Hospital, in Kampala. Upon conclusion of the demonstration, the women were provided the opportunity to ask questions and address any concerns.

Most questions asked surrounded the causes of cancer or the difference between types of cancer. My research associates and I did our best to answer questions based on information we had previous accessed, but were also honest with the women in explaining that we were not medical professionals and were not fully versed in cancer health care practices or information. We had prepared information on where women could go or who they could contact if they had any major concerns or needed further consultation. Once such contact was a doctor at IHSU.
In total, about 30 women attended the workshop. Initially, the location of the workshop was set in a woman’s compound outdoors. Shortly after, the rain came and forced us to move inside the bus we had driven from Kampala. The bus was able to seat all the women and provided a convenient space for the remainder of the workshop. Overall, women were enthusiastic and engaged in the workshop, asking questions at the end. Some women even took extra brochures such that they could pass them along to other members of the community who were unable to attend and help spread the information learned during the workshop, especially regarding the breast self-examination. The workshop was a success under the circumstances of the weather and having been planned somewhat impromptu post data collection. See Figures 5, 6, and 7, showing images from the day of the workshop on cancer.

**Figure 5**: Image of women gathering for the workshop on cancer. Photo taken by Martin Muganga.
*Women provided verbal permission to take and use their photo.*
Figure 6: Image of women gathering on the bus for the workshop on cancer. Photo taken by Martin Muganga.
*Women provided verbal permission to take and use their photo.

Figure 7: Image of research associate from IHSU and I talking to the women about cancer and breast self-examinations during the workshop on cancer. Photo taken by Martin Muganga.
*Women provided verbal permission to take and use their photo.
CHAPTER FIVE: DISCUSSION

The findings from this research support previous studies on breast cancer in Uganda and reinforce knowledge on the interaction between socio-cultural pressures and structural issues which dictate health-seeking behaviors and medical decision-making patterns. This research also highlights new information on perceptions of cancer, and breast cancer specifically, from a rural population of women not diagnosed with breast cancer, but with preconceived attitudes towards the disease and beliefs about diagnosis, screening, prevention, causes, and treatment. This chapter will critically explore the overall findings of this research with respect to relevant literature and research.

Discussion of Findings

Economics

An important finding from this study is that of the 35 women who participated in the in-depth interviews, the majority earned an average of about 50 to 60 US Dollars per month, which remains substantially below the gross national income per capita estimated for all of Sub-Saharan Africa. Furthermore, of the women who had male partners, which was the majority of participants, most were unaware of their partner’s monthly earnings, as he was unwilling to share the amount of income he earned or further share tangible monetary benefits. For these women, either their personal monthly income was substantially low or they had no personal income at all, demonstrating a lack of financial autonomy for these female participants. In fact, the reality of a
lack of women’s financial autonomy was also addressed by one of the local health care providers from the government health care center who pointed out that the women in rural households face financial uncertainty because as the head of the household, the man controls the finances. This further impacts health-seeking behaviors for the women when attempting to access health care services on little personal income and minimal or restricted help from their male partners. Even if financial assistance was provided by male partners, it was strictly controlled such that the woman and any children were directed where and when to access health care, as was seen by a couple participants in the demographics section of Chapter Four. Overall, this remains an important contribution to the analysis of the study’s findings and a better understanding of women’s health-seeking autonomy and medical decision-making patterns.

According to the World Bank (2016), data from 2014 indicate that the average yearly gross national income (GNI) per capita in Uganda was at 670 US Dollars. This amounts to about 55 US Dollars per month, which is in line with the average earnings of the majority of the women who participated in this study. This average income, however, rests substantially below the GNI per capita in 2014 for all of Sub-Saharan Africa (World Bank 2016). In fact, the GNI per capita for Sub-Saharan Africa at this time was about 1600 US Dollars per year, which equates to an average of about 133 US Dollars per month; over double the GNI average seen in Uganda (World Bank 2016).

When comparing the GNI in Uganda to that of all of Sub-Saharan Africa, we can see that women in this study who earned a monthly personal income of about 50 to 60 US Dollars or had no personal income often faced financial hardship in providing for their households. This is especially the case for women with no personal monthly income and male partners who refused to share their personal income. In fact, the majority of women had at least three or more
biological children. Their monthly fees relating to food, household supplies, school supplies, and transportation costs would sustainably deplete their monthly earnings.

It is important to further note that most of the women interviewed said they spend an average about 10 US Dollars per month on medical services or health care needs for themselves or their immediate family. In this regard, an important factor related to why women chose certain health care facilities over others for their basic health care needs was due to finding cheaper services, next to receiving satisfactory patient care. Overall, finances played a pivotal role in the daily lives of the female participants in this study. In fact, financial status shaped the majority of decisions made by these women and even carried substantial weight in the shaping of attitudes towards breast cancer, and cancer in general.

Economic stability becomes especially relevant when discussing women’s perceptions of breast cancer, or any cancer diagnosis; that the disease is financially debilitating. When women spoke about their perceptions of breast cancer, most women attached a breast cancer diagnosis to death because of the grueling expenses involved. Women spoke about not only how this disease would cause personal financial problems, but also how this disease would burden extended family members. In fact, when the women were asked how they might handle a hypothetical cancer diagnosis, most women mentioned the need to inform family such that they can provide not only emotional support, but also, and possibly more importantly, assist financially.

In the end, women’s fear of extreme financial burdens in the face of cancer is not misled. Cancer care in Uganda is sustainably high compared to the average monthly income for women in this study. In fact, surgery at the comprehensive Uganda Cancer Institute in Kampala averages about 500,000 Ugandan Shillings; about 200 US Dollars (Nantume 2015). Furthermore the six cycles of recommended radiotherapy cost about 200,000 Ugandan Shillings per session;
averaging about 80 US Dollars per six sessions (Nantume 2015). Already, the total cost of a breast cancer diagnosis could average about 680 US Dollars; just above the average GNI per capita for a year in Uganda. Women’s fear of financial deficits when thinking about a cancer diagnosis is justified, and their need to seek support from family and possibly even friends ends up being a necessity in order to receive adequate treatment. An additional reality for the women in this study living in a rural setting is their distance from the Uganda Cancer Institute. These women would have to calculate an additional expense for transportation in order to reach adequate cancer care services in Kampala. Overall, the reality of cancer in low-income countries and rural settings, such as in Uganda, harnesses a justified fear.

**Attitudes and Perceptions**

Attitudes and perceptions towards cancer varied, highlighting specific themes that emerged throughout the in-depth interviews and focus groups when discussing cancer in general or breast cancer specifically. Overwhelmingly, women referred to cancer, and specifically breast cancer, as a death sentence; that it is a fatal disease causing a wound that never heals and will inevitably lead to death. This finding supports those found in previous studies discussed in Chapter Two, where death was commonly seen as an outcome of breast cancer primarily among women already within the clinical setting (Gonzaga 2013, Koon, Lehman, and Gralow 2013). In this study, often times this immediate connection with death was in direct correlation to high financial costs of a cancer diagnosis, which was discussed in the preceding section. Not only did women see barriers in finding life-saving cancer treatment, but they also understood cancer to be a troubling disease with no cure. In this regard, cancer was seen as painful and a “wound that never heals,” subsequently leading to death.
This highlights the need to think critically about screening measures in cancer care, specifically breast cancer screening techniques available to women in rural settings of low-income countries. One study by Galukande and colleagues (2014) involving women recently diagnosed with breast cancer in Uganda found that delays in treatment were excessive, particularly among women living in rural areas who faced geographical and socio-economic barriers to receiving life-saving treatment. This factor of extreme prolonged delay contributes to the high percentage of advanced stage diagnoses in breast cancer, therefore lowering the overall survival rates (Galukande, Mirembe, and Wabinga 2014). The authors found that the mean delay in seeking treatment for patients in their study was 29 months, with the maximum delay at 100 months, and that most women discovered their lumps incidentally through self-massage but then presented to the hospital late due to limited accessibility and affordability (Galukande, Mirembe, and Wabinga 2014). These factors warrant a need to investigate more critically why women delay in seeking breast cancer treatment or even early screening.

A similar study, published one year later by Odongo and colleagues (2015), looked at delay in treatment for women recently diagnosed with breast cancer in Uganda, and found that most often this delay is attributed to a lack of social support, perceived seriousness of the disease, and a lack of knowledge about available services. The authors found that nearly 90% of their 162 participants delayed seeking treatment by more than three months, with a total median delay of 13 months, and almost 50% of the participants had perceived their symptoms at onset as not serious enough to warrant the need for medical attention (Odongo et al. 2015). Additionally, the authors found that when social support, mostly from family and spouses, was lacking, the chance for longer delay periods was much greater (Odongo et al. 2015). If women face challenges in accessing adequate social support from family and spouses, who previously
demonstrated not only emotional but also financial support, and if women do not perceive breast cancer as serious or are unaware of health care services available to them, then a closer look at actual attitudes towards and knowledge about the disease prior to onset is necessary. This research study has done just that.

With a critical medical anthropological perspective, we can see that “people develop their own individual and collective understandings and responses to illness and to other threats to their well-being” (Singer and Baer 2007, 34). Through a critical lens we can assess that women in Uganda faced with a breast cancer diagnosis will be guided by perceptions held in regards to the disease prior to their diagnosis. This means that an examination of these preceding attitudes towards breast cancer, and cancer in general, will shape health outcomes.

So what are Ugandan women’s perceptions of breast cancer, particularly those currently without a breast cancer diagnosis? The findings from this study reveal that women who participated in the interviews and focus groups hold internal fears of a cancer diagnosis because they know the disease to be life-threatening, painful, incurable, exhausting, and financially burdensome, not only for themselves, but also for their immediate family and social support line. Perhaps understanding these factors before investigating the actual delay of a breast cancer diagnosis can shed more light onto women’s existing perceptions of the disease, and therefore, anticipate health-seeking behaviors that dictate preventive and screening steps within reproductive health care, long before an actual cancer diagnosis.

Recognizing the importance of knowledge about breast cancer prior to any diagnosis is critical in the shaping and implementation of any breast cancer awareness initiative or treatment outreach. In fact, one article looking a national framework for the management of breast cancer in Rwanda puts forth a list of recommendations, including rigorous training and education within
the health care field, better care-delivery improving access, patient-centered care with direct sensitivity to psychosocial health beliefs and behaviors, and critically informed breast cancer research (Murthy et al. 2015). Though the authors do not directly highlight the need for in-depth on-the-ground studies looking at perceptions of the disease, even prior to a breast cancer diagnosis, their recommendation for patient-centered care informs this need. Because women in this study viewed breast cancer as a fatal disease that brings pain and financial distress, patient-centered care initiatives can be well-informed on attitudes towards the disease which in turn dictate health-seeking behaviors, in particular breast cancer screening practices, those self-induced and those clinically based. In fact, stronger awareness initiatives that provide women, and even their family, adequate information about cancer and breast cancer specifically has the potential to lessen the fear associated with the disease. If women are knowledgeable about the disease and furthermore understand how to prevent, screen for, and treat the disease, then fear has a better chance of subsiding. A recent study in Jordan conducted by Taha and colleagues (2012) found that women with no history or symptoms of breast cancer perceived the disease with fear; that breast cancer is incurable, will diminish femininity, and will cause hardships within family units. Their findings are similar to this study’s and further demonstrate recommendations for designing health interventions that teach women about early detection, show survivor stories through inclusion of breast cancer survivors in awareness initiatives, and involve family in the process of encouragement for better breast health (Taha et al. 2012). In fact, a recent study in Uganda conducted by Koon and colleagues (2013) and discussed earlier in Chapter Two highlights the critical role played by breast cancer survivors in education efforts; that survivors can give testimony to the lived-reality of breast cancer in Uganda by providing women knowledge about cancer control and management.
This further demonstrates a critical observation in breast cancer research where there is a need to investigate first-hand knowledge of the disease prior to clinical diagnoses; knowledge that is structurally shaped by cultural, social, and economic influences which govern human behavior. This was in fact revealed during the focus group discussions when women raised points about not understanding the positive benefits of early screening and knowing one’s breast cancer status. The negativity attributed to a breast cancer diagnosis simply perpetuated fears and delayed a woman’s actions in cancer management. If we are to better understand health-seeking behaviors and “recognize the physical, emotional, social, and spiritual needs of the patient” (Murthy et al. 2015, 6), then we must, as critical medical anthropologists, recognize the initial collective attitudes towards breast cancer. These early attitudes towards the disease, beyond the clinical setting, have the power to catalyze effective awareness initiatives that are sensitive to personal beliefs and structural barriers that shape health-seeking behaviors at the primary and secondary level of health.

Equally relevant in perceptions of breast cancer are beliefs about causes of the disease. In this study, the majority of women in both the in-depth interviews and focus groups discussed causes of breast cancer, and even cancer in general, as regular contact with artificial substances or germs and/or any form of irregular breastfeeding practices. Some women even mentioned the cause from certain types of food or hereditary connections. In the end, these women present many partial truths in their beliefs about breast cancer causes. In fact, in an earlier chapter I discussed what the National Cancer Institute (NCI) highlights as major risk factors for cancer. In particular, they mention cancer-causing agents in the environment, or carcinogens which when exposed to such agents, the body’s genes can undergo changes causing abnormal cell growth (NCI 2016a). Women in this study mentioned the harm that contact with certain artificial
substances or carcinogens in the environment can cause to the body, such as chemicals found in bodily perfumes and lotions or contact with various metals found in bras or on cooking ware. These partial truths are indicative of information these women previously received over the radio or during community outreach events by health care providers. Some misconceptions were then formed from possible misinterpretations of health information, such as the belief that money held near the breasts could cause breast cancer. This is evident when remembering discussions from women in the focus groups who emphasized the need for local health care campaigns run by local Chair persons from within the village who are familiar with the local dialect and cultural norms.

Other women mentioned diet as a major factor in the development of cancer, which is also highlighted by the National Cancer Institute as a potential risk factor (NCI 2016c). Though much of the information on dietary risk in cancer development is inconclusive, the connection between food intake and cancer is still believed to have some type of correlation (NCI 2016c). In fact, as mentioned in Chapter Two, some literature has pointed towards the adoption of “westernized” lifestyles in low-income countries such as Uganda, specifically in regards to eating habits (Parkin et al. 2010, Porter 2008, Wabinga et al. 2014). The adoption of this externally influenced dietary lifestyle rich in fatty and processed foods has led to higher rates of obesity which is seen in direct correlation with cancer risk (NCI 2016c, Porter 2008). Findings from this study demonstrate that some women recognized this connection between diet and cancer and understood the risk factors involved. Though women did not directly mention fatty foods, they did acknowledge the poor diet consisting of processed foods, rather than garden grown products, and even diets high in sugar.
Furthermore, some women acknowledged the connection between breast cancer and inheritability; that if one family member has the disease, then any other family member is at risk of developing the disease. Beliefs about inheritable cancer are seen across the literature in low-income countries (Mwaka et al. 2014). Some women in this study understood the connection between cancer and family history of the disease and were not off-target in their belief. The American Cancer Society (2016a) discusses the reality of family cancer syndromes which arise from sharing similar risk factors with family members, such as smoking or obesity, or having the presence of an abnormal gene which is passed down from one generation to the next.

The idea of breast cancer as an inheritable disease was only expressed among a few women; nevertheless, it points towards a need to further investigate beliefs about inheritable cancer in low-income countries. Do the women who recognized familial risk of breast cancer understand the risk at a genealogical level or believe it to be viral in the blood? This question is justified when reflecting on the woman in particular who believed the disease was passed down in the family through instant blood transmission; when she highlighted that being pregnant and having breast cancer can cause the spread of the disease to the baby. What are local beliefs about genetic predisposition or even the inheritance of certain behavioral patterns? Understanding this can point towards more culturally sensitive educational initiatives which recognize local beliefs about the body before engaging in instruction of how cancer affects the body.

This brings attention to women’s perceptions that cancer in general is caused by contact with germs. Specifically women in this study addressed the belief that cancer is a blood-borne disease which spreads through contact with infected bodily fluids, such as blood and the use of someone else’s razor blade which was discussed by a participant in Chapter Four. Other women believed cancer to be related to poor hygiene; that a woman who does not clean herself
adequately, especially the breast with regard to breast cancer, will be at high risk of developing cancer. Furthermore, HIV/AIDS and syphilis were even compared with cancer as being similar, if not the same type of disease. Women’s general perceptions of germs, poor hygiene, and viruses causing cancer carried with it many misconceptions. Based on this knowledge, it is important to investigate a deeper level of women’s beliefs about viral infections, poor hygiene, or germs triggering cancer risk. What information is being relayed to women in regards to causes of cancer? How are women then digesting this information based on their cultural construction of the human body and illness and disease? In regards to cervical cancer and the direct link with the human papillomavirus (ACS 2016b), it could be postulated that these women’s ideas about causes of cancer are skewed from an understanding of other types of cancer, such as cervical cancer. There have also been studies in Uganda that have regularly assessed the connection between HIV/AIDS and cancer risk and how the co-morbidity of both diseases drastically affects survival (Coghill et al. 2013, Mbulaiteye et al. 2006). One study in particular examined the high increase of Kaposi sarcoma, non-Hodgkin lymphoma, and cervical cancer among HIV/AIDS patients in Uganda (Mbulaiteye et al. 2006). Are women drawing conclusions between viral infections and cancer due to the often co-morbidity of these diseases, of which they witness first-hand? How are women’s observations between germs, poor hygiene, and viral infections further shaping their belief that cancer, specifically breast cancer, fits into the category of communicable infections and diseases?

The majority of women in this study also referred to childbirth and breastfeeding as a key component in breast cancer risk. Though some women believed breastfeeding for too long a period or too short a period or irregularly throughout a baby’s first few years could lead to breast cancer, their perceptions are not misguided. Various institutions across the United States have
studied the potentially protective factor of breastfeeding in regards to specifically breast cancer, though other reproductive cancers have also been associated (Cordeiro 2014). In fact, a study conducted by the Collaborative Group on Hormonal Factors in Breast Cancer (2002) found that the relative risk of developing breast cancer decreased by about 4% with every consecutive and exclusive 12 months of breastfeeding. The American Institute for Cancer Research (2016) explains that the observed protection of breastfeeding is related to hormonal changes which occur during lactation, such as the delay in menstrual periods, therefore reducing a woman’s exposure to estrogen, the main hormone linked to breast cancer risk.

Although women in this study did not explain the connection of breastfeeding to breast cancer risk or reduction in the same manner as understood by cancer researchers in the United States, they still made the association; an association they had been ambiguously informed of a time before by medical personnel, family, friends, or community acquaintances. Their belief that somehow breastfeeding is directly connected to breast cancer, though misleading, still demonstrates a connection between a certain action and a disease. This is also true when discussing women’s connection between artificial substances in the environment and breast cancer risk or the common belief by some women that if one family member has breast cancer that means it runs in the family and will be inherited.

This demonstrates the need to examine further information provided to women regarding breast cancer awareness. In thinking critically about such initiatives, it is important to reflect on how cancer awareness is relayed to communities, what information is being digested by the community members, whether the information is given in local tongue, how ambiguous is the information, who is providing this information to the community, and how often is this information being presented. In the interviews with the health care providers, when asked how
they would describe cancer, and breast cancer specifically, as well as the causes of cancer to a patient, their explanations were dependent upon a biomedical terminology that is indicative of their higher level medical trainings. It is important to remember that the majority of these women in this study had a partial secondary level education (equivalent to completing sophomore year of high school in the United States), while only five women received vocational or tertiary education. Medical information provided at the clinical level and the doctor-patient relationship are vital to informing cancer awareness initiatives that are culturally sound and delivered at a level of understanding conducive to the population.

In an article looking at efficacious cancer control in low-income countries, Hanna and Kangolle (2010) highlight the limitations in quality of and access to cancer services, specifically first-hand information about cancer. The authors note that in low-income countries the issue of “modest or limited health care worker training in basic principles of oncology and sometimes even a lack of awareness of the curability of cancer” often places strain on awareness campaigns (Hanna and Kangolle 2010, 4). In fact, they further discuss the need for health services research at the community level in rural settings to play a key role in “improving awareness on these fronts, informing communications and targeting messages as effectively as possible” (Hanna and Kangolle 2010, 4).

The effective offering of cancer information is critical, especially in rural communities of low-income countries where cancer is still believed to be a “new” disease or a disease which lacks information, as many of the women in this study stressed. Often times, women would answer “I don’t know” to a mixture of questions during the interviews and focus groups before explaining their thoughts or simply stopping. When women did go further to explain their perceptions of breast cancer and its causes related to breastfeeding or contact with artificial
substances, they were often times not confident in their response or sought reassurance from the interviewer on whether their response was correct. Overall, women were very interested in learning more about cancer, and breast cancer specifically, or equally interested in being reassured that their current perceptions were right or wrong. This highlights the need for awareness initiatives, culturally sensitive initiatives, socio-culturally relative initiatives, and locally communicated awareness campaigns. In fact, women in the focus groups and health care providers in this study discussed this need; that more information on cancer, information that is easily interpreted and culturally relative, needs to be brought to these rural communities on a regular basis.

It remains important to discuss here the impact of the rising cancer incidence and mortality in Uganda. Studies reveal that cancer is on the rise in low-income countries, specifically that there is to be a projected 75% increase in cancer incidence in low-income countries by 2020 (Hanna and Kangolle 2010, Parkin et al. 2010). In Uganda specifically, breast cancer has been seen at a nearly 4% rapid annual increase (Wabinga et al. 2014). Women in this study recognized the alarming increased occurrence of cancer as they discussed their fears of the disease. About 40% of the women interviewed admitted to fearing a personal breast cancer diagnosis at some point in their lifetime. They recognized the growing incidence of breast cancer in Uganda and even witnessed close friends or relatives being diagnosed with the disease.

Interestingly, the other 60% of women who did not regularly think of being diagnosed with breast cancer attributed this to not wanting to know their status, never feeling alarming changes in their body, or never knowing a person diagnosed with the disease, therefore not believing the disease to be close to them. This highlights the reality of cancer as a “new” disease in certain areas of Uganda. In fact, only five women interviewed had ever witnessed a relative
with breast cancer; all other participants had never personally interacted—that they were aware of—with an individual diagnosed with the disease. It is not to say that women who do not think about being diagnosed with breast cancer are wrong, but rather it demonstrates the need for stronger awareness initiatives that provide adequate knowledge about cancer in a culturally sensitive and appropriate manner. This means explaining to women the reality of breast cancer; that the disease, including many other types of cancers, have various risk factors involved in their development. These risk factors are potentially evident in everyone’s life, therefore, require awareness such that individuals have the choice to take action in maintaining their health. With awareness comes the onset of action to take control of one’s health; a movement towards empowerment, which will be discussed in detail in a later section of this chapter.

It is important to discuss the ideas of early and late diagnoses that were addressed by many of the women in both the interviews and focus groups; that simply an early diagnosis is better than a later diagnosis which will often result in immediate death. Most women in this study were aware of cancer as a progressive disease that develops over time and escalates in severity. Though most women related breast cancer to death, they saw the importance of early treatment in order to prolong life or make the disease more bearable. The American Joint Committee on Cancer (2016) defines staging in cancer as the process by which cancer has developed in the body; meaning how much cancer has actually grown and where it is found in the body. Cancer is often identified based on four different types of staging, where stage one is less severe than stage four (AJCC 2016). Women in this study might not have referred to the actual concrete definition of staging in cancer, but were mostly aware of the fact that cancer progresses and will steadily worsen if untreated.
This relates back to the previous discussion on delaying cancer management upon facing a diagnosis. In their study on why women delay receiving breast cancer treatment in Uganda, Odongo and colleagues (2015) found that this could be in part due to women not perceiving the severity or seriousness of the disease. Findings from this study offer a different conclusion. Though none of the women in this study were diagnosed with breast cancer, their perceptions of the disease highlight ideas about breast cancer formed long before a potential diagnosis. In fact, most of the women in this study understood the severity of breast cancer, or cancer in general, and that the disease will lead to death immediately if not treated early on. Women were aware that while cancer treatment might not save a person’s life, it can at least prolong life or aide in symptomatic management of the disease, such as reducing pain that was often discussed by the women as a common outcome of cancer.

In the end, results from this study demonstrate that most women believed breast cancer to be a serious disease, so serious in fact that a woman would likely die from the disease, but that early treatment could help to possibly save her life or simply prolong it. This illustrates a need to examine further other structural barriers to accessing cancer care which women might face upon learning of a breast cancer diagnosis. Women in this study often pointed towards financial burden, lack of social support, and limited access to cancer care as key barriers to cancer management both at the screening and treatment levels. Another key barrier identified by the women in this study is internal fear of the disease. In fact, most women in this study were aware of the seriousness of breast cancer, so much so that fear overwhelmed them. Fear of being diagnosed with the disease, fear of dying from the disease, fear of the disease burdening their family, and fear of the disease hindering their womanhood to bare and raise children. It is remains important to ask, how fear internally shapes an individual’s health-seeking behaviors.
Furthermore, how does fear along with tangible structural barriers restrict access to primary, secondary, and even tertiary health care? These factors need further investigation in better understanding delays in cancer management, especially within the rural setting.

Knowledge about cancer sites, and understanding cancer in its various forms throughout the body, among women in similar rural settings is also important to further investigate. Though this research study primarily focuses on attitudes towards and beliefs about breast cancer, a segment of the research gathered women’s perceptions about cancer in general, even asking what types of cancer the women believed to be the most common. The majority of women identified breast and cervical cancer as the most common types of cancer affecting women in Uganda. Furthermore, the health care providers interviewed also recognized cervical cancer as the most commonly seen throughout Uganda. It is important to note here that with regard to cervical cancer, most women identified this disease in connection with uterine cancer. How does knowledge about common cancers within one region affect local women’s attitudes towards the disease and health-seeking behaviors in regards to prevention, screening, and even treatment? This highlights the need to address cancer awareness with specific regard to types of cancer; better informing communities that cancer might be explainable as one type of disease, but how it affects certain sites on the body determines health outcomes.

As mentioned in Chapter Four, the native language of Luganda, which all women in this study spoke, refers to the cervix and the uterus as nabana; one general female organ where the baby develops and is birthed. Often times, women did not discern between the two body parts but acknowledged that cancer of the cervix would also relate to cancer of the uterus. This has also been seen in a previous study looking at women’s perceptions and beliefs about cervical cancer in Northern Uganda (Mwaka et al. 2014). Mwaka and colleagues (2014) found that
women’s knowledge about the anatomy of female reproductive organs and about where and how
cervical cancer affects a woman, was not accurate from a biomedical perspective. In fact, the
authors report that women referred to the cervix using local names that sometimes did not
differentiate between the cervix and the uterus. They suggest that health information should take
into account this local terminology with regard to educating women about reproductive cancers
and about the differences between anatomical sites (Mwaka et al. 2014). These authors’ findings
are directly related to findings from this study which unveil the same issue in discerning
anatomical organs, specifically in not seeing a difference between cervical and uterine cancers. It
is not to say that local beliefs about the body are incorrect, but it highlights the need to recognize
such language differences and adapt a culturally relative bio-medically structured educational
campaign; one that takes into account cultural beliefs about the body which shape an
understanding of illness and disease.

**Health-Seeking Behaviors**

After examining in detail women’s perceptions of and attitudes towards cancer, and
breast cancer specifically, it remains important to discuss women’s health-seeking behaviors in
regards to cancer care, specifically screening activities, since no woman in this study had been
diagnosed with breast cancer. As outlined in Chapter Four, when asked about basic health care,
the women were almost evenly divided in their preference for private health care facilities versus
public ones. Subsequently, women were asked if they knew whether clinical breast cancer
screening services were offered at their preferred health care facility. The responses varied
between women who believed they could seek such screening services at their preferred health
care facility, those who believed they could not, and those were unsure. Furthermore, there were
discrepancies between the answers, where some women spoke of the same health care facility when saying they believed clinical breast cancer screening was offered there compared to another woman who believed it was not.

This points towards an argument in health equity, since different women referring to the same facility had conflicting information about clinical services offered at that institution. This suggests a failure on the part of the health care system to adequately inform its patients of the variety of services offered at its establishments, especially about screening and prevention services meant to maintain women’s reproductive health. By triangulating the research findings in this study from the women individually interviewed, to the focus groups, to the health care providers, there exists a disconnect between what the women understood about cancer care and had learned from previous teachings compared to what the health care providers claimed they are relaying to women at the clinical setting. Equity in health care has been widely discussed across the globe within various health arenas, especially within low-income countries (WHO 2010). In fact, the World Health Organization in 2004 established a Task Force on Research Priorities for Equity in Health which spelled out research priorities on the policy agenda (2010). Specifically in Uganda, the discussion of health equity in health care services has attempted to identify gaps in health care and to revitalize primary health care services, especially among socially disadvantaged communities and through policy change and immediate action (Orach 2009).

An individual not educated on the basis of health care might not be aware—and rightfully so—of what is expected of them in reference to personal health care management. When should a woman be clinically screened for breast cancer, or for other cancers such as cervical or ovarian? How often should these screenings take place? What is the purpose of such screenings? These are questions upon which every woman has the right to be informed of, yet all too often
does not have the privilege of acquiring. Findings from this study demonstrate the failure of health care services in this rural setting of Uganda to achieve this capacity of health equity, for “coherent actions across government sectors including…education…and health at all levels are essential in improving health equity” (Orach 2009, S50). Based on findings from this study, health care providers believed they were providing adequate and comprehensible information about cancer and cancer care to women in this rural setting, however, knowledge acquired by the majority of women in this study suggests a disconnect from accurate information about cancer.

The lack of health equity is further demonstrated through a discussion of results from the health care interviews. It is important to note that the five health care providers from the two health care facilities, one private and one public, were sometimes discrepant in their explanations of the types of clinical breast exams that are available at their facilities. In fact, at the government health care facility, one provider mentioned the personal use of needle biopsies when facing a severe cancer case, while another provider mentioned the existence of an ultrasound machine to conduct breast exams. Information given by these health care providers where not shared amongst each other. This poses an issue with transparency in the health care workforce between providers from the same institution. The lack of transparency has the potential to structurally hinder a patient’s access to the proper screening or treatment service they need. Furthermore, there was a consistent theme throughout the health care provider interviews that manual clinical breast exams were most often performed only among women receiving pre-and post-natal care. Women who have not yet given birth and who may never give birth are excluded from breast examinations unless they have knowledge and will request an exam from their provider. The lack of health equity is paramount here when observing discrepancies in the groups of women who have access to certain cancer screenings.
This highlights another key area for discussion. Of the 35 women who completed in-depth interviews, only nine had ever received a clinical breast examination. Furthermore, these nine women had only received this examination once or twice in their lifetime, yet were in their mid-20s to mid-30s. Of the 26 women who never received clinical screening for breast cancer, 19 believed they knew where they could go if they wanted to receive screening, and seven were unsure. This mixed array of knowledge about cancer screening services, access to such services, availability of such services, and even affordability of such services is dependent upon the standards of health equity within this setting.

In Uganda, much of the research on health equity has looked specifically at financial burden and how policies should address the health needs of the marginal and poor communities (Kwesiga et al. 2015). In fact, health care in Uganda more often than not places less attention on poor disadvantaged communities than on the rich or proportionately less needy populations (Kwesiga et al. 2015). Women in this study live in a rural setting of Uganda where access to and knowledge about different reproductive services is sparse. Though either private or public health care clinics are nearby and widely accessible—per the means of distance—to the population of women interviewed, a deeper look at health equity is needed in order to determine where and why discrepancies in health information exist. For instance, why did women in this study speak about lack of or misguided cancer knowledge within their community, yet the health care providers did not address at length the struggle women in this rural setting face to access and afford health care services, specifically cancer screening services?

Another important finding to discuss is in regards to breast self-examinations. Less than half the woman interviewed claimed they knew how to conduct a breast self-examination. These women further indicated that they learned these techniques from family, friends, traveling
nurses, or were simply self-taught. In some studies looking at women’s knowledge of breast self-examinations, use of the technique is associated with a stronger sense of self-efficacy which aides in the foundation of cancer control by the individual (Loh and Chew 2011). Another study suggests that part of the awareness that contributes to learning breast self-examinations is confidence building which in turn increases self-efficacy and therefore results in better screening practices for early detection of cancer or even prevention (Jirojwong and MacLennan 2002). Women’s lack of awareness about the importance of breast self-examinations warrants a discussion of self-efficacy and even empowerment. Can awareness of breast self-examinations demonstrate a step forward in female empowerment among disadvantaged groups?

Research has shown controversy in the promotion of breast self-examinations due to its lack of beneficial evidence or even adequate techniques which can be difficult to master or employ (McCready, Littlewood, and Jenkinson 2004). Whatever the truth behind this statement, “one could argue that the ability of women to make their own health care decisions is being undermined because of the lack of clarity in the BSE debate” (McCready, Littlewood, and Jenkinson 2004, 575). In the end, it must be realized that “the potential of BSE for detecting breast cancer in early stages far outweighs the negative feelings women may experience when engaging in the practice” (Kline 1999, 136). This is especially the case in resource-poor settings where access to health care services might be challenging due to financial or social barriers. Furthermore, where health equity might fall short in these resource-poor settings, self-efficacy and empowerment of the individual have the potential to increase health awareness and self-preservation.

Women in this study, in particular, who lack financial autonomy or fail to receive services which are beneficial to reproductive health could benefit from gaining the skills related
to breast self-examinations, therefore strengthening their self-efficacy and health equity. By triangulating data from this study, we can see that women from both the individual interviews and focus groups confirmed that health-related knowledge is allocated through social circles more so than through clinical settings, even though health care providers did not acknowledge this social system, but rather were under the impression that most health-related information came from the health care setting. There is a clear disconnect between community knowledge about health care, specifically cancer care, and physicians’ belief that they are providing accurate and comprehensible health-related information to their community. Such an apparent disconnect points towards the need for community advocacy and individual empowerment with regards to health management and cancer care.

This demonstrates an opportunity for shifting the control of knowledge, where women who are well-informed on breast self-examinations can aide other women in learning the techniques involved, therefore, strengthening community empowerment. In fact, this study provides evidence that women share knowledge with each other in order to create a stronger knowledge base; women mentioned how most of the information they learned on cancer was through family and friends and at times from medical providers. Furthermore, women who attended the workshop on cancer we offered after data collection were more than willing to share the knowledge they gained from the workshop with women who were unable to attend. In the end, more research needs to be conducted which looks at community engagement in awareness campaigns regarding cancer care. Furthermore, research needs to be done which investigates how breast self-examinations could shape self-empowerment for women and how health equity and self-efficacy can be strengthened through awareness initiatives within the community.
CHAPTER SIX: CONCLUSION AND RECOMMENDATIONS

This final chapter presents the conclusion and recommendations related to cancer care. Recommendations are outlined based on their applicability to advancing cancer care in the rural setting of Uganda and on how well they inform applied anthropology and public health. A discussion of how this research contributes to anthropology and public health will then be highlighted. Lastly, the study’s limitations will be traced to inform the success and shaping of future research in this area.

Recommendations and Future Research

Based on the findings from this study, a number of recommendations have been formulated:

1. Routine educational/awareness workshops need to be implemented in the rural setting of Uganda. These workshops should be designed and delivered in collaboration with local Chair persons of villages and local health care facilities, as well as with the Uganda Cancer Institute. The workshops need to be led by local Ugandans and in the respective native tongue of the community and furthermore at an appropriate educational level of the target population. The information disseminated during these workshops needs to dispel misconceptions about cancer and educate about the known causation and prevention, screening, and treatment measures for all types of cancers, specifically addressing female related cancers. Is it imperative that information about cancer be
delivered in a manner that is comprehensible by the local community, including not only the women but also the men of the community. These workshops need to be implemented routinely and encourage the inclusion of all women and their families from within the targeted community. Cancer education which demonstrates a local route towards implementation and dissemination, as well as defines the disease at an educational level relatable to those targeted, is sure to spawn greater success in cancer awareness and routine cancer management.

2. These workshops also need to build a community network of female advocates in cancer knowledge and management. These advocates should be women from within the community who acquire accurate knowledge about breast cancer, and cancer in general, dispelling misconceptions about the disease, in order to become sponsors of this information for other women within and nearby the community. The female advocates need to be trained as community health workers and liaisons between biomedical doctors and female community members. Their position as community health workers and liaisons can help to disseminate knowledge on cancers affecting women in Uganda as well as inform communities about screening practices available to them. In particular, they need to be well-versed in breast self-examinations and share this knowledge with other women in the community. This creates an extension of the workshops beyond the one event and builds a network of accurate information sharing and female empowerment. More importantly, this aids in the community level sharing of sensitive and relevant cancer information which is otherwise misinterpreted through biomedical channels of health care education.
3. Access to cancer care in the rural setting needs to be revamped. This entails policy change at the government and private sectors of health care. Though this recommendation poses major challenges for implementation, it cannot go ignored and unopposed. The major need is to implement routine cancer screening and preventive measures within rural health care settings. This means training health care personnel on cancer care and management, instilling routine cancer screenings during all female patient visits, and partnering with local communities to engage in routine educational sessions on health care and cancer care. Furthermore, information on cancer at the clinical setting needs to be recrafted by local physicians such that facts about the disease and screening practices are grasped by community members who do not have similar training in health care and biomedicine. For instance, biomedical messages about cancer care must conform to the targeted community at an appropriate and relevant educational level; one which is digestible by the recipients of the message.

4. A final recommendation is for the extension of cancer support groups to rural settings of Uganda. Currently, there are few support groups for cancer in Uganda (UICC 2016b). Strengthening of such support groups and extending them to rural settings could build a bridge between cancer knowledge outside of the clinical setting and cancer realities from within the clinical setting. A central message that needs to be conveyed through these support mechanisms is that people can face a cancer diagnosis and survive. If women can interact with other women who openly speak about their cancer experience and provide first-hand insight into how someone can survive the disease, than women have the opportunity to better understand cancer and gain advice in how to be proactive in their own health care management. An important extension of cancer support must also
include familial support and community level support. Generating awareness about cancer in order to initiate support means involving the unit which extends out from the women within the community, encompassing spouses, partners, parents, children, siblings, extended relatives, neighbors, and friends.

In addition to the implementation of the above recommendations, is it important to discuss the need for future research. Overall, future research is needed when looking at cancer care in low-income countries where access to preventive, screening, and treatment services is scarce. Mixed-methods research needs to be conducted such that the quantitative component of data collection and analysis is not lost, however, the qualitative component is enriched and strengthened in order to inform the exploration of cancer knowledge, perceptions, and beliefs. This is especially the case when recognizing that most previous research on cancer in Uganda has been quantitative in nature and clinically centralized (Coleman et al. 2008).

Furthermore, research needs to look at the outcome evaluation of potentially existent cancer awareness campaigns within other rural settings of low-income countries, most especially those in Eastern Africa. This would also entail a deeper look at how best to implement the above recommendations through culturally sensitive and sustainable measures. Overall, any future explorations of cancer knowledge and beliefs need to be examined within the realm of cultural sensitivity and relativity, such that local beliefs and values are understood and recognized as a critical influence on health behaviors and decision-making patterns prior to reaching the clinical setting.

More research needs to explore health equity within rural health care settings. This research needs to investigate health care services offered with specific regard to cancer control and management. Some literature exists which looks at cancer control in low-income countries
and defines ways forward in improving quality and capacity building (Hanna and Kangolle 2010, Murthy et al. 2015). The only component omitted from this previous literature is a deeper look at the capacity to build culturally relative cancer control within the rural setting of low-income countries. Further research needs to take into account the structural barriers and socio-cultural indicators of health care and how such realities for individuals shape access to health care amenities. This entails the need for more research among a wider network of rural health care facilities to shed light on the current provision of health care and cancer care.

Finally, this highlights the need for more research on cancer in low-income countries to engage in an exploration of cultural competence. In fact, cultural competence is critical in the field of biomedicine; where “the crux of cultural competence for biomedicine is how to reconcile its own belief that the scientific method supersedes all other theoretical paradigms of medical explanation with the inevitable realization that not everyone in the world believes this” (Erickson 2007). Research needs specifically to investigate the doctor-patient relationship and how medical information is disseminated from a higher level trained health care provider to a patient with only a primary or secondary level education. Future research on cancer in low-income countries must continue to explore capacity building, but do so within a framework of better understanding cultural competence on the part of the health care provider and patient.

Contributions to Anthropology and Public Health

Previous research has shown the major increase in cancer, and breast cancer specifically, in low-income countries like Uganda and has highlighted the need to investigate further women’s cancer care seeking behaviors in regards to prevention, screening, and treatment (Mwaka, Okello, and Orach 2015, Odongo et al. 2015, Wabinga et al. 2014). This research
study, in particular, confirms this need and provides an examination of breast cancer perception in a rural setting of Uganda. Specifically, this study highlights findings in cancer knowledge for women prior to any cancer diagnosis, which presents original insight into health-seeking behaviors and attitudes towards the disease which have been previously lacking. Not only does this study outline exploratory findings on perceptions of the disease, but it frames a discussion on financial autonomy, health efficacy, health equity, and empowerment in cancer-related resource-poor settings. Furthermore, this study explores the context within which financial autonomy, health efficacy, health equity, and empowerment exist through on-the-ground insight from women in this study and through a critical medical anthropological perspective.

This research demonstrates a rigorous understanding of cancer from a perspective beyond the clinical setting; one which has not yet been explored in-depth. For instance, very little qualitative research has been done in Uganda looking at the cancer experience or perceptions of the disease outside of the clinical setting and beyond those women already diagnosed with cancer. Furthermore, very little research has critically framed its approach in gathering first-hand knowledge about health and illness and basic health-seeking behaviors in this rural areas of Uganda. This research captures women’s attitudes towards cancer, and breast cancer specifically, while exploring their basic health-seeking behaviors within their rural community. Moreover, it highlights these women’s major fears in regards to cancer and hopes for innovative change within cancer care management, such as prevention, screening, and treatment. In fact, the study contributes to public health recommendations for rural health care facilities in Uganda which can be used to improve cancer awareness and management. Furthermore, this research has the potential to contribute to the strengthening of health equity and health efficacy within the rural
health care settings and of knowledge empowerment for women facing limited access to health care and cancer care.

Based on the data gathered, it is important to express the need for further educational initiatives on breast cancer and breast self-examinations. This should entail efforts from local health care facilities and local chair persons in the rural setting to provide information about cancer in general and breast cancer specifically to women, including screening techniques and treatment options. Most important here is the need for educational initiatives on breast self-examinations. Since women face structural difficulties in accessing screening services at health care facilities in the rural setting, it would be beneficial for the women to learn about breast self-exam techniques in order to demonstrate self-awareness and self-empowerment. Furthermore, this would include a policy recommendation on breast cancer awareness initiatives within the private and government health care sectors in the rural settings of Uganda. Overall this research highlights a gap in knowledge about breast cancer, and cancer as a whole, and validates the existence of cultural and economic barriers for women to access comprehensive health care services primarily for screening purposes. Breast cancer is gradually becoming a major health issue in Uganda, and without adequate attention to this chronic disease, especially in the rural setting, the disease will become an even greater burden for women and for the population at large.

Finally, this research contributes to applied anthropology and public health advocacy through a demonstration of a trial workshop on cancer awareness. Through the successful completion of a cancer educational workshop within Nakirebe post field research, this study has pointed towards the examination and implementation of program development in similar rural settings of Uganda. In fact, this study informs cancer care advocacy at a preventive and
screening level rather than post-diagnosis and only during treatment. Little research has demonstrated the applicability of such an approach yet has consistently recommended the extension of awareness campaigns and educational workshops (Galukande, Mirembe, and Wabinga 2014, Murthy et al. 2015, Odongo et al. 2015). Overall, anthropological and public health research would benefit from more exploratory research examining on-the-ground perspectives and beliefs about disease and illness from outside the clinical setting which shape health-seeking behaviors and subsequently health outcomes.

**Limitations**

Due to the sample size and location of the research within one rural setting of Uganda, the generalizability of findings is limited. Findings from this research are not representative of all women in Uganda or in low-income resource-poor settings. Time and financial constraints limited the number of in-depth interviews and focus groups which could be conducted. Saturation in this study was met; nevertheless, with more available time and funds additional women could have been approached to participate, as interest in the study was widespread. Time and financial constraints further limited the number of health care facilities which could be visited to gather more information about the provision of services within and nearby the community.

Another major limitation was the potential for both female and health care provider participants to relay information which they felt was desired rather than their personal understanding about health care and cancer. This is common in open-ended data collection, when participants face aversions to be assessed or questioned in-depth. During the focus groups, in particular, women were hesitant in the beginning to discuss openly the topic of cancer. Selection
bias may have posed another limitation, in that the Vice LC who helped to congregate women to participate in this study might have strategically chose certain women over others. Bias of the data collectors, including me and IHSU research staff, might have further shaped certain responses or observations of participants, especially in regards to probing open-ended questions. Lastly, the issue of language and the translation of certain questions into and out of English and Luganda posed a major limitation at times to gathering rich in-depth information from certain participants. Through translation, specifically from Luganda into English, certain cultural context of meaning were potentially lost.
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APPENDIX A: ENGLISH IN-DEPTH INTERVIEW INSTRUMENT

Participant ID # _____________________________

Thank you for taking the time to meet with me today. The following questions will ask you about demographic information and your general beliefs and perceptions about cancer, specifically breast cancer, in Uganda. Please answer the questions to the best of your ability and please feel free to add any other information that you think is relevant. There is no right or wrong answer; I am simply interested in your personal views.

PART A: Demographics:

1. What is your age?

2. How long have you lived here?

3. What is your marital status?
   [ ] Single
   [ ] Married/Cohabitating
   [ ] Divorced/Separated
   [ ] Widowed

4. What is your religion?
   [ ] Catholic
   [ ] Protestant
   [ ] Muslim
   [ ] Pentecostal
   [ ] SDA/others

5. What is your highest level of education completed?
   [ ] Never gone to school
   [ ] Primary school
   [ ] Secondary school
   [ ] Tertiary (University/diploma)
   [ ] Vocational

6. What tribe do you come from?

7. Do you have any biological children?
   a. No (skip to Q11)
   b. Yes

8. [If yes]: How many biological children do you have?
9. [If yes]: What is the age of the oldest and the youngest child?
   a. Oldest ________
   b. Youngest ________

10. [If a participant has a child 2 yrs of age or below]: Are you currently breastfeeding?
    a. No
    b. Yes
    c. Not applicable

11. Do you live with any other family members?
    a. No
    b. Yes (please specify how many in total): ________

12. Are you currently working?
    a. No (skip to Q15)
    b. Yes

13. [If yes]: What do you do for work?

14. [If yes]: About how many Ugandan shillings do you earn in one month?

15. Does your partner work?
    a. No (skip to Q18)
    b. Yes

16. [If yes]: What does your partner do for work?

17. [If yes]: About how many Ugandan shillings does your partner earn in one month?

18. Tell me about any other sources of income for your household?

19. What is the estimated household income per month (all household income combined)?
    Probe: What is included in this?

20. Tell me about how much money your household spends on health care in one month (i.e. medicine, appointments, etc.)?

PART B: Basic health care behaviors:
21. Where do you typically go for basic health care (1st point of consultation)?
    [ ] Public/government health care facility
    [ ] Private health care facility
    [ ] Traditional healer
    [ ] NGO Health care facility
    [ ] Drug shop/pharmacy
    [ ] Other: _____________________________________________
22. Tell me why you choose this health care/facility?

23. How far from your home do you have to travel for this health care (distance in Km)?

24. What means of transport do you commonly use to get to this health care?
   - [ ] Walking
   - [ ] Taxi/Car
   - [ ] Motorcycle/Boda boda

25. How much time does it take you to reach this health care from your home (in minutes/hours)?
   *Probe: Does this match with what was stated in #23?*

26. How often have you visited this health care provider within the past 6 months?

27. When was the last time you visited this health care provider?

28. Tell me about the main reason for your most recent visit to this health care provider?

29. Tell me about how comfortable you are with this health care provider?
   *Probe: Do you trust this provider? Do you feel at ease with this provider?*

30. Do you know whether you can be screened/checked for breast cancer through this health care provider?
   - a. No
   - b. Yes
   - c. I don’t know

**PART C: Cancer beliefs/knowledge/attitudes:**

31. Tell me about what you believe cancer is?
   *Probe: How would you describe cancer? What does cancer mean to you?*

32. What do you think are the most common cancers in Uganda?

33. Tell me why you think these cancers are the most common in Uganda?
   *Probe: What are their causes?*

34. If you were diagnosed with cancer, tell me how you would initially handle it?
   *Probe: Would you discuss this disease with your family and friends? What would you discuss, why would you discuss this? Would you seek any type of support?*

35. Tell me about how this community perceives cancer?
   *Probe: Are there any taboos about cancer within this community?
PART D: Breast cancer screening/diagnosis and beliefs/knowledge/attitudes:

36. Have you heard of breast cancer?
   a. No (skip to Q71)
   b. Yes

37. [If yes]: Tell me what you have heard about breast cancer?

38. [If yes]: Where or by who have you heard this about breast cancer?

39. [If yes]: Tell me how you would describe breast cancer to someone?
   Probe: What is breast cancer to you? If someone asked you what breast cancer is, how would you explain it to them?

40. [If yes]: Tell me about the ways women can be screened/checked for breast cancer?
   Probe: What are the techniques that screen or diagnose a woman with breast cancer?

41. Have you ever been screened/checked for breast cancer?
   a. No, Why not? (then skip to Q48)
   b. Yes

42. [If yes]: When were you screened/checked?

43. [If yes]: Where were you screened/checked? Why did you get checked at this location?

44. [If yes]: Describe for me how the screening was done.
   Probe: What kind of screening?

45. [If yes]: Tell me about why you chose to screen/check for breast cancer?
   Probe: What was the reason you chose to check for breast cancer?

46. [If yes]: How many times have you been screened/checked for breast cancer in your lifetime?

47. [If yes]: Tell me what the experience was like for you?
   Probe: How did you perceive the experience of getting screened/checked for breast cancer?

48. [If no]: Do you know where to go if you wanted to get checked for breast cancer?
   a. No (skip to Q51)
   b. Yes

49. [If yes]: Where can you go if you wanted to get checked for breast cancer?

50. [If yes]: Tell me about the accessibility to this location for you?
   Probe: Could you travel there if you wanted? How much would it cost you?
51. Do you know what a breast self-examination is?
   a. No (skip to Q55)
   b. Yes, please explain what this is:

52. [If yes]: How do you conduct a breast self-examination?

53. [If yes]: Tell me how you learned to conduct a breast self-examination?

54. [If yes]: Tell me if you have ever taught/explained to someone else how to conduct a breast self-examination?
   Probe: Who, why, and how?

55. Have you ever been told by a doctor that you have breast cancer?
   a. No (skip to Q60)
   b. Yes

56. [If yes]: At what age were you told you have breast cancer?

57. [If yes]: Where were you told?
   Probe: Who diagnosed you with cancer? Which type of health care provider?

58. [If yes]: Besides the time a doctor told you that you have breast cancer, how long have you known you have breast cancer?

59. [If yes]: Tell me about the support you receive for breast cancer?
   Probe: Emotional, physical, and financial support?

60. Have any of your family members been told by a doctor that they have breast cancer?
   a. No (skip to Q63)
   b. Yes
   c. I don’t know (skip to Q63)

61. [If yes]: Which family member was told they have breast cancer?

62. [If yes]: At what age were they told they have breast cancer?

63. [If you have not been told you have breast cancer]: Do you ever think about having breast cancer?
   a. No, Why not?
   b. Yes, Why?

64. Tell me what you think are the causes of breast cancer?

65. Do you think breast cancer can be prevented?
   a. No, Why not?
   b. Yes, How?
66. Do you think breast cancer can be treated?
   a. No, Why not?
   b. Yes, How?

67. Tell me what you feel are the major risks/fears of being told you have breast cancer?

68. What would your first thought be when you learn that a woman has been told she has breast cancer?

69. Tell me about any taboos in this community when talking about breast cancer?
   Probe: Can you think of any taboos within this community in regards to breast cancer?

70. Tell me about any taboos in your culture when talking about breast cancer?
   Probe: Can you think of any taboos in your culture in regards to breast cancer?

71. How would you describe your self-awareness about your breasts?
   Probe: Are you comfortable with your breasts? At what point can you tell something is wrong with your breasts?

72. [If not already mentioned]: Tell me about any taboos in this community when talking about breasts?
   Probe: Can you think of any taboos within this community in regards to breasts?

73. [If not already mentioned]: Tell me about any taboos in your culture when talking about breasts?
   Probe: Can you think of any taboos in your culture in regards to breasts?

Additional comments:
74. Is there anything else you would like to add to what we have discussed today?
   Probe: Anything important to women’s health or breast cancer?

End of questionnaire:
Thank you very much for your time! The information you provided is very helpful to this study.
APPENDIX B: LUGANDA IN-DEPTH INTERVIEW INSTRUMENT

Ennamba y’omunoonyerezebwa/ ID # ______________________________

Weebale nnyo nyabo okumpa obudde bwo olwaleero. Ebibuuzo bino wammanga byetaaga okumanya ebikukwatako, by’okkiririzaamu n’entegeera yo ku kkansa nadda kkansa w’amabeere mu Uganda. Tukwegayiridde oddem mu ebibuuzo bino nga bw’osobola, era bambi oli wa ddembe okwongerako ebira byonna by’olowooza nti bikulu. Tewali kiddibwamu kituufu oba kikyamu; wabula njagala bwagazi ndowooza zo.

EKITUNDU A: Ebikukwatako:
1. Olina emyaka emeka nyabo?

2. Mukitundu kino obaddemu ebbanga lyenkana ki?

3. Oli otya mu bigambo by’okufumbirwa?
   [ ] Tofumbirwanga
   [ ] Wafumbirwa/Olina gw’obeera naye
   [ ] Mwayawukana mu mateeka/Temukyali mwenna
   [ ] Oli nnamwandu

4. Oli wa ddini ki?
   [ ] Mukatuliki
   [ ] Mupulotesitanti
   [ ] Musilaamu
   [ ] Mulokole
   [ ] Museveniside/Ddiini endala yonna

5. Mu by’emisomo wasoma kutuuka wa?
   [ ] Ssimala ngako kusoma kwonna
   [ ] Pulayimale
   [ ] Ssiniya
   [ ] Yunivaasite (Diguli/Dipulooma)
   [ ] Okuyiga eby’emikono

6. Oli wa ggwanga ki?

7. Olina yo ku baana abava mu ntumbwe zo?
   a. Nedda (buuka ogende ku kibuuzo Q11)
   b. Yye
8. [Bwekiba nga Yye]: Olina abaana bameka bewezaalira ggwe? __________________

9. [Bwekiba nga Yye]: Omwana wo asinga obukulu n’asinga obuto alina emyaka emeka?
   a. Asinga obukulu _______
   b. Asinga obuto _______

10. [Omukyala bw’aba alina ow’emyaka ebiri oba wansi]: Omwana wo omuyonsa?
    a. Nedda
    b. Yye
    c. Ensonga eyo tenkwatako

11. Olina ab’enganda abalala oba ow’oluganda gw’obera naye awaka?
    a. Nedda (buuka ogende ku kibuuzo nnamba kkumi na mukaaga)
    b. Yye (nyonnyola kiki ddala)

12. Olina omulimu gw’okola gwonna kati?
    a. Nedda (buuka ogende ku kibuuzo Q15)
    b. Yye

13. [Bwekiba nga Yye]: Kitongole ki oba muntu ki gw’okolera?

14. [Bwekiba nga Yye]: Ofuna ssente nga mmeka eza Uganda mu mwezi ogumu?

15. [Bw’oba ng’oli mufumbo]: Omwami wo akola?
    a. Nedda (buuka ogende ku kibuuzo Q18)
    b. Yye

16. [Bwekiba nga Yye]: Omwami wo akola mulimu ki?

17. [Bwekiba nga Yye]: Omwami wo akola ssente nga mmeka eza Uganda mu mwezi ogumu?

18. Bintu ki ebikulu byemufunamu ssente mu nyumba eno oba mu nyumba eno/luggya luno?

19. Muyingiza ssente nga mmeka mu nyumba eno oba mu luggya luno mu mwezi ogumu?
   (ssente zonna ezifunibwa mu nyumba ng’ozigasse wamu)?
   Yongera okubuuza: Ssente ziva muki naki?

20. Mbuuliraako ku ngeri gyemusaasaanya sente mu nyumba eno ku by’obulamu mu mwezi ogumu
    (i.e. ku ddagala, mu kugenda ew’omusawo, n’ebirala)?

**EKITUNDU B:**  **Empisa z’ebyobulamu ezisookerwako:**

21. Obujjanjabi bwo obusookerwako obujjawa (gy’osooka okugenda okwebuuza
    ng’olwadde)?
   [ ] Mu ddwaliro lya Gavumenti/ery’lukale
   [ ] Mu ddwaliro ly’obwannanyini
22. Mbulira lwaki walondawo okugenda mu kifo kino?

23. Eddwaliro eryo liri kabanga ki oba lugendo ki okuva w’obeera (mu kilomita)?

24. Otera kukozesza ntabula ki okutuuka ku ddwaliro eryo?
   [ ] Ntabula butambuzi
   [ ] Takisi/Mmotoka
   [ ] Pikipiki/Bodaboda

25. Kikutwalira budde ki okutuuka ku ddwaliro eryo (essaawa n’eddakiika)?
   Yongera okubuuza okunyonnyolwa: Kyayogedde kikwataagana ne kyeyayogedde mu kibuuzo #23?

26. Omusawo oyo agaba obujjanjambi omulabye emirundi emeka mu myezi omukaaga egivise?

27. Wasemba ddi okulaba omusawo oyo agaba obujjanjambi?

28. Mbulira ensonga enkulu eyakutwala okulaba omusawo agaba obujjanjambi oyo?

29. Mbulira engeri/oba omusawo oyo yakwanguyira oba wamuwulirilamu emirembe?
   Yongera okubuuza okunyonnyolwa: Owulira emirembe ng’oli n’omusawo oyo?

30. Okimanyi oba osobola okukeberebwa kkkansa w’amabeere okuyita mu musawo oyo?
   a. Nedda
   b. Yye
   c. Ssimanyi

EKITUNDU C:  Enzikiriza mu kkansa, okumanya kkansa n’entwala ya kkansa:
31. Mbuulira mu kukkiriza kwo, kkansa ky’ekki?
   Yongera okubuuza okunyonnyolwa: Kkansa omunyonnyola otya? Ku ggwe kkansa ategeeza ki?

32. Kkansa ki z’olowooza zeezinga obungi mu Uganda yattu eno?

33. Ggw’olowooza lwaki kkansa zino ze zisinga obungi mu Uganda yattu?
   Yongera okubuuza okunyonnyolwa: Bintu ki ebizireeta?

34. Bw’ozuulibwa ng’olina kkansa, wandiyogeraganyizza otya endwadde eno ne famile yo,
   kko n’abenganda zo ne mikwano gyo?
Yongera okubuuza okunyonnyolwa: Wandiyogedde ku ndwadde eno ne ab’omukaago ne mikwano gyo? Mwandiyogeraganyizza ki, era lwaki mwandibadde mwogera kw’ekyo? Wandinoonyezza ku buyanbi bwonna?

35. Mbuulira ku bantu mu kitundu kino byeboogeraganya ku kkansa
Yongera okubuuza okunyonnyolwa: Waliwo eby’omuzizo byonna mu kitundu kino?

EKITUNDU D: Okukebera n’okuzuula kansa w’amabeere

36. Wali owuliddeko kansa w’amabeere?
   a. Nedda [buuka ogende ku “kitundu ky’okwekebera wekka amabeere” Qn# 71]
   b. Yye

37. [Bwekiba nga Yye]: Mbuulira biki byewawulira ku kkansa w’amabeere

38. [Bwekiba nga Yye]: Ludda wa era kuva kw’ani kwewawulira ku kkansa w’amabeere ono?

39. [Bwekiba nga Yye]: Mbuulira engeri gyewandinyonnyoddemu kkansa w’amabeere eri omuntu?
   Yongera okubuuza okunyonnyolwa: Kkansa w’amabeere kuggwe kyekki? Omuntu bw’akubuuza kkansa w’amabeere wandimunyonyodde otya?

40. [Bwekiba nga Yye]: Mbuulira ko engeri abakyala gyebakeberebwamu kkansa w’amabeere.
   Yongera okubuuza okunyonnyolwa: Byuma oba ngeri ki zebakozesa okukebera okuzuula kkansa w’amabeere mu mukyala?

41. Wali weekebezzaako kkansa w’amabeere? (ku buli ky’oddamu, wa ensogna zo)
   a. Nedda (buuka ogende ku kibuuzo Q48)
   b. Yye

42. [Bwekiba nga Yye]: Lwali ddi lwbaakukebera?

43. [Bwekiba nga Yye]: Ludda wa gyebaakukeberera? Lwaki wagenda okkukeberera mu kifo ekyo?

44. [Bwekiba nga Yye]: Nyinyonnyola engeri kino gyekyakolebwamu.
   Yongera okubuuza okunyonnyolwa: Kikaki kyebaakozesa okkukebera?)

45. [Bwekiba nga Yye]: Mbuulira lwaki wasalawo okkukebera kkansa w’amabeere?
   Yongera okubuuza okunyonnyolwa: Nsonga ki eyakulobera okwekebeza kkansa w’amabeere?

46. [Bwekiba nga Yye]: Waakakeberebwa emirundi emeka kkansa w’amabeere mu bulamu?
47. [Bwekiba nga Yye]: Mbuulira bwekyakuyisa nga bakukebera.
  Yongera okubuuza okunyonnyolwa: Entegeera yo yali etya ku ngeri gyekyakuyisa nga bakukebera kkansa w’amabeere?

48. [Bwekiba nga Nedda]: Omanyi ew’okugenda bw’oba oyagadde okwekebeza kkansa w’amabeere?
   a. Nedda (buuka ogende ku kibuuzo Q51)
   b. Yye

49. [Bwekiba nga Yye]: Ludda wa ew’okugenda bw’oba oyagadde okwekebeza kkansa w’amabeere?

50. [Bwekiba nga Yye]: Mbuulirako ku ngeri y’okusobola okutuuka mu kifo kino?
  Yongera okubuuza okunyonnyolwa: Osobola okugenda yo lw’oyagalidde lwonna? Kiyinza kukutwalira ssente nga mmeka?

51. Omanyi kyebayita “okwekebera wekkka amabeere”?
   a. Nedda (buuka ogende ku kibuuzo Q55)
   b. Yye, bambi nyinyonnyola kyekitegeeza:

52. [Bwekiba nga Yye]: Weekebera otya wekkka amabeere?

53. [Bwekiba nga Yye]: Wayiga otya okwekebera wekkka amabeere?

54. [Bwekiba nga Yye]: Mbuulira engeri gy’oyinza okunyonnyola oba okuyigiriza omuntu omulala yenna okwekebera yekka amabeere?
  Yongera okubuuza okunyonnyolwa: Ani? Lwaki? Era otya?

55. Omuwawo Dokita yali akugambyeko nti olina kkansa w’amabeere?
   a. Nedda (buuka ogende ku kibuuzo Q60)
   b. Yye

56. [Bwekiba nga Yye]: Baakubuuila ku myaka emeka nti olina kkansa w’amabeere?

57. [Bwekiba nga Yye]: Ebyo baabikugambira wa?
  Yongera okubuuza okunyonnyolwa: Ani eyakuzuulamu kkansa? Kika kya musawo ki?

58. [Bwekiba nga Yye]: Ng’ogyeko ebiseera omuwawo Dokita lweyakugambira nti nti olina kkansa w’amabeere, omuze bbangi ki ng’otegedde nti olina kkansa w’amabeere?

59. [Bwekiba nga Yye]: Mbuulira ku buyambi bw’ofuna ku bikwatagana ku kkansa w’amabeere.
  Yongera okubuuza okunyonnyolwa: Mukubudaabudibwa, mu bikwatibwako, mu nsimbi?
60. Olinayo omuntu yenna mu benganda zo Dokito gweyazuulamu kansa w’amabeere?
   a. Nedda (buuka ogende ku kibuuzo nnamba Q63)
   b. Yye
   c. Ssimanyi (buuka ogende ku kibuuzo nnamba Q63)

61. [Bwekiba nga Yye]: Wa luganda ki eyazuulibwa ne kansa w’amabeere?

62. [Bwekiba nga Yye]: Kansa w’amabeere oyo baamutegeeza nti amulina ku myaka emeka?
   [bwe baba nga bangi, buli omu yamumuzuuliramu ku myaka emeka?]  

63. [Bw’oba nga tobuliddwa nti olina kkansa w’amabeere]: Wali okirowoozezzaako eky’okuba ne kkansa w’amabeere?
   a. Nedda, lwaki nedda?
   b. Yye, lwaki Yye?

64. Mbuulira biki by’olowooza nti bye bireeteera kkansa w’amabeere.

65. Gwe olowooza kansa w’amabeere asobola okwewalibwa?
   a. Nedda, lwaki nedda?
   b. Yye, lwaki Yye?

66. Gwe olowooza kansa w’amabeere asobola okujjanjabibwa?
   a. Nedda, lwaki nedda?
   b. Yye, lwaki Yye?

67. Mbuulira bintu ki ebyteriikiza/ebitiisa ebikulu ebiri mu kukugamba nti olina kansa w’amabeere?

68. Bintu ki byewandisoose okulowoozaako bw’otegeera nti omukyala azuuliddwamu kansa w’amabeere?

69. Mbuulira ku mizizo gyonna mu kitundu kino bw’oyogera ku kkansa w’amabeere.
   Yongera okubuuzu okunyonyolwa: Osobola okulowooza ku mizizo gyonna mu kitundu kino nga gyekuusa ku kkansa w’amabeere?

70. Mbuulira ku mizizo gyonna egya eb’obuwangwa bw’oyogera ku kkansa w’amabeere.
   Yongera okubuuzu okunyonyolwa: Osobola okulowooza ku mizizo gyonna mu by’obuwangwa nga gyekuusa ku kkansa w’amabeere?

71. Osobola otya okunynnoka ku kumanyakwo ku mabeere?
   Yongera okubuuzu okunyonyolwa: Owulira tolina nsonga yonna ku mabeere go?
   Kiseera ki w’osobolera okutegeera nti waliwo ekikyamu ku mabeere go?

72. [Bw’oba kino tonnaba kuygerako]: Mbuulira ku mizizo gyonna mu kitundu kino bw’oyogera ku mabeere. Yongera okubuuzu okunyonyolwa: Osobola okulowooza ku mizizo gyonna mu kitundu kino nga gyekuusa ku mabeere?
73. Mbuulira ku mizizo gyonna egya eby’obuwangwa bw’oyogera ku mabeere. **Yongera okubuuza okunyonnyolwa: Osobola okulowooza ku mizizo gyonna mu by’obuwangwa nga gyekuusa ku mabeere?**

**Eby’okwogerako ebirala:**

74. Waliwo ekintu ekirala kyonna kyewandiyagadde okwongera ku ebyo byetwogeddeko olwaleero?
   **Yongera okubuuza okunyonnyolwa:** Olinayo ensonga endala nga nkulu eri obulamu bw’abakyala ne kkansa w’amabeere?

**Ebibuuzo bikomye wano:**

*Weebale nnyo nnyini olw’obudde bwo! B’yotugambye byamugaso nnyo eri omusomo guno.*
APPENDIX C: FOCUS GROUP INSTRUMENT

Focus Group # _________________

Thank you for taking the time to meet with me today. The following questions will ask you about cancer, specifically breast cancer, in Uganda. Please discuss the questions as a group and answer them to the best of your ability and please feel free to add any other information that you think is important. There is no right or wrong answer; I am simply interested in your personal views.

First, I would like to ask if you will be ok with me recording this focus group?
Yes
No

Beliefs/knowledge about breast cancer:
1. Tell me what you know about breast cancer?
   a. How do you all describe breast cancer?
   b. What do you think are the major causes of breast cancer?
   c. What do you think are the major fears when a woman is told she has breast cancer?

2. Tell me how people in this community perceive/think about/talk about breast cancer?

Health-seeking behaviors:
3. If you wanted to know about your breast cancer status, what would you do?
   a. How can women in this community be screened/checked for breast cancer, if they want?
   b. How can women in this community be treated for breast cancer if they are found to have the disease?

4. Tell me about what support is available in this community for women who have breast cancer?

Additional information:
5. In terms of breast cancer what would you want to see change or improved in your community?
   a. What resources do you wish were available for women regarding breast cancer awareness?
   b. How do you think breast cancer screening could most effectively be handled in this community?
c. How do you think breast cancer treatment could most effectively be handled in this community?

Final Question:
6. Is there anything else you would like to add to what we have discussed today?
APPENDIX D: SEMI-STRUCTURED INTERVIEW INSTRUMENT

Participant ID # ________________________________

Thank you for taking the time to meet with me today. The following questions will ask you about breast cancer in Uganda. Please answer the questions to the best of your ability and please feel free to add any other information that you think is important. There is no right or wrong answer; I am simply interested in your personal views.

First, I would like to ask if you will be ok with me recording this interview?
   Yes
   No

Introduction:
   1. Tell me what you do at this facility?
      Probe: What is your position? What are your duties?

Knowledge/perception of cancer:
   2. Tell me how you would describe cancer to a patient?
      Probe: If a patient asks you what cancer is, how would you broadly explain it?

   3. Tell me what you think are the most common types of cancers in Uganda? Why do you think these are the most common?

   4. Tell me how you would describe breast cancer to a patient?
      Probe: What would you tell a patient breast cancer is?

   5. Tell me what you think are the most common causes of breast cancer?

Health-seeking patterns:
   6. How would you describe breast cancer screening patterns among women in this community?
      Probe: In regards to cultural stigma, finances, education, etc. Why do women come or not come for screening?
7. How would you describe breast cancer treatment patterns among women in this community?
   Probe: For those women who come here for treatment, maybe when they cannot go elsewhere. In regards to cultural stigma, finances, education, etc.

8. Do women come to this facility suspecting to have breast cancer?
   a. No, Why not?
   b. Yes, What do women come complaining about?

**Services/education provided to women:**

9. Tell me about the types of breast cancer screening you have available at this health care facility, if any?

10. Do you teach women how to conduct breast self-examinations?
    c. No, Why not?
    d. Yes, Describe for me what you teach them?

11. If you found that a woman has symptoms of breast cancer, how would you handle it?
    Probe: What do you do for that patient? Do you refer elsewhere? If so, where? Do you attempt to treat?

12. Tell me about the breast cancer awareness programs you (this facility) are providing to this community?
    Probe: Health education, community outreach, etc. How do you do it?

13. What would you like to see provided to this community in regards to breast cancer awareness?

**Additional comments:**

14. Is there anything else you would like to add to what we have discussed today?
    Probe: Anything important to women’s health or breast cancer awareness?
APPENDIX F: USF IRB APPROVAL LETTERS

May 5, 2015

Ann Tezak
H Lee Moffitt Cancer Center
12902 Magnolia Drive
MRC - Cancer Epidemiology
Tampa, FL 33612

RE: Expedited Approval for Initial Review
IRB#: Pro00021709
Title: An In-Depth Examination of Ugandan Women’s Health Seeking Behaviors and Attitudes Towards Breast Cancer


Dear Ms. Tezak:

On 5/4/2015, the Institutional Review Board (IRB) reviewed and APPROVED the above application and all documents outlined below.

Approved Item(s):
Protocol Document(s):
Protocol Ver#1 4.28.2015.docx

Consent/Assent Document(s)*:
ICF Ver#1 PRO21709.docx.pdf

*Please use only the official IRB stamped informed consent/assent document(s) found under the "Attachments" tab. Please note, these consent/assent document(s) are only valid during the approval period indicated at the top of the form(s).
It was the determination of the IRB that your study qualified for expedited review which includes activities that (1) present no more than minimal risk to human subjects, and (2) involve only procedures listed in one or more of the categories outlined below. The IRB may review research through the expedited review procedure authorized by 45 CFR 46.110 and 21 CFR 56.110. The research proposed in this study is categorized under the following expedited review category:

(6) Collection of data from voice, video, digital, or image recordings made for research purposes.

(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

As the principal investigator of this study, it is your responsibility to conduct this study in accordance with IRB policies and procedures and as approved by the IRB. Any changes to the approved research must be submitted to the IRB for review and approval by an amendment.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely,

John A. Schinka, Ph.D.
Chairperson
USF Institutional Review Board
4/6/2016

Ann Tezak  
H Lee Moffitt Cancer Center  
12902 Magnolia Drive  
MRC - Cancer Epidemiology  
Tampa, FL 33612

RE: Expedited Approval for Continuing Review  
IRB#: CR1_Pro00021709  
Title: An In-Depth Examination of Ugandan Women’s Health Seeking Behaviors and Attitudes Towards Breast Cancer


Dear Mrs. Tezak:

On 4/6/2016, the Institutional Review Board (IRB) reviewed and APPROVED the above application and all documents contained within including those outlined below.

Approved Item(s):
Protocol Document(s):
Protocol Ver#1.1 7.27.2015 cleanversion.docx

The IRB determined that your study qualified for expedited review based on federal expedited category number(s):

(6) Collection of data from voice, video, digital, or image recordings made for research purposes.

(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.
As the principal investigator of this study, it is your responsibility to conduct this study in accordance with USF HRPP policies and procedures and as approved by the USF IRB. Any changes to the approved research must be submitted to the IRB for review and approval by an amendment. Additionally, all unanticipated problems must be reported to the USF IRB within five (5) calendar days.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely,

[Signature]

John Schinka, Ph.D., Chairperson
USF Institutional Review Board
APPENDIX G: IHSU IRB APPROVAL LETTER

IHSU-REC/0003

22nd June, 2015

Ms. Teddy Nagaddya
Co-Principal Investigator
International Health Sciences University
P.O Box 7782, Kampala

RE: SUBMITTED PROTOCOL ENTITLED “AN IN-DEPTH EXAMINATION OF UGANDAN WOMEN’S HEALTH SEEKING BEHAVIORS AND ATTITUDES TOWARDS BREAST CANCER”

Reference is made to the above mentioned protocol which was submitted to the Research Ethics Committee for initial review and approval.

You have addressed all issues raised earlier by the committee and basing on the changes you made and submitted in version 1.1 dated 16th June, 2015.

I am glad to inform you that your study has been approved for a period of one year from 22nd June, 2015 to 22nd June, 2016 and the documents approved include the following:

<table>
<thead>
<tr>
<th>Document</th>
<th>Language</th>
<th>Version</th>
<th>Submission Date</th>
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<tbody>
<tr>
<td>Consent Forms</td>
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<tr>
<td>Informed Consent</td>
<td>English</td>
<td>Version 1.1</td>
<td>16th June, 2015</td>
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<tr>
<td>Semi-structured questionnaire</td>
<td>English</td>
<td>Version 1.1</td>
<td>16th June, 2015</td>
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<tr>
<td>Semi-structured questionnaire</td>
<td>Luganda</td>
<td>Version 1.1</td>
<td>16th June, 2015</td>
</tr>
<tr>
<td>Focus group discussion guide for women</td>
<td>English</td>
<td>Version 1.1</td>
<td>16th June, 2015</td>
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<tr>
<td>Focus group discussion guide for healthcare workers</td>
<td>Luganda</td>
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<td>Version 1.1</td>
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Please note that any problems of serious nature as a result of this study to the participants should be reported to IHSU-REC and Uganda National Council of Science and Technology (UNCST) immediately.

Also note that annual report and request for renewal where applicable should be submitted at least one month before the expiry date of approval. In addition, you are also required to submit copies of the stamped approved documents to the Uganda National Council for Science and Technology (UNCST) before the study can commence.

We would like to congratulate you and wish you a successful conduct of the study.

Yours Sincerely

[Signature]

Dr. Samuel Kabwigu
REC Chairperson

22 JUN 15

[Date]