Cancer Management in Kenya - Awareness and The Struggles Patients Face to Access Treatment, Care & Support

Ashley Nmoh
SIT Study Abroad

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Cancer Management in Kenya- Awareness and The Struggles Patients Face to Access Treatment, Care & Support

An Independent Study Project

“I asked God to give me courage to undergo this journey. Please God wipe all my tears so I don't cry”

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SIT Kenya: Global Health & Human Rights
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ACKNOWLEDGEMENTS

This project was not one I could have done on my own. I would like to thank Nancy Githomo, the founder of Limau Cancer Connection, Phillip Odiyo from Faraja Cancer Support and Emily Ochieng from the Kenya Cancer Association. Thank you so much for welcoming me with open arms, providing me with direction and introducing me to so many cancer warriors who were willing to share their story. The work your organizations do and the work you have done for me have not gone unrecognized. I would also like to thank all the cancer warriors who were brave enough to share their story with me. Through our tears and laughs, you all have inspired me and encouraged me to live every day like it’s my last. Thank you for sharing pieces of your reality with me. I would also like to thank my host families. Mama Gladys, Mama Alice, Sharon and Maryanne, thank you so much for your help throughout this semester. Thank you for introducing me to your networks, helping me hand out surveys and encouraging me when I was feeling overwhelmed. I would also like to thank the SIT staff for their support and guidance throughout the semester. Thank you for facilitating an unforgettable four months in Kenya. Thank you also to my other fellow SIT students. Thank you for all of the laughs, support and encouragement you have given me. Finally, thank you God for allowing this experience to be possible and for guiding this project from its beginning to its completion. It is my hope that this project is yours and not my own, and the purpose in which it was created will be accomplished.
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ABSTRACT

The amount of cancer cases in Africa, and Kenya specifically, are rising at an alarming rate. This study was conducted to determine the challenges that patients with cancer in Kenya face to access treatment, care and support. Thirty-nine cancer patients were interviewed and thirty cancer patients filled out a questionnaire about their experiences of having cancer in Kenya. In addition, twenty key informants were interviewed including doctors, caregivers, cancer NGO executives, a researcher, a psychologist, a National Health Insurance Fund official and a director from the Ministry of Health. A breast cancer awareness survey was also administered to fifty-nine women in Kenya to determine their level of breast cancer awareness. Many challenges that cancer patients face in Kenya were identified by the participants. The most common challenge identified was the expensive cost of cancer treatment in Kenya. Other challenges identified include the lack of access to cancer centers and trained specialized oncologists, especially for individuals who live outside Nairobi or in rural areas. Professional burnout and frustration of many medical personnel was reported by doctors and identified by patients and key informants. Psycho-social support and counselling for patients in the hospital setting was found to be lacking. A lack of awareness and knowledge about cancer was found to be rampant throughout Kenya and many study participants identified this as the main cause of stigma faced by cancer patients. Patients suggested that the Kenyan Government should begin to take cancer more seriously and look at ways to decrease the cost of treatment and increase awareness, access to facilities and support for cancer patients.
INTRODUCTION

General Statistics
Cancer is an illness that has received little awareness and research in Kenya and all of Africa. Previously thought of as a “rich man’s disease”, Cancer is now becoming more and more prevalent in lower and middle income countries. The increase in obesity, urbanization, processed foods, abuse of alcohol, smoking, lack of exercise and lifespan in developing countries coupled with a lack of infrastructure to treat cancer is one reason why, today, more than 70% of all cancer deaths occur in low- and middle-income countries (Kenya, 2011). There were 8.8 million deaths due to cancer in 2015, and mortality due to cancer each year is projected to increase by 70% by the year 2030 (Atieno, 2018). The growing problem of cancer and other non-communicable disease in Africa is one too costly to ignore. African women have been found to be only 20% less likely to develop cancer than Western European women by the age of 65 (Parkin, 2008). The number of cancer deaths are continuing to rise at an alarming rate and with malaria and tuberculosis soon to be eradicated, more research, infrastructure and investment into cancer is desperately needed as Africa’s disease burden is soon beginning to change.

In Kenya specifically, cancer is the third leading cause of death after infectious and cardiovascular diseases; it causes over 7% of deaths in Kenya each year (Atieno, 2018). Kenya has the largest number of cancer related deaths in East Africa, compromising 40% of the 83,426 deaths annually in Kenya, Tanzania and Uganda (Atieno, 2018). In 2018, the World Health Organization revealed that there are around 47,887 new cases of cancer occurring each year and it is estimated that around 32,900 Kenyans die of cancer annually with an average of about 90 people dying from cancer and 130 new diagnosis each day (Niyaundi, 2018). There is a significant lack of cancer data in Kenya, and these figures do not include individuals who die without receiving a proper cancer diagnosis. To put this number into context, this is 10x the amount of individuals that die each year from motor vehicle accidents in Kenya. A Kenyan National Control Strategy was drafted for 2017-2022. The goal of the strategy was to reduce cancer incidence, morbidity and mortality by improving prevention, early detection, early diagnosis, cancer registries and surveillance, treatment, palliative care and survivorship,
coordination, financing and research in cancer in Kenya (National Cancer Control, 2017). However, little is known if the government has actually made progress in achieving these goals.

**Lack of Expertise**

According to the Kenyan Network of Cancer Organizations, in 2013, there were only 4 radiation oncologists, 6 medical oncologists, 4 pediatric oncologists, and 3 oncology nurses in all of Kenya’s public sector, however, there is evidence that the numbers have improved with another source suggesting that there were 22 oncologists present in Kenya in 2018 (Cancer Free Woman Organization, 2013). Many medical professionals in Kenya have not been trained to recognize the signs and symptoms of cancer since it is a relatively new and emerging disease. This leads them to treat patients for the wrong illness which thus, delays treatment. Additionally, most oncologists are located in the capital city of Nairobi which causes many individuals to have to travel far distances to get specialized care. This lack of cancer expertise in Kenya can thus serve as a barrier to detection as well as proper treatment.

**Lack of Mammogram Machines, Diagnostic and Treatment Equipment in Kenya**

Often times, doctors in Kenya do not have the proper equipment to diagnose breast cancer (as well as other cancers) even if they suspect that a patient might have it. There are very few mammogram machines available in the country, and most of them are located in Nairobi. This presents a barrier to proper diagnosis of women in rural areas and other cities. It can be very expensive for women to pay for accommodation and a means to travel to Nairobi or one of the few other cities where mammogram machines are available. In addition, in 2018, Kenya only had 12 facilities to diagnose and treat cancer, of which included seven private hospitals, 2 mission hospitals and 3 public hospitals. Kenyatta National Hospital is the only public hospital among these equipped to provide the three major cancer treatment modalities: surgery, radiotherapy, and chemotherapy (Makau-Barasa, 2018). Though chemotherapy may be offered in a few counties, radiotherapy is only primarily offered in Nairobi and Eldoret. Furthermore, even though chemo may be offered in different facilities, the availability of chemotherapy is scarce and could lead to
overcrowded facilities which may force a woman to wait a long time to receive treatment or force her to have to travel to Nairobi where there are more treatment options available. This is a potential barrier to treatment.

*Cost of Mammograms & Treatment*

Even if the proper equipment for diagnosis is available, the average cost of a mammogram in Kenya is about KSH 8,000 or the equivalent of $80 (Cancer Free Women Organization, 2013). Though this is cheaper than the cost of a mammogram in most countries, this cost is too expensive for the many Kenyan women who live on an average of US$1 per day or less. Kenya is a low income country and according to the World Bank, four out of 10 people in Kenya live below the poverty line (Atieno, 2018). In addition, the cost of cancer treatment in Kenya is very expensive, which leads many cancer patients to go to India to receive treatment. Dr Alfred Karagu, the CEO at the National Cancer Institute, revealed that an estimated Sh10 billion is spent annually by people seeking medical attention abroad, and 50 to 60 percent are for cancer-related services (Benson 2008). This high cost could present itself as a barrier to treatment especially for individuals who do not have the resources to travel abroad to receive more affordable treatment. The National Health Insurance (NHIF) helps cover some of the treatment costs for patients, but not everything. The amount NHIF gives varies on the type of facility a patient accesses, how much money it has given a patient in the past and the kind of treatment needed.

*Breast Cancer & the Importance of Early Detection*

The burden of cancer disproportionately affects women with women being more likely to have cancer than men. Breast cancer is also the most common cancer affecting women. Breast cancer affects at a rate of 34 cases per 100,000 and compromises 23.3% of all cancers in Kenya (Atieno, 2018). Since women are often the caretakers of households, children and the elderly in the African society, this disparity can potentially have dire impacts on the social structure of Kenya. Studies have found that the average age in which women in Africa present with breast cancer is 35-45 years which is 10-15 years older than caucasian women develop breast cancer (Fregene,
In order to conquer cancer, early detection and treatment is key. 30% of treatable cancers can be cured if treated early, but according to the Kenya Medical Research Institute (KEMRI), about 80% of reported cases of cancer in Kenya are diagnosed at an advanced stage which increases the likelihood of morbidity (Naanyu, 2015). Mammograms are X-Rays of the breast that can be used to detect cancer very early. The Center of Disease Control recommends that women over the age of 40 receive a mammogram annually, however, this rarely ever happens in Kenya where many women can barely even afford transportation to a hospital, not to mention the cost of an actual hospital visit.

Breast cancer can also be detected through a breast ultrasound, a biopsy or a breast MRI, but the cheapest and easiest method of detection is via a self breast exam. Women can perform these exams on themselves for free by simply feeling their breasts and lymph nodes on their armpits for any abnormalities or lumps. Though mammograms are more reliable and can detect breast cancer even before tumors develop, regular self breast exams are a great way for women to detect any cancer abnormalities early before cancer advances into later stages. According to the National Health Interview Survey (NHIS) done in the U.S. in 2003, Most women survivors of breast cancer (57%) reported a detection method other than mammographic examination. These women often detected breast cancer themselves, either by self-examination (25%) or by accident (18%) (Roth, 2011). Breast cancer can only be detected early if women are educated on the signs and symptoms of breast cancer as well as the importance of the various detection methods. These detection methods must be affordable and easily accessed to be effective for all women.

**LITERATURE REVIEW**

Most studies in Kenya has been focused on communicable diseases and have ignored non-communicable diseases. There is a general lack of knowledge about cancer in Kenya. Previous studies done in both rural and urban areas to assess knowledge about breast cancer, have found that few men or women in Kenya know the causes of breast cancer and even less know the early onset symptoms of it. Some women in a rural community in Kenya, assumed that
cancer came from milk retained in the breast from breastfeeding or bras that were too tight. In addition, the only benefits women in this study identified for pursuing early detection methods focused on preparing themselves earlier for an inevitable death (Muthoni, 2010). In a study done in Kapsokwony, Mosoriot and Turbo towns in 2015, 19.7% of people viewed cancer as a “killer disease” and 75.5% of men and women did not know the severity of it. The most common signs and symptoms men and women from this tribe identified were incorrect or signs of breast cancer in a later stage such as nipple discharge, swelling of the breast and intense pain (Naanyu, 2015).

A study on the costs of cancer conducted in 2016 found that on average, patients who were on chemotherapy paid an average of KES 138,207 (USD 1364.3); while those treated with surgery paid an average of KES 128,207 ($1265.6), and those on radiotherapy paid an average of KES 119,036 ($1175.1). Some patients had a combination of all three costing, on average, KES 333,462 ($3291.8) per patient during the year. They found that the cost of treatment varied depending on the type of cancer the patient had (Atieno, 2018).

A qualitative study conducted by Louise K. Makau-Barasa et al. in 2016 identified seven barriers to cancer treatment and testing in Kenya: the high cost of testing and treatment, low level of knowledge about cancer among the population and clinicians, poor health-seeking behaviors among the population, long distances to access diagnostic and treatment services, lack of decentralized diagnostic and treatment facilities, poor communication and lack of better cancer policy development and implementation (Makau-Barasa, 2018). Treatment abandonment has been identified as the most important reason for childhood cancer treatment failure in low income countries. In a 2012 study, financial difficulties, inadequate access to health insurance and transportation difficulties were cited as the main reasons why parents in Kenya abandoned cancer treatment of their children (Njuguna, 2014). In addition, in a mixed methods study conducted by Njuguna et al. in 2013 with parents of children who have cancer, researchers found that 89% reported that their child’s cancer treatment resulted in financial difficulties, 88% reported that more information about cancer and treatment was required and 83% said that more contact with their child’s doctors was needed. Some parents reported travel costs and hospital costs as the reason that they sometimes missed hospital appointments (Njuguna, 2014).

Stigma and a lack of psycho-social support has also been identified as a challenge cancer patients face. Some parents of children with cancer reported that there families were isolated by
community members because their child had cancer and some believed that the child was bewitched. In a study on cervical cancer patients in Western Kenya in 2014, patients reported financial costs to be a huge challenge as well as accessing psycho-social support. No patient in the study received any assistance from well-wishers, and only a few received assistance from charity organizations, friends and colleagues. In addition, only 10% of patients reported receiving some assistance from relatives or the church. Individual health care providers in this study identified a lack of specialised training, difficulty in disclosure of diagnosis to patients, a poor attitude towards cervical cancer screening procedure and a poor attitude towards cervical cancer patients to be a challenge in the care of cervical cancer patients (Owenga, 2018). A previous study conducted in 2013 had the same findings. Challenges found included a large number of patients presenting in the late stage of disease, low levels of knowledge on cancer, low levels of screening and a poor attitude towards screening procedure. Individual health care providers identified a lack of specialised training, difficulty in disclosure of diagnosis to patients, a poor attitude towards the cervical cancer screening procedure and a poor attitude towards cervical cancer patients (Kivuti-Bitok, 2013).

A study assessing the psychosocial effects of breast cancer patients who had a mastectomy in Nigeria found that six months after surgery, the survey responses revealed that 67.9% of women felt inadequate as a woman because of the mastectomy and that 79.0% experienced a decrease in frequency of conjugal relations. Three years after primary breast cancer treatment, 61.7% of the participants were still married while 38.3% reported being divorced/separated from their husbands compared with the national average divorce rate of 2.6% (Odigie, 2009). Another study done in 2018, found that in South Africa, cancer stereotypes contributed to delayed treatment, use of traditional healers instead of biomedical treatment and secrecy of symptoms and/or diagnosis. This was partly because cancer was conflated with HIV/TB due to previous education campaigns (Oystacher, 2018).
STATEMENT OF INTENTION AND ISP PROBLEM

The intent of this independent study project is to research the plight of individuals with cancer in Kenya. Interviews with cancer patients will be conducted to assess any barriers they may face in accessing detection methods, oncologists, treatment options as well as psycho-social support. The study will also be conducted to assess if patients suffer from any misconceptions or stigma, whether intra or interpersonal, for having cancer. Ultimately it is hoped that through this research, along with the help of key officials in the campaign against cancer, possible ways to improve the conditions of cancer patients, create awareness and help lessen the amount of deaths from cancer in Kenya can be surmised.

RESEARCH JUSTIFICATION

For many years in developing countries in Africa, research has been focused on the three most common communicable diseases: malaria, HIV/AIDS and Tuberculosis. Though this focus is justified due to high rates of communicable diseases in Kenya, this has led to a depletion of funding, resources and research in the area of non-communicable disease. Furthermore, cancer has been framed as “a sickness of the rich” and this ideal has led many people to believe that cancer is an illness of the Western World and not as rampant in a country like Kenya. The emerging rates of cancer in Kenya prove this to not be true. This research is justified because it examines a very deadly illness not often talked about in the Global Health context.

There have only been a few studies that have examined the plight of individuals living with cancer in Africa. Cancer is rarely discussed and many Kenyans remain uneducated about the causes of cancer and how to detect it early. This lack of education and awareness has cost many lives. In addition, absolutely no studies done in Kenya have asked general cancer patients themselves to report the barriers that they face in accessing treatment, care and psychosocial support. Studies that have been done have either asked key informants about the barriers patients may face or have focused on cervical cancer or childhood cancers only. This study incorporates interviews from both key informants and patients themselves allowing for a more comprehensive study. This study also encompasses patients with all kinds of cancers in Kenya including cancers that have not yet been addressed in previous studies. In addition, no study has looked at the stigma that general cancer patients may face in Kenya. A study of this sort is justified because it creates awareness of an illness rarely talked about and also generates knew
academic knowledge. This research will provide valuable information on the realities of having cancer and the state of cancer detection and treatment in Kenya. The information gathered in this study can then influence policy, encourage research and mobilize individuals to improve conditions and prevent a cancer diagnosis in Kenya from being a death sentence both figuratively and literally.

**RESEARCH OBJECTIVES**

1. To examine the current management of cancer patients in Kenya including the struggles, stigma, concerns and challenges cancer patients have especially when it comes to accessing cancer detection methods, oncologists, treatment & psycho-social support.

2. To conduct qualitative interviews with key people in the campaign against cancer (e.g. hospice officials, doctors, NGO executives, individuals working in the Ministry of Health, hospital in-charges) in order to examine how cancer awareness, detection and treatment can be improved.

3. To identify the level of breast cancer awareness among women of reproductive age in Kenya by using the Breast Cancer Awareness Measurement Tool (BCAM).

**METHODOLOGY**

*Cancer Patient Survey & Interview Methodology*

Study participants who have cancer were recruited from NGOs and cancer support groups that provide support and advocacy for cancer patients in Nairobi County. These institutions included Limau Cancer Connection, Faraja Cancer Support and Kenya Cancer Association. Because the Limau Cancer Connection has a strong online presence, a founder and board members who travel all over Kenya to provide support and awareness and is not operated from a physical facility, this NGO is able to support a wide range of patients from all over Kenya including patients that attend different treatment facilities, both private and public. The Faraja Cancer Support NGO is located inside the same building as the HCGCCK Cancer Center in
Nairobi. It is also across the street from M.P. Shah Hospital and so it primarily support patients who access cancer treatment at these two private facilities. The Kenyan Cancer Association is located on the Kenyatta National Hospital (KNH) campus and works mostly with patients who primarily access the public hospital for treatment. Permission was first obtained from these NGOs before participants were recruited at these institutions.

Questionnaires were handed out to participants who were living with cancer and willing to tell their story. Patients will all cancers were welcome to fill out the survey as well as cancer survivors. Only individuals over the age of eighteen were interviewed. The NGO staff helped to identify individuals who would be the most comfortable with sharing their story. In some instances, close caregivers were given the survey and interviewed on behalf of the patients when patients were unable to complete the forms themselves. The questionnaire inquired about the cost of their treatment as well as various challenges cancer patients may encounter when it comes to accessing treatment, psycho-social support, proper diagnosis, pain medication as well as any stigma or misconceptions patients may face from having cancer. After the questionnaire was filled out by the participant, the participants were briefly interviewed individually. The interviews were semi-structured and inquired further about what patients filled out in their surveys. These interviews lasted about 15 minutes. Some participants preferred to be interviewed at a later time or could not be interviewed at that moment in person. For these participants, a phone interview was conducted and the survey was filled by the researcher on their behalf after being told the patient’s responses over the phone. All interviews were recorded and transcribed verbatim for analysis. The questionnaire used is located in Appendix B and the interview guide used is located in Appendix C.

In one instance, a focus group interview was conducted with a group of nine women living with various cancers. This focus group interview was conducted at the Texas Cancer Center (TCC) in Nairobi. It was conducted during the Uwezo Cancer Support Group Meeting that is held at TCC once a month. The focus group lasted about 35 minutes and followed the same semi-structured interview structure as the other individual interviews that were conducted. These participants did not fill out surveys.

**Qualitative Interviews with People in Campaign Against Cancer Methodology**

Qualitative interviews with key people in the campaign against cancer were conducted in order to examine ways in which cancer in Kenya has been managed in the past and ways in
which cancer management can be improved. These interviews were individual, semi-structured and each lasted about twenty minutes. These interviews were recorded and transcribed verbatim for analysis. The interview guide is located in Appendix C.

**Breast Cancer Awareness Survey Methodology**

In order to identify the level of breast cancer awareness among women of reproductive age in Kenya, the Breast Cancer Awareness Measurement (BCAM) tool was used. This was the same measurement tool used by Naanyu et al. in their research on lay perceptions of breast cancer in Western Kenya. Research studies have found the BCAM to be sensitive to change, have high readability, good construct validity and moderate to good test-retest reliability for most items. The BCAM questionnaire used included items to access women’s knowledge of breast cancer’s symptoms as well as risk factors. The questionnaire also included items to assess the skills Kenyan women have to detect cancer and the behavior they may exhibit in response to noticing breast changes. Additional questions were added to the survey to address things that may be unique to the Kenyan context. For example, some questions were included to ask whether the women thought that cancer could come as the result of a curse or bewitchment or if the women believed that having cancer in Kenya is a death sentence. Additional questions that were added for the purpose of this particular research study were indicated with an asterisk in the questionnaire. Additional demographic questions were also asked such as the education level of the participants as well as their age. A copy of the questionnaire used is located in Appendix B.

This questionnaire was handed out to Kenyan women above the age of 18. The participants were recruited from various social locations. These locations included the Prestige Mall in Nairobi, the Citam Valley Road Church congregation in Nairobi, as well as the social networks of friends and family who helped hand out surveys at their various workplaces. These questionnaires were mostly handed out in person, with a few surveys completed online via a Google Form for those willing individuals whom could not be met in person. Consent was obtained from each participant before they completed the questionnaire. The questionnaire was then scored.

**ETHICAL CONSIDERATIONS**

Individuals suffering with cancer are apart of a very vulnerable population. Individuals in this population may be suffering an intense amount of pain as well as other physical and
emotional stressors. The cancer patient survey and interview contained questions about very sensitive topics such as death and illness and so it was emphasized on the consent form and interview that patients had the right to skip questions that were too sensitive and even deny participation in the study completely if they so chose. Participants faced no risk in refusing to participate in the study and no reward for doing so. Permission was also given by NGO executives before research was conducted in these facilities. Patients with cancer were not approached randomly. The researcher was guided by NGO officials to approach patients who the officials had worked with before and who they believed to be in a comfortable emotional and physical state at the moment to answer the sensitive survey and interview questions. Individuals who were resting from just receiving chemotherapy and radiotherapy were avoided so as to not cause them increased discomfort. Time was taken to get to know the research participants before the interviews were conducted so as to get them comfortable with the researcher before sharing their story. For those patients who received a phone interview, NGO officials reached out to them for consent first before the researcher contacted them and asked for consent herself. Consent was always obtained before any interview or survey was administered. This research project was approved by the SIT Local Review Board as well as the County Government of Kisumu County.

For both the awareness survey and the cancer patient survey, names were also not recorded so as to maintain each participant’s privacy. All responses were recorded using an ID number. All names in this study have been kept confidential, and the names listed in the qualitative part of the research paper are all pseudonyms and not the real names of participants. All recorded interviews were stored on a password protected phone and laptop. All filled out surveys were stored anonymously in a folder. Only the researcher had access to the phone, laptop and folder and kept them on her at all times. Most participants thoroughly understood and read English, but there was always a translator around for individuals who may have had trouble reading the consent form or understanding English.
FINDINGS

Participant Demographics

Cancer Patient Survey & Interview

Thirty patients with cancer were interviewed and filled out the survey. Patients had a range of different cancers including breast, cervical, prostate, ovarian, lymph node, gallbladder and pancreatic cancer. They came from different counties including Nairobi, Machakos, Mombasa, Nakuru, Kisumu, Embu, Kiambu and Nyandarua County. The year of cancer diagnosis for the patients ranged from the year 1993 to 2019. Five were recently diagnosed in 2019 (16.7%), six were diagnosed in 2018 (20%), five in 2016 (16.7%), three in 2017 (10%), two in 2014 (6.7%), three in 2015 (10%), two in 2005 (6.7%) and the remaining four (13.3%) were diagnosed in 2013, 2011, 2008 and 1993. Nine additional women in the Uwezo focus group were interviewed but did not fill out surveys. They had a range of cancers including breast, blood, cervical and brain cancer.

<table>
<thead>
<tr>
<th>STUDY PARTICIPANTS WITH CANCER</th>
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<tbody>
<tr>
<td></td>
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<tr>
<td>87% Female</td>
</tr>
<tr>
<td>39 Participants (30 filled out a demographic survey &amp; were interviewed. 9 were only interviewed)</td>
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<tr>
<td>15 Recruited From Faraja Support Group</td>
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<tr>
<td>67% Breast Cancer</td>
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<td>53.3% Nairobi County</td>
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Texas Cancer Center focus group was composed of 9 women with various cancers including blood, brain, breast and cervical cancers. These women were interviewed but did not fill out a survey.

Qualitative Interviews with People in Campaign Against Cancer

For the qualitative interviews with key informants in the campaign against cancer, six cancer NGO officials, four oncologists, four caregivers, two cancer researchers, one psychologist, one NHIF official, one cancer center CEO and one official from the Ministry of Health in Kisumu were interviewed. Overall, twenty key informants were interviewed.
Breast Cancer Awareness Survey

Fifty-nine Kenyan women above the age of eighteen filled out a breast cancer awareness survey. These women lived in various counties including Nairobi, Kisumu, Mombassa and Meru County. These women varied in age with most being below the age of 39. Most participants had at least a tertiary education. Participants were recruited from various social locations. These locations included the Prestige Mall in Nairobi (about 5%), the Citam Valley Road church congregation in Nairobi (about 15%) , as well as other social networks of friends and family who helped to hand out surveys at their various workplaces (about 80%). An online Google Form was sent to willing participants who could not be met in person. Ten participants filled out an online version of the form.

Qualitative Findings

The Different Challenges That Were Identified

Many challenges that cancer patients face in Kenya were identified by the participants with cancer as well as key informants in the campaign against cancer. The most common challenge identified was the expensive cost of cancer treatment in Kenya. Other challenges identified include the lack of access to cancer centers and trained specialized oncologists, especially for individuals who live outside Nairobi or in rural areas. Professional burnout and frustration of many medical personnel was reported by doctors and identified by patients and key informants. Psycho-social support and counselling for patients in the hospital setting was found to be lacking as well. A lack of awareness and knowledge about cancer was found to be rampant throughout Kenya and many study participants identified this as the main cause of stigma faced by cancer patients. Informants identified the mismanagement of funds given by donors and a lack of government response to be a few reasons why cancer awareness and detection as well access to treatment have been lagging behind in Kenya.
High Cost of Treatment

The cost of treatment was reported to be the biggest challenge that patients with cancer in Kenya face. The cost of treatment was found to be so expensive, that some caregivers and patients reported not being able to pay for medication or even treatment at all.

“It's very expensive... One of my sisters actually didn't even have a mastectomy. She died because... she didn't have money. She had children she was educating... A single mother with no one to take care of her so she made the decision to use the little money she had to take her children to school before she dies” - Mary, Uterine Cancer Survivor and Caregiver

“Even now I can’t afford medication... my children have stopped going to school. That's why I stopped to continue with medication. I lost my job so I'm just here” - Rose, Breast Cancer Survivor

This high cost of treatment was found to disproportionately serve as a barrier for women to receive treatment, especially for women in rural areas where the man is expected to be the breadwinner and women are often unemployed.

“... sometimes when I see some ladies who are jobless and the husband is the one having the work they sometimes don't get treatment because of money issues. I've been here for a month and I've already seen 2 or 3 patients like that... the woman is not working and the husband is working and is the one to decide if he can afford to pay for the treatment or not. There is one patient... I'm still waiting for her. She told me that the husband is the one that is not agreeing with the treatment. She promised me that she will convince him and come back... I haven't seen her.” - Dr. Mwangi, Oncologist

“Here men are the breadwinners of most families so when a woman gets sick... the woman has to ask the man for the money and the husband has to decide if he’ll give the woman for health or give it for food or other priorities in the house.” - Dr. Oluoch, Oncologist
Though Kenya’s National Health Insurance Fund (NHIF) began to cover radiotherapy and chemotherapy in 2016, patients and key informants reported that NHIF is selective, does not cover everything fully and often leaves patients with a hefty balance to pay. An NHIF official reported that NHIF only covers the first line of chemotherapy (six sessions) and covers only twenty sessions of radiotherapy. Patients who had a second or third recurrence of cancer, reported having to pay the cost of their additional lines of chemotherapy completely by themselves. Since a patient might need up to thirty five sessions of radiotherapy depending on the type of cancer and stage, patients who needed more than twenty sessions of radiotherapy also reported having to pay for that by themselves. The NHIF official reported that each radiotherapy session averages around KSh 2,000 and chemotherapy can range from KSh 900 - 200,000 per session depending on what type of medicine a doctor prescribes. A doctor shared that this high cost of treatment has led to some patients stopping treatment as soon as they reach maximum coverage from NHIF. Inpatient fees are only partially covered and the amount NHIF pays depends on the facility. Even the cost for a consultation with an oncologist is expensive, with the cost ranging from KSh 1,150 (at the public Kenyatta National Hospital) to KSh 6,000 each time a patient meets with a doctor.

The amount that NHIF agrees to cover for treatment and medication was reported to depend on the facility the patient accessed. At certain private facilities, NHIF was reported to not pay for any medication other than that used for chemotherapy and radiotherapy. Patients reported having to pay for supplements, pain medication, drugs to deal with treatment reactions and immune boosters completely on their own. Though NHIF covers more for medication at public facilities, NHIF still does not cover completely for all medication and patients reported that there are often frequent stock outs and extremely long wait times at public facilities. These stock outs often force patients to have to purchase medication elsewhere and pay for it fully on their own.

“Its 500 shillings for one tablet and then I have to take pain killers and blood pressure...
So now in one day you’re spending like 700 shillings on medication alone. You have a house to pay, food to buy. Sometimes you buy your food, and then now after eating because of your body and your reactions, you puke all that food. Now you’re hungry and
you don't have money to buy more food. It's really tough." - Linda, Breast Cancer Warrior

"I'm a blood cancer survivor. I've spent over 20 million... very expensive to treat blood cancer. I take medication about 20 a day. Every month about 200,000 shillings [for medication] that I must buy from India. Its expensive. Survivors can only survive if they have money." - Nancy, Blood Cancer Survivor

For individuals who are unemployed or self employed, it costs KSh 500 a month to get NHIF insurance coverage. Patients and key informants reported that this cost for NHIF also serves a barrier to treatment for patients who can not even afford food, let alone pay for an NHIF card. Many patients reported having to sell personal possessions, ask for donations from family and friends and take out loans just to pay for treatment. Many reported that the stress of finding how to pay for treatment took a toll on them mentally and emotionally.

"Before, I used NHIF to help pay, but now I can't even afford my NHIF card. I sold my land, by the time my husband was also sick with cancer we sold our land to get money and to at least take him to the hospital... it was not easy." - Grace, Breast Cancer Survivor

"We have learned to live one day at a time. Tomorrow is God’s. He gives us our daily bread. When we think about the debts and whatever you have, you can stop eating. So I don't think of the debts... Sometimes when you call someone they think you’re calling for money so some switch off their phones. They block the money and block their phones and don't give you anything." - Lilian, Brain Cancer Survivor

“You see why my account for NHIF is getting exhausted? How many people can afford 15,000 per month? You're a mother and have so much affecting you. Getting cancer doesn't mean that you stop thinking of your family. While I was in hospital I was still paying my sons college fees. So you must be strong... almost 2 million and I'm still taking medicine” Nancy, Blood Cancer Survivor
“At first it was shock, then it was panic. All of this was because I didn’t have enough finances. I was so scared because cancer is very expensive to treat... I am a school teacher and a single mother of one... So I had serious challenges of finance. I had my family and friends to help me. When finances were done we had fundraisers to raise money... Before getting that money you’re dealing with emotions. You're sick, you’re single, talking about a child, you don’t know where the next money will come from for you to get the next regime of treatment and that alone puts you down. You get so scared”
- Maryanne, Breast Cancer Survivor

In addition to the cost of medication and treatment, many patients reported the cost of vegetables and fruits to be a huge challenge as well. Many patients reported that though they were told by their doctors that eating a strict diet primarily composed of fruits and vegetables was paramount to starving cancer cells, they often times could not afford to buy the healthy foods they needed.

“Diet is very expensive because when a cancer patient is serious on their diet things must change. Fruits are very expensive. Taking juice one liter everyday. You need food that can starve these cells. If you are aware you must change your diet completely....”
- Joyce, Breast Cancer Warrior

“Your food is also not the same as you were eating before because you change your lifestyle a bit. Now our main diet is fruit that’s our main diet and vegetables. And those are very expensive. So your life is not the same. Not what you were used to before.”
- Alice, Cervical Cancer Survivor

For many breast cancer patients who have had mastectomies, the cost of breast prosthesis in Kenya is also too expensive for many to afford. Participants reported that prosthetic breasts cost on average around KSh 8,000- 20,000 for the bra and insert and are highly taxed by the government because they are viewed as non-medical, purely cosmetic items. There are some government programs that give prosthetics out for free, but participants reported that the
government given ones are of very poor quality and only last a few weeks or months forcing patients to have to buy longer lasting, better quality ones themselves.

**Lack of Access to Treatment, Medication & Oncologists**

Access to treatment, medication and oncologists was also identified to be a major challenge that patients face. While chemotherapy is offered in many county referral hospitals and private facilities throughout Kenya, radiotherapy is only available in Nairobi and Eldoret. Diagnostic machines such as the PET Scan and the cyclotron are only available at Aga Khan Hospital in Nairobi. X rays were also reported to be hard to access depending on where a patient lives. The care given at these cancer facilities often times is also not comprehensive and patients reported having to travel to different facilities to receive different services. It was reported that often times the nutritionist, radiologist, therapists, oncologists and other cancer care providers are all located in different facilities which makes it hard for patients to access comprehensive treatment.

Many patients reported having to travel far distances to reach facilities for treatment. Because outpatient radiotherapy sessions usually occur daily with only a break on the weekends, many patients reported not only having to find transportation to access these facilities, but also struggling to find accommodation while they were there. An NGO executive even disclosed that many cancer patients who travel far for outpatient services are forced to sleep on the KNH hospital hallways overnight because they cannot afford accommodation. Though there are plans to build an affordable hostel at KNH to accommodate cancer patients who travel far for treatment, the building of the hostel was reported to often get delayed due to lack of funding. The hostel will also only accommodate seventy patients at a time, leaving many patients still without access to accommodation.

“All the services you have to go to Nairobi. You have to look for accommodation. Sometimes you get booked months later in Kenyatta Hospital where you can at least afford... Mombasa to Nairobi is quite a distance. You'd have to travel by road about 8 - 10 hours. And you can imagine a patient sitting in a bus for 8-10 hrs.”- Mary, Uterine Cancer Survivor
This centralization of cancer centers in Nairobi was reported to have caused a large amount of congestion in cancer facilities. Patients complained that there are often long wait times for treatment as well as overcrowding of cancer wards, especially at the public Kenyatta National Hospital which is the only cancer treatment center that most lower income Kenyans can afford. Some informants even reported that at times, cancer patients in the wards have to sleep two to a bed or even on mats on the floor due to lack of space. In addition, many of the radiotherapy and chemotherapy machines at both private and public facilities were reported to be prone to breaking down, delaying the treatment of many patients.

“Its very bad [Kenyatta National Hospital] ... I remember when my husband was sick I took him there, they told us they dont have space for now until next year... I just called my oncologist to explain to him and he called one of the doctors there and then we get helped, but it took around three months. Kenyatta isn't nice. There is so much congestion there. People dying.” - Theresa, Breast Cancer Survivor and Caregiver

Many patients and key informants also agreed that there are not enough oncologists in Kenya to deal with the growing number of cancer cases. Some key informants disclosed that in some parts of the country, there are no oncologists at all. In areas where there are oncologists, participants reported that they might only be specialized in particular cancers or may only be specialized in radiation oncology, but not medical oncology, leaving a gap in access to medical expertise. There are no oncology specialty schools in Kenya which forces doctors to have to travel outside of the country and spend a lot of money to receive that training. Even when there were oncologist available, patients reported only being able to meet with them for a few minutes and not getting adequate enough time with them to address their needs.

“When you have an issue it's very hard to see a doctor. Especially when you're going through chemo. And when you see her she has no time for you she's just rushing to see so many people ...I felt no this is not that way...I wish there was someone who you have her available to ask questions. What she used to do is bring other doctors who weren’t trained in this and said if you have any questions ask the other doctors. But you see, I
signed a contract with her because she’s the oncologist. But in the process she disappeared. She’s not available.” - Alice, Breast Cancer Warrior

Patients also disclosed that there are often frequent stock outs of essential cancer medications at public facilities. Medication was also reported to be very difficult to access for individuals who live outside of Nairobi.

“In the public hospitals to get access to the medication you go and spend the whole day waiting for your turn. You find other people who are there filing up everyday... Sometimes even the chances of you getting your treatment at that time is rare because people are many travelling for the same facility. So sometimes they’ll tell you to come next time...” - Mercy, Pancreatic Cancer Survivor

Burnout of Medical Personnel, Lack of Counselling & Violations of Patients Rights

Most of the doctors and patients interviewed agreed that many of the oncological medical personnel suffer from burnout. One informant reported that Kenya is now in the process of training about thirty new oncologists, but as for right now there is still a gap in the number of doctors available. Currently there are only about thirteen oncologists in all of Kenya. Due to the low number of oncologists as well as nurses in Kenya, oncologists were reported to be overworked with many working in both private and public facilities. Many patients and key informants reported that this burnout and frustration was often taken out upon patients. Many patients reported being treated horribly by the medical staff despite their fragile condition. Many patients identified this as a problem whether they attended public or private facilities, however, those individuals who could only afford to get treatment at the public hospital were more likely to identify this as a problem.

“The nurses there [at KNH] are so jaded...I don’t know what’s going on there... they’re not there to do a job ... Of course there has to be some doctors there who are passionate about what they’re doing who want to help their patients, but I think there are also others there because that’s where they’re supposed to be and they get their paycheck at the end
Informants reported a lack of counselling in health facilities to be a challenge as well. Though some had good experiences, many disclosed that doctors gave them their cancer diagnosis in a very informal and insensitive way and that there were no counsellors or psychologists they could access in the hospital to receive support. Even caregivers reported being told of the death of their loved one in an insensitive way as well. Both a psychologist and researcher reported that the problem is not primarily a lack of psychologists available in Kenya, but the fact that counselling is not streamlined to be a part of cancer patient care. They reported that cancer care in Kenya tends to focus primarily on the physical, while ignoring the psychological and mental well being of the patient.

“... so what happens is that counsellors appear as people who are isolated... They are not incorporated into the medical system so that someone can be able to say I can access a counselor when I need one... And this gap can only be addressed when people know that mental health is apart of the general health... We don't have a shortage of counsellors. Because if we were to count the number of counsellors... I think we have quite enough. They are not fully engaged the ones that are there.” - Dr. Mutunga, Psychologist

“In public hospitals they are there...but most probably you'll end up finding just one or two people so they are not very effective. Just because of the shear numbers that they have to take care of. In public hospitals they are free or if not, offered at a minimal fee. If you go to private hospitals, wow, it's going to be very expensive. Which most of the time you're looking at cost of medicine and you'd opt to pay for your medicine instead of a counsellor to come sit down and talk to you.” Margaret, NGO Executive and Breast Cancer Survivor

“I didn't come across any counsellor or psychologist. Even the breaking the news that you have cancer is so hardcore and bland. You just go to the doctor and they say you have cancer. It’s that bad.” - Alice, Breast Cancer Survivor
“After my mum passed on, the doctor that was handling her case failed to communicate about the loss of our beloved patient thus leaving us to find out about it from the nurses... and even after our several attempts to reach out to her she never got back to us.” - Josephine, Caregiver

Many cancer warriors and survivors also reported that doctors did not thoroughly explain to them their diagnosis, what was going on during the course of treatment and the possible side effects they could expect from their medication. Some of the few patients who did report that they were informed about their condition, reported that doctors did it in a way that was too complicated for them to understand.

“Even the time I was going through chemo, the oncologist told me some things that the hair will fall off you might vomit and that was all... It is more than vomiting and hair falling. I wish there was someone who could sit down with you and explain exactly what will happen stage from the other so you face the chemo at least knowing what to expect... nails turned, appetite goes, sometimes diarrhea, sometimes constipation... the first chemo I did the medicine was red in color and so when I first went to use the bathroom I found red in my urine. I almost screamed. I'm emitting blood. Little did I know that the medicine could come out red in my urine. It was traumatizing and then no doctor briefs you that this can happen...there's a lot of gaps.” - Alice, Breast Cancer Survivor

“They would tell you this is what you need to do but they wouldn't appreciate when you would ask questions about details like why are you giving me this, what is it going to do to me...what happens is that many people going through this don't expect to receive answers for their questions so they don't even bother asking and so through the treatment they just say ‘the doctor told me to do this’. Why is he telling you this? ‘No I don't know, they just told me’ so therers alot of that.” - Margaret, Breast Cancer Survivor and NGO Executive
Key informants and patients stated that they believed that many oncologists were simply in the medical profession to get money and did not truly care about the well being of their patients. Some patients told stories of doctors withholding their hospital labs and records as a means to prohibit patients from seeking a second opinion from other doctors. A key informant and some patients also reported how many Kenyan oncologists work in both the private and public sector and how at times this can lead to a conflict of interest where doctors do whatever they can to get patients to switch to receiving treatment at the private facilities instead of the public facilities to gain more profit.

“Alot of corruption comes from people not knowing it is their right to demand. The doctor gets to scare you that he's the only doctor you can talk to and you can't get a second opinion. They hold onto your patient files, you can't ask questions which is a complete contrast to what your patient rights are. People call that corruption but really its people being taken advantage of because they're ignorant. -Gladys, NGO Executive and Breast Cancer Survivor

“We had doctors squabbling over who would do the biopsy because of the money involved… Everybody is building hospitals. We have one of the biggest doctors in charge of a public facility… but also has a private facility. look at that conflict of interest. How will you treat me if I go to public hospital and you need to make and income? They'll definitely say ‘why don't you come to my hospital and I treat you there?’”- Phillip, Caregiver

“You have some doctors who won't buy gel for a scanning machine [at public facilities] so that they can send patients outside to be scanned. Some don't have a machine, but some just don't use them… they rarely use them because they make more money when a patient goes to their clinic outside. You see, for example, if I don't have gel in a hospital… I can't do a scan because I don't have the gel… So I don't requisition for it or make it a priority so the county hospital doesn't make it a priority… But you see there is a corruption behind it since I intentionally never bought the gel... or the machine will just...
fail and then I intentionally don’t requisition for the service because you know I make more money when they come to my private facility” - Sharon, NGO Executive

Professional negligence was also identified as a challenge as well.

“.... Left without being attended for hours and in a lot of pain... Proper procedures not adhered to especially after chemotherapy treatment...Prescriptions given over the phone where she required physical examination...” - Josephine, Caregiver

“The untold story of cancer is that most patients don't die of cancer. They die of secondary infections that come out of chemotherapy treatment. That’s how I lost my wife. They don't give you the proper care. They don't isolate you. They put you in a normal ward. You start getting infected. Doctors give you the chemo but because you can't afford the aftercare, they take shortcuts. Here in Kenya, the doctor is giving you medication by phone because they know you can't pay.” - Phillip, Caregiver

Since breast prosthetics are imported from abroad, many breast cancer patients reported frequent stock outs of quality prosthetics to be a challenge as well.

**Stigma & a Lack of Psycho-social Support**

Many patients reported facing various forms of stigma for having cancer, including facing accusations that they are cursed, bewitched, or that they have done something evil to deserve their illness. One caregiver even revealed that in the village, she knew of a man with cancer who believed that his cancer was the result of him not paying dowry for his wife. So instead of paying for treatment, he went to pay for his wife’s dowry so as to reverse the “curse”. The belief that cancer is a curse was also reported to have led newly diagnosed patients to seek out traditional and herbal medicine for treatment instead of conventional medicine after being diagnosed. Many patients reported losing friends and family support after their diagnosis because of their fear of being associated with a person who is cursed.
Many patients reported being viewed as “dying” or “already dead” for having cancer. Because of the view of cancer as a death sentence, many individuals reported that they soon stopped receiving support from their family and friends after diagnosis because of beliefs that they were going to die soon. Many women disclosed that their partners and husbands left them after diagnosis because of this reason.

“You know here in Africa when people hear cancer they think it is a death sentence, so they think oh well just be wasting your money. So me I’m just here with my children. I Don't have any friends. They run away. Even relatives because they believe that cancer is a death sentence so there is nothing that you can do.” - Grace, Breast Cancer Warrior

“Some of my friends ran away and some of my family ran away... when you call ‘oh this is [Lillian], is she dead or alive,’ yes this is how they used to ask... sometimes I just wanted to hear their voice. My children were very young, husband ran away... I used to smell because I had a bedsore. I used to fear sitting by others. People would walk away. I used to encourage myself saying that they don't know what I am going through. It's not my wish to smell. It's us fighting for ourselves. - Lillian, Brain Cancer Survivor

Women with breast cancer reported facing an increased amount of stigma, both inter and intra personal. Some women reported that their husband left them after their mastectomy because they looked “ugly” and like less than a woman. Many women reported self stigma because they viewed their breasts as an indication of their womanhood.

“Young ladies who get their breasts removed and have husbands. They feel discouraged. I heard a young man who was complaining. He said, ‘Ah my wife is not pretty. She looks very ugly. She just has one breast’ ...there is that stigma.” - Cecilia, Breast Cancer Survivor

“Men have an attitude that a woman with breast cancer is not sexually active and is a bother, it’s expensive so they run away and divorce. The divorce rates here are very high
because of sickness not because of other things like in the West.” - Dr. Oluoch, Oncologist

“A lot of the women that I work with have husbands that have kicked them out or said that they're no longer women... they tell them 'oh you're no longer a woman and I don't have use for you so please go away’, but they don't say please. They just kick them out... we don't really have access to prosthesis... they have to wear unnatural stuff like they put a sock or a cloth in [for a breast]... they feel unnatural. They don't feel like a woman anymore... You get a lot of that. Just them not feeling like a woman like they are lacking something.” - Margaret, NGO Executive & Breast Cancer Survivor

A patient who got breast cancer at the age of twenty-two emphasized how stigmatization is even worse for younger women of reproductive age. Younger women who have gotten mastectomies face challenges as they struggle to find a partner who accepts them and battle with stigma that comes from a tremendous lack of awareness in the younger Kenyan population.

“I didn't have a husband... so the experience if a guy is approaching you, having to explain to them that you know I have gone through cancer before and have lost a breast because of it and you know this is my situation. Now most people will think that ah because she has gone through cancer before that oh maybe she might relapse or get sick or maybe she's still sick and people shy away from interacting with you so those are some of the challenges I face as a young person... I don't take it personally. Its because most of the times they just don't know better and society associates cancer with death.” - Millicent, Breast Cancer Survivor

Some cancer patients reported being able to access support groups to help them through their cancer, while others were not able to find any at all. Most of these support groups were said to be located in Nairobi, leaving many individuals living in rural areas without any support or companionship from other cancer warriors and survivors.
**Lack of Awareness and Knowledge about Cancer, Late Detection & Misdiagnosis**

Informants revealed that most of the stigma surrounding cancer is simply the result of a lack of awareness and knowledge about cancer. Key informants believed that since cancer is just beginning to become widespread in Sub-Saharan Africa, a huge knowledge gap exists. This lack of knowledge and awareness has also led many to ignore cancers causes, signs and symptoms which has led to many late diagnoses. A lack of awareness was reported to especially be prominent among the younger generation. Many Kenyans were said to believe that cancer is an automatic death sentence and so this belief keeps individuals from to access detection methods.

“People don't really talk about cancer. It's still that dreaded disease we don't talk about. You'll go out there and tell people 'oh you need to go get checked. Nothing is wrong with you but go to get check cause if there is something it can be detected early.' Some are like ‘oh no I don't want to do that, I’m gonna die if I have it so what's the point? Let me just live my life.”- Margaret, NGO Executive and Breast Cancer Survivor

“I was 22... my friends were as young as myself at that time. And I had to go through this type of treatment and they were like oh no you can't do that, you cant even have cancer, maybe the doctor got it wrong. Don't even go through with the mastectomy. And that confusion... people are not educated enough to know what cancer is ....There's a lack of knowledge among the young people that's different from the older generation because probably by the time you get to 40 years you have heard, seen and met someone . So when you are young your education about cancer is very little... ”- Millicent, Breast Cancer Survivor

It was reported that there is not only a lack of knowledge among community members, but also a lack of knowledge among many doctors and healthcare professionals as well. This lack of knowledge was reported to be the reason why even when individuals present to the healthcare facilities with symptoms of cancer, many receive a late diagnosis. A late diagnosis increases the chance of an individual dying from cancer and makes it much harder to treat. This lack of knowledge on behalf of medical professionals was also shown to have led to faulty treatment.
“The first doctor I met was a clinician. The clinician actually told me not to worry about the breast lump because young girls at that age get breast lumps that come and go because of growing fat or its just a normal process in growing so he had already dismissed it even before treating me” - Millicent, Breast Cancer Survivor

“I also had a misdiagnosis. Since I had uterine cancer, I was bleeding and I was just told no its hormonal... I had never been on family planning. I was given hormonal drugs to regulate my “menses” for like one year and now was loosing so much weight... I was unable to eat and somebody [a friend] said wait a minute there could be more to it and so I did a pap smear and that's when I found the cancerous cells and had my uterus also removed...” - Mary, Uterine Cancer Survivor and Caregiver

“It took me like four months to find the right hospital cause they would give me the painkillers and treat me for Hepatitis and I’ll go home and take the drug and I won't have any improvement and... they’ll give me other drugs....” - Mercy, Pancreatic Cancer Survivor

Detection methods were also reported to not be widespread and to be too expensive for some individuals to afford. Mammograms were reported to cost anywhere from KSh 3,500 to 6,000 depending on whether a patient gets it done at a private or public facility. However, informants reported that they are mostly done in private facilities because the queue at public hospitals like Kenyatta National Hospital are very long. They reported that mammogram machines are also not available at all in the more rural areas of Kenya and this prevents a barrier to detection. There have been many campaigns to spread breast cancer awareness and offer free breast exams in more rural areas of Kenya, but many informants say that these campaigns are often times fruitless given the lack of oncology centers, machinery or oncologists in rural parts of Kenya to assist a patient if a breast lump is discovered.

“I have some ladies, some friends of mine that would go out to rural areas to do awareness... they'll call a school or church and say they were coming... but if they find
that anybody has a suspicious lump, the only place they can send them is the district hospital and when they go to the district hospital they don't know what to do so they'll tell them maybe you need to go to Nairobi to Kenyatta ... So rural areas are see no evil hear no evil sort of thing. 'I don't even want to hear about it because if I do find I have cancer I don't know what I would do about it' ... you'll find those who do have cancer they'll just go home and just live on pain medication until they die and you'll find that maybe it's something that could have been treated at the time.” - Margaret, NGO Executive and Breast Cancer Survivor

Lack of Government Response to Cancer & Possible Proposed Solutions Identified by Participants to Improve Cancer Management in Kenya

When participants were asked what the government could do to help improve the lives of individuals who have cancer in Kenya, many participants responded that the government should provide more information and spread awareness about cancer, make cancer care and detection more accessible to all especially outside of Nairobi, train more oncologists, train community health volunteers and clinical officers to detect signs of cancer earlier, bring the cost of cancer down, create a specific cancer budget for each county, increase data surveillance, make better use of donor funds and, the most common suggestion, declare cancer in Kenya to be a national disaster.

“Information. Credible simplified information. The same way they do for all these other diseases cholera: wash your hands, eat clean fruit... Going out to the communities letting them know to go in for early screening so it can be managed early. How to eat right... Because it doesn't make sense to have a good system and good hospitals yet people are still eating junk... if you put info out there for people to know how to prevent it, how to live better lifestyles and even if you do get an early diagnosis where to go, then things would be better” - Gladys, NGO Executive and Breast Cancer Survivor

“In our Kenyan constitution, healthcare is a right to every Kenyan. But you find that... we have not been able to develop our structure so that we can be able to have accessible, affordable quality cancer treatment centers in the country. This one can be attributed to
our government's blindness to accepting cancer as a national disaster. Because it is one. But as much as it is a national disaster, until it is declared one and enacted in our laws and constitution that it is a national disaster little can be done about it. And if that is not done than that means patients will keep on suffering, their families will keep on suffering...” - Dr. Odera, Cancer Researcher

“Every household or at least every second household in Kenya is getting cancer... If they declare cancer a national disaster that means it becomes the responsibility of the government because now, the government will have to explain where their budgets are for cancer like they did with AIDS... when they declared AIDS a national disaster we started having VCT points all around the country where you can just walk in get diagnosed and do an AIDS test... they gave us free medicine... Awareness was created in every part of this country. We had posters talking about how to avoid AIDS and how to take care of AIDS patients. Now that's what we need we need to create awareness. Government gave out free condoms and encouraged people to have safe sex, that's what we need. If anything, if we can prevent we don't need treatment. All we ask is that we have a facility that is creating awareness. We're not looking for cures... We just want to prevent it. And this entails us declaring it a national disaster. If we did declare it, everything will be covered. Even the big donors would come in and support in a big way and say okay, we're going to help you create awareness... As long as cancer is not a national disaster, USA will not give funding. It will give funding about AIDS, it will give funding for other things because the country won't admit the problem” - John, Caregiver

Quantitative Findings
Cancer Patient Survey Findings
Thirty patients filled out questionnaires that asked about various aspects of their cancer experience. Participants were told that they have the right to skip any questions that they were uncomfortable answering and so though most questions had responses from 100% of the participants, for some questions there were a little less than thirty respondents who answered them.
The biggest challenges that patients reported are indicated in the table below. Other big challenges some patients reported included the lack of information given by doctors as well as the treatment decision making process with family members.

<table>
<thead>
<tr>
<th>What Patients Reported Being the Biggest Challenge of Having Cancer in Kenya</th>
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<tbody>
<tr>
<td>Cost of Treatment and Medication</td>
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<tr>
<td>Fear of Dying From Cancer</td>
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<tr>
<td>Lack of Psychosocial Support and Counselling</td>
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<tr>
<td>Lack of Accessible Treatment and Cancer Care Centers and Specialists in Some Parts of the Country</td>
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<tr>
<td>Stigma and Misconceptions People Have about Your Cancer</td>
</tr>
<tr>
<td>Other</td>
</tr>
</tbody>
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Patients reported using NHIF, personal savings, money earned from selling personal belongings, donations from family, friends and community as well as other sources such as private insurance and loans from work to help pay for their cancer treatment. Patients reported paying from KSh 21,000 to KSh 6,000,000 a year on treatment. Most patients spent more towards the higher side with the average amount of money spent by the participants in a year being KSh 1,539,142.86.
Patients who marked that they only sometimes had access to pain medication or did not have access to it at all reported reasons such as medication being too expensive (37.5%), the medicine not being available at their hospital (37.5%) or their lack of pain (25%) as reasons for not always accessing pain medication.

Examples of the kinds of stigma and misconceptions that participants reported they faced included ideas that they were cursed or bewitched and ideas that they are dying. Breast cancer patients especially reported high levels of self stigma and ideas of “not being complete” without their breasts. Some wrote about others who told them that they are not feminine enough without a breast. Some patients also reported that they were kept alone from others and that some family friends avoided them after hearing of their cancer diagnosis. One women reported that since some individuals around her knew obesity was a risk factor for cancer, they blamed her weight as the only reason she got cancer.

Participants who reported suffering from misdiagnosis, had to wait from one month to three years to receive a proper diagnosis and, together, they waited an average of about ten months for proper diagnosis. After receiving their cancer diagnosis, patients reported waiting from one week to up to two years to receive the initial stage of cancer treatment. Together on average, patients waited about three months to receive treatment after diagnosis. Patients who had to delay getting treatment mainly reported reasons such as denial, lack of access to a proper cancer treatment
centers, lack of doctor encouragement for immediate treatment and the doctor’s strike as the reason why. The most commonly cited reason, however, was a lack of funds. The patients reported travelling from 10 km to 500 km to receive treatment. Together they travelled an average of 116 km to access treatment.

Patients Reported Access to Psycho-social Support and Medication & Encounters with Misdiagnosis

<table>
<thead>
<tr>
<th>Question</th>
<th>Strongly Agree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly Disagree</th>
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</thead>
<tbody>
<tr>
<td>Do you have access to pain medication to help you cope with your pain?</td>
<td>64.30%</td>
<td>25%</td>
<td>10.70%</td>
<td></td>
</tr>
<tr>
<td>Do you believe that you face any stigma or misconceptions from others for having cancer?</td>
<td>66.70%</td>
<td>33.30%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>When you first came to the hospital to present your symptoms, did you receive a misdiagnosis?</td>
<td>27.60%</td>
<td>72.40%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Are you aware of any cancer support groups near you where you can go to get support?</td>
<td>66.70%</td>
<td>33.30%</td>
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</tr>
<tr>
<td>Are there any free counselors or therapists at your hospital or clinic that you can talk to for counselling and psychological support?</td>
<td>50%</td>
<td>50%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

How Much Patients Agreed to Some Statements About Their Cancer Experience

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>During my diagnosis and treatment process, I was well informed by my doctor about my diagnosis, treatment options and the side effects that might come from my cancer and my treatment.</td>
<td>41%</td>
<td>7%</td>
<td>14%</td>
<td>38%</td>
</tr>
<tr>
<td>My family and friends have been supportive of me since my diagnosis of cancer and while I have undergone treatment.</td>
<td>7%</td>
<td>0%</td>
<td>14%</td>
<td>79%</td>
</tr>
<tr>
<td>Having cancer in Kenya is a death sentence.</td>
<td>48%</td>
<td>8%</td>
<td>28%</td>
<td>16%</td>
</tr>
<tr>
<td>Doctors and nurses have treated me with empathy and respect throughout my cancer diagnosis and treatment.</td>
<td>11%</td>
<td>11%</td>
<td>32%</td>
<td>46%</td>
</tr>
<tr>
<td>Cancer should be declared a national disaster in Kenya</td>
<td>0%</td>
<td>8%</td>
<td>8%</td>
<td>84%</td>
</tr>
</tbody>
</table>
When asked an open ended question about whether or not there was anything else they would like to share about the challenges of having cancer in Kenya, most respondents emphasized how big of a challenge the high cost of treatment was. Many emphasized how the government needs to be spread more knowledge and education about cancer. They emphasized the need for more psycho-social support of cancer patients and increased accessibility of cancer treatment centers.

**Breast Cancer Awareness Survey Findings**

On the Breast Cancer Awareness Survey, Participants were asked both open ended and close ended questions that asked them to identify early warning signs of cancer. In response to the open ended questions, 31.2% of responses said that a lump in the breast, 14.4% said that discharge or blood from the nipples, 9.6% said pain when the breast were touched, 8.8% said swollen breasts, 8% said a change in color or shape of the areola, and the remaining 28% identified various things including inverted nipples, asymmetry of breasts, dimpling of breast skin, change in breast size, birth anomalies, peeling and rashing of breast skin, chest problems, poor immunity, wounds, visible veins and breast itching as early warning signs of breast cancer. The closed ended question responses are in the chart below. The correct answer for all of these questions was ‘yes’.

**Research Participant’s Identification of the Warning Signs of Breast Cancer**

<table>
<thead>
<tr>
<th>Question</th>
<th>YES</th>
<th>NO</th>
<th>DON'T KNOW</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you think dimpling of the breast skin could be a sign of breast cancer?</td>
<td>53%</td>
<td>20%</td>
<td>27%</td>
</tr>
<tr>
<td>Do you think pain in one of your breasts or armpit could be a sign of breast cancer?</td>
<td>73%</td>
<td>17%</td>
<td>12%</td>
</tr>
<tr>
<td>Do you think a change in the shape of your breast or nipple could be a sign of breast cancer?</td>
<td>52%</td>
<td>28%</td>
<td>21%</td>
</tr>
<tr>
<td>Do you think a change in the size of your breast or nipple could be a sign of breast cancer?</td>
<td>53%</td>
<td>26%</td>
<td>21%</td>
</tr>
<tr>
<td>Do you think redness of your breast skin could be a sign of breast cancer?</td>
<td>57%</td>
<td>22%</td>
<td>22%</td>
</tr>
<tr>
<td>Do you think a rash on or around your nipple could be a sign of breast cancer?</td>
<td>44%</td>
<td>30%</td>
<td>20%</td>
</tr>
<tr>
<td>Do you think a change in the position of your nipple could be a sign of breast cancer?</td>
<td>44%</td>
<td>30%</td>
<td>26%</td>
</tr>
<tr>
<td>Do you think the pulling in of your armpit could be a sign of breast cancer?</td>
<td>45%</td>
<td>23%</td>
<td>28%</td>
</tr>
<tr>
<td>Do you think bleeding or discharge from your nipple could be a sign of breast cancer?</td>
<td>81%</td>
<td>8%</td>
<td>11%</td>
</tr>
<tr>
<td>Do you think a lump or thickening under your armpit could be a sign of breast cancer?</td>
<td>49%</td>
<td>32%</td>
<td>19%</td>
</tr>
<tr>
<td>Do you think a lump or thickening in your breast could be a sign of breast cancer?</td>
<td>85%</td>
<td>5%</td>
<td>0%</td>
</tr>
</tbody>
</table>
In response to the open ended questions about breast cancer causes included in the survey, 20% identified family genetics, 17.6% identified lifestyle, 16.5% identified diet, and the remaining 54% identified other things as causes of breast cancer such as men sucking on a woman’s breasts during sex, the use of contraceptives, old age, ultraviolet rays, infertility, failure to breastfeed kids, types of sprays and body oils used, sleeping with a bra or wearing a bra that is too tight, putting on bras that are new or unwashed, bad body hygiene and dirty bras, collection of blood in the breasts, smoking, drugs and alcohol as possible things that affect a woman’s chance of developing breast cancer. To the question asking who is most likely to develop breast cancer in the next year, 78% of participants said a woman of any age, 10% said a thirty year old, 9% said a fifty year old and 3% said a 70 year old. The correct answer to this question is ‘a 70 year old woman.’ The closed ended question responses are in the chart below. The correct answer for all of these statements should have been ‘strongly agree’.

Research Participant’s Identification of Factors That Can Increase the Likelihood of Developing Breast Cancer

<table>
<thead>
<tr>
<th>Factor</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Not Sure</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Having a past history of Breast Cancer</td>
<td>14%</td>
<td>7%</td>
<td>16%</td>
<td>25%</td>
<td>3%</td>
</tr>
<tr>
<td>Drinking more than 1 unit of alcohol a day</td>
<td>11%</td>
<td>36%</td>
<td>32%</td>
<td>20%</td>
<td>2%</td>
</tr>
<tr>
<td>Being overweight</td>
<td>19%</td>
<td>24%</td>
<td>29%</td>
<td>22%</td>
<td>5%</td>
</tr>
<tr>
<td>Having a close relative with breast cancer</td>
<td>24%</td>
<td>17%</td>
<td>20%</td>
<td>27%</td>
<td>18%</td>
</tr>
<tr>
<td>Having children later on in life or not at all</td>
<td>25%</td>
<td>21%</td>
<td>36%</td>
<td>14%</td>
<td>4%</td>
</tr>
<tr>
<td>Starting your periods at an early age</td>
<td>35%</td>
<td>22%</td>
<td>38%</td>
<td>4%</td>
<td>2%</td>
</tr>
<tr>
<td>Having a late menopause</td>
<td>33%</td>
<td>20%</td>
<td>44%</td>
<td>0%</td>
<td>2%</td>
</tr>
<tr>
<td>Doing less than 30 mins of moderate physical activity 5 times a week</td>
<td>19%</td>
<td>36%</td>
<td>26%</td>
<td>11%</td>
<td>8%</td>
</tr>
<tr>
<td>Being bewitched or cursed****</td>
<td>73%</td>
<td>16%</td>
<td>9%</td>
<td>0%</td>
<td>2%</td>
</tr>
</tbody>
</table>

Of the women who reported knowing how to conduct a self breast exam, 28% said that they were very confident in their ability to detect a change in one of their breasts, 43% said they were fairly...
confident, 17% said they were not very confident and 12% said that they were not confident at all. 18% of participants reported having seen a doctor about a change they have noticed in their breast, 37% reported not having seen a doctor about a change they noticed in one of their breasts and 45% reported never noticing a change in one of their breasts at all.

**Percentage of Research Participants Who Were Aware of How to Properly Conduct a Self Breast Exam**

- Not Aware: 34.0%
- Aware: 66.0%

**How Often Research Participants Reported Conducting Self Breast Exams**

- At least once a week: 8.0%
- At least once a month: 19.0%
- Rarely or never: 53.0%
- At least once every 6 mo: 20.0%

**Percentage of Research Participants Who Were Aware of a Place Near Them to Get a Mammogram**

- Not Aware: 52.2%
- Aware: 47.8%

**Percentage of Research Participants Who Have Ever Gotten A Mammogram**

- Have not gotten a mammogram: 86.0%
- Have gotten a mammogram: 14.0%
When asked whether participants believed if breast cancer was a death sentence, 33% agreed that it was and 67% said that it was not. When asked how many women out of ten survive Breast Cancer in Kenya, 25% said one woman, 22% said two women, 16% said three women, 9% said zero women, 9% said six women, 7% said three women and the remaining 12% said other answers including four, seven, nine or ten women. 78% of participants correctly identified October as Breast Cancer Awareness Month. 22% either did not know, or identified various other months as Breast Cancer Awareness Month, such as March, June, August and September.

**DISCUSSION**

Both the quantitative and the qualitative data from this study support each other. The same barriers of high cost, limited accessibility to cancer treatment centers and trained specialized oncologists, professional burnout and frustration of many medical personnel, a lack of psycho-social support and counselling for patients in the hospital setting, a rampant lack of awareness and knowledge about cancer as well as stigma faced by cancer patients were reported. The breast cancer awareness survey results exemplified the lack of cancer awareness reported by patients and other key informants. This research study’s results are comparable to the results of other research studies conducted in the past. Studies conducted by Muthoni et al. in 2010 and Naanyu et al. in 2015 identified the same lack of breast cancer awareness in both urban and rural women in Kenya. A study by Louise K. Makau-Barasa et. al. conducted in 2016, a study conducted by Kivuti-Bitok et al. in 2013 and a studies by Njuguna et al. in 2014 and 2016 all identified the same barriers to cancer treatment for patients in Kenya. The stigma against cancer patients that was identified by Owenga et al. in 2018 was identified in this study as well.

**LIMITATIONS OF RESEARCH**

There are some limitations to this research study. Because cancer patients were recruited from three support NGOs, cancer patients who may not have access to support groups and NGOs were left out of the study. Studies have also shown that men are less likely to seek mental health and support services. This led to a slightly biased sample with more women participants than male participants available to be recruited at these NGOs. This is the reason why most participants had cancers that only affect women and the sample of patient cancers in the study were not as diverse as they would have been had more males been involved. In addition, this
study was conducted primarily in Nairobi. Though patients who had travelled to Nairobi from various areas for treatment were interviewed and others from other counties received phone interviews, this study was primarily only able to access those individuals who lived or had the resources to travel to Nairobi. Because of this, the population of individuals with cancer in rural areas and other areas who may not have been able to access these facilities were not well represented. Most patients were also recruited from Faraja Cancer Support Group which primarily serves a wealthier population that accesses private facilities. This might have skewed the results in some areas and some challenges that less wealthy patients face may not have been as emphasized. Some individuals underwent cancer treatment prior to NHIF providing some help with cancer treatment services. If the study was composed of only individuals who received treatment after NHIF perhaps some of the financial challenges and data might have been a bit different.

Random sampling was not used to conduct the breast cancer awareness surveys. Primarily convenience sampling was used. This skewed the populations that this awareness survey was able to reach. In addition, due to time constraints and access, an online form was created for the breast cancer awareness survey for individuals to easily send out to their family and friends. Due to the online nature of this form, individuals without access to internet, a smartphone or laptop to complete the survey were not able to fill it out, thus created a barrier in the population this survey was able to meet. These surveys were only primarily filled out by women from Nairobi and Kisumu and there were only 59 participants. The low number of participants in this study may not be enough to determine overall awareness.

**CONCLUSION & RECOMMENDATIONS FOR FURTHER STUDY**

As the plight of cancer patients in Kenya is gaining more awareness and the government is beginning to draw more attention to it, there are various emerging government plans to build more radiotherapy centers, increase research and awareness as well as train more oncologists to meet the need. It is recommended that studies should be conducted in the future to access how these interventions, if implemented, have increased or decreased cancer patient challenges over time. It is also recommended that more research should be done on ways to not only spread cancer awareness and knowledge, but also ways to effectively influence cancer detection and health seeking behavior in order to prevent late stage cancer diagnosis. Research on how CHVs
can be used to help detect cancer patients earlier in Kenya should also be conducted. Studies
should also be conducted to examine various ways in which integration of mental health services
into the healthcare system can help improve cancer patient outcomes and illness experiences. It
is also recommended that a more random and extensive breast cancer awareness survey should
be administered in urban areas of Kenya to better gauge awareness. Non-communicable diseases
are becoming an emerging problem that sub-Saharan Africa cannot afford to ignore. Awareness
& education are paramount to eradicate the stigma cancer patients face and to lessen the amount
of deaths from cancer in Kenya.

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APPENDIX A: CONSENT FORM

CANCER SURVEY CONSENT FORM

TITLE OF STUDY
Cancer Management in Kenya- Awareness & The Struggles Patients Face to Access Treatment, Care & Support

PURPOSE OF THE STUDY
The purpose of this study is to assess the current management of cancer patients in Kenya. This study will explore any barriers patients with cancer may face in accessing detection methods, oncologists, treatment options as well as psychosocial support. This study will also assess if people with cancer suffer from any misconceptions or stigma, whether intra or interpersonal, for having cancer. The ultimate purpose of this study is to find possible ways to improve the management of cancer patients, create awareness and help to lessen the amount of deaths from cancer in Kenya.

STUDY PROCEDURES
Your participation will consist of you completing this very short questionnaire and/or participating in an interview.

NOTICE OF RIGHTS
Your participation in this study is voluntary. In an endeavor to uphold the ethical standards of all SIT ISP proposals, this study has been reviewed and approved by The County Government of Kisumu and the SIT Institutional Review Board. If at any time, you feel uncomfortable answering any of these questions, you may stop filling out the survey or ask to skip the question in the interview.

a. Privacy - all information you present in this interview will be confidential, recorded and safeguarded. The information will be stored on my laptop which will be on my possession at all times and locked by a password.

B. Anonymity - Your questionnaire data will be stored with an ID number. I may quote your responses in discussions of my research or in my research paper, and, in that instance, only pseudonyms will be used unless you have even me permission to do otherwise. Your identity will remain anonymous.

C. Confidentiality - all information given will remain confidential and fully protected. By signing below, you give me, Ashley Nmoh, full responsibility to uphold this contract and its contents. No one other than myself will have access to the information.

POTENTIAL BENEFITS AND RISKS
There are no monetary benefits for participating in this survey. However, your participation can help increase the knowledge of cancer management in Kenya. There are no foreseeable risks to participating in this study and no penalties if you choose not to participate.

RESEARCHER AND IRB CONTACT INFORMATION
If you have any questions, concerns or want to get more information about this study, please contact me at ashley.c.nmoh@vanderbilt.edu or at 0798552003 or if you are unable to contact me please contact the Institutional Review Board at: irb@sit.edu or 802-258-3132

Researcher Ashley Nmoh’s Signature: Date: April 10th, 2019
Participant Signature: Date:
APPENDIX B: QUESTIONNAIRES

Breast Cancer Awareness Questionnaire

Most of this survey instrument (Breast CAM) was developed by Cancer Research UK, King’s College London and University College London in 2009 and validated with the support of Breast Cancer Care and Breakthrough Breast Cancer. Additional Questions developed specifically for this study and NOT Taken from the Breast CAM are denoted with an asterisk.

1. What is your age?

<table>
<thead>
<tr>
<th></th>
<th>18-29</th>
<th>30-39</th>
<th>40-49</th>
<th>50+</th>
<th>Prefer Not to Say</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2. What is the highest level of education qualification you have obtained?
   - Primary Level
   - Secondary Level
   - Tertiary Level
   - Masters
   - Doctorate

3. Where do you live?
   - Kisumu County
   - Nairobi County
   - Other: ______________________

4. Do you have a friend or relative that has breast cancer?
   - Yes, Close Family Member
   - Yes, Distant Family Member
   - Yes, Close Friend
   - Yes, Distant Friend
   - No, None of the Above

5. What are some of the early warning signs of breast cancer you are aware of?

6. Do you think any of these are warning signs of breast cancer?

<table>
<thead>
<tr>
<th></th>
<th>YES</th>
<th>NO</th>
<th>DON’T KNOW</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you think a lump or thickening in your breast could be a sign of breast cancer?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you think a lump or thickening under your armpit could be a sign of breast cancer?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you think bleeding or discharge from your nipple could be a sign of breast cancer?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you think the pulling in of your nipple could be a sign of breast cancer?</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Do you think a change in the position of your nipple could be a sign of breast cancer?  

Do you think a rash on or around your nipple could be a sign of breast cancer?  

Do you think redness of your breast skin could be a sign of breast cancer?  

Do you think a change in the size of your breast or nipple could be a sign of breast cancer?  

Do you think a change in the shape of your breast or nipple could be a sign of breast cancer?  

Do you think pain in one of your breasts or armpit could be a sign of breast cancer?  

Do you think dimpling of the breast skin could be a sign of breast cancer?  

<table>
<thead>
<tr>
<th>7. Are you aware of how to properly conduct a self breast exam?*</th>
</tr>
</thead>
<tbody>
<tr>
<td>❑ Yes</td>
</tr>
<tr>
<td>❑ No</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>8a. How often do you check your breasts/ do a self breast exam?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rarely or Never</td>
</tr>
<tr>
<td>❑</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>8b. Are you confident you would notice a change in your breasts?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at All Confident</td>
</tr>
<tr>
<td>❑</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>8c. Have you ever been to see a doctor about a change you have noticed in one of your breasts?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>❑</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>9. In the next year who is most likely to develop breast cancer?</th>
</tr>
</thead>
<tbody>
<tr>
<td>❑ A 30 year old Woman</td>
</tr>
<tr>
<td>❑ A 50 Year Old Woman</td>
</tr>
<tr>
<td>❑ A 70 Year Old Woman</td>
</tr>
<tr>
<td>❑ A Woman of Any Age</td>
</tr>
</tbody>
</table>
10. Are you aware of a place near you where you can get an affordable mammogram? *
   ☐ Yes
   ☐ No

11. Have you ever gotten a mammogram?*
   ☐ Yes
   ☐ No
   → If YES, how supportive were your family and friends when you went to get one?*

<table>
<thead>
<tr>
<th>Not at All Supportive</th>
<th>Not Very Supportive</th>
<th>Fairly Supportive</th>
<th>Very Supportive</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

→ If NO, what was your reason for not getting one? Check ALL that apply:*
   ☐ It was too expensive
   ☐ The wait times and queues to get one were very long
   ☐ You did not know what a mammogram was
   ☐ You did not think you needed to get one
   ☐ You were afraid of getting a diagnosis and did not want to know
   ☐ The long distance to access a mammogram
   ☐ Your husband did not support you getting one
   ☐ Other:___________________________

12. What things do you think affect a woman’s chance of developing breast cancer?

13. How much do you agree that each of these can increase the chance of developing breast cancer?

<table>
<thead>
<tr>
<th></th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Not Sure</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Having a past history of Breast Cancer</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drinking more than 1 unit of alcohol a day</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being overweight</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Having a close relative with breast cancer</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Having children later on in life or not at all</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Starting your periods at an early age</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Having a late menopause</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Doing less than 30 mins of moderate physical activity 5 times a week</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being bewitching or cursed*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

14. How many women out of every 10 do you think survive breast cancer in Kenya?* __________

15. Do you think a breast cancer diagnosis in Kenya is a death sentence?*
   ☐ Yes
16. What month is breast cancer awareness month?* ____________

CANCER QUESTIONNAIRE

TITLE OF STUDY: Cancer Management in Kenya- Awareness and The Struggles Patients Face to Access Treatment, Care & Support

PURPOSE OF THE STUDY: The purpose of this study is to assess the current management of cancer patients in Kenya. This study will explore any barriers patients with cancer may face in accessing detection methods, oncologists, treatment options as well as psychosocial support. This study will also assess if people with cancer suffer from any misconceptions or stigma for having cancer. The ultimate purpose of this study is to find possible ways to improve the management of cancer patients, create awareness and help to lessen the amount of deaths from cancer in Kenya. Your responses will be anonymous and by completing the survey below, you consent to me using your responses in my research.

1. What is your gender?
   - Male
   - Female

2. What year were you diagnosed with cancer?
   - 2019
   - 2018
   - 2017
   - 2016
   - 2015
   - 2014
   - Other:________

3. What kind of cancer were you diagnosed with?
   - Breast Cancer
   - Cervical Cancer
   - Prostate Cancer
   - Lung Cancer
   - Esophageal Cancer
   - Brain Cancer
   - Skin Cancer
   - Other:_________________

4. At what stage was your cancer diagnosed?

<table>
<thead>
<tr>
<th>Stage 1</th>
<th>Stage 2</th>
<th>Stage 3</th>
<th>Stage 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>✔️</td>
<td>✔️</td>
<td>✔️</td>
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</table>

5. Where do you live?
   - Kisumu County
   - Nairobi County
   - Other:____________
6. Are there any free counselors or therapists at your hospital or clinic that you can talk to for counselling and psychological support?
   - Yes
   - No

7. Are you aware of any cancer support groups near you where you can go to get support?
   - Yes
   - No

8a. Do you have access to pain medication to help cope with your pain?
   - Yes
   - No
   - Sometimes

8b. If you answered NO or SOMETIMES to question 8a above, why have you not always been able to access pain medication to help with your pain? If you do have access to pain medication, write N/A

9. Where does the money you use to pay for your cancer treatment come from? Check ALL that apply
   - The National Hospital Insurance Fund (NHIF)
   - Universal Healthcare Coverage (available only in Kisumu County)
   - Your Personal Savings
   - Money You Earned by Selling Your Personal Belongings
   - Donations from your Family Members, Friends or Community
   - Other:_____________________________________________

10. Out of all of these funding sources where does MOST of the money you use to pay for your cancer treatment come from? (Only pick ONE answer)
    - The National Hospital Insurance Fund (NHIF)
    - Universal Healthcare Coverage (available only in Kisumu County)
    - Your Personal Savings
    - Money You Earned by Selling Your Personal Belongings
    - Donations from your Family Members, Friends or Community
    - Other:_____________________________________________

11. Around how much (in Kenyan shillings) did you have to fundraise and spend out of pocket for cancer treatment and medication in a year?

12a. When you first came to the hospital to present your symptoms, did you receive a misdiagnosis?
    - Yes
    - No

12b. If you answered YES to the question above, how long did it take you to get your cancer diagnosed? If you did not have a misdiagnosis, write N/A

13a. After being diagnosed with cancer, how long did you have to wait to actually receive treatment?

13b. If you waited for a while, why did you have to wait that long? If you did not wait long, write N/A
14. How many kilometres do you travel from your home to access cancer treatment?

15 a. Do you believe that you face any stigma or misconceptions from others for having cancer?
   - Yes
   - No

15b. If YES, what are some examples of stigma or misconceptions you face? If you do not think you face stigma write N/A

16. What is the biggest challenge you face or have faced while having cancer in Kenya?
   - The cost of Treatment and medication
   - The fear of dying from your cancer
   - The lack of psychosocial support and counselling for patients
   - The lack of accessible treatment and cancer care centers and specialists in some parts of the country
   - Stigma and Misconceptions other Kenyans and your family and friends have about your Cancer
   - The lack of accessible and affordable breast cancer detection methods
   - Other:_______________________________________________

17. How much do you agree with the following statements?

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>During my diagnosis and treatment process, I was well informed by my doctor about my diagnosis, treatment options and the side effects that might come from my cancer and my treatment.</td>
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<tr>
<td>My family and friends have been supportive of me since my diagnosis of cancer and while I have undergone treatment.</td>
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<tr>
<td>Having cancer in Kenya is a death sentence.</td>
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<tr>
<td>Doctors and nurses have treated me with empathy and respect throughout my cancer diagnosis and treatment.</td>
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<tr>
<td>Cancer should be declared a national disaster in Kenya</td>
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</tbody>
</table>

18. What else would you like to share with me about the challenges of having cancer in Kenya?
APPENDIX C: INTERVIEW GUIDES

Breast Cancer Professional Semi-Structured Interview Questions

1. What does your NGO do to support cancer patients?
2. What are some challenges that cancer patients and caregivers in Kenya face? (ex: costs, access to treatment, misdiagnosis, long wait times, housing, social support, stigma etc.)
3. What cancer treatment and detection options are available to patients in Kenya & where?
4. What treatment funding options are available in Kenya? What services does NHIF and UHC fund for cancer patients? What services do they not fund?
5. What are some challenges that doctors and nurses face? Do you think Kenyan healthcare professionals are trained well enough to deal with cancer? Why do you believe there are so few oncologists in Kenya?
6. What has been done in Kenya to increase cancer awareness, detection and support for cancer patients? What additional things do you think need to be done?
7. How do you think corruption has played a part in cancer management in Kenya?
8. Do you think cancer should be declared a national disaster in Kenya? Why or why not?
9. Many Kenyan cancer patients tend to go to India for treatment. Why do you think that is?

Cancer Patient Semi-Structured Interview Questions

1. How did you first detect that you had cancer? Did you suffer from a misdiagnosis? How long did you have to wait to actually receive treatment and why?
2. What is the hardest part about having cancer in Kenya? What are some other challenges you face? What do you think the government can do to alleviate these challenges?
3. Do you ever get treated differently, wrongly or face any stigma for having breast cancer? If yes, what are some experiences you have had?
4. Do you feel as if you have been well informed throughout your treatment process about your diagnosis, possible side effects, etc?
5. Have you been treated with empathy and respect by doctors and nurses throughout your treatment process? What are some experiences that you have had?
6. Do you think cancer should be declared a national disaster in Kenya? Why or why not?
7. Have you been able to access counselling, support groups, and adequate support from family and friends? Why or why not? How has it helped?
8. Do you believe having cancer in Kenya is a death sentence? Why or why not?
APPENDIX C: APPROVAL FORMS

COUNTY GOVERNMENT OF KISUMU

DEPARTMENT OF HEALTH

REG N133 VOL. IX (410)               Date: 29th February 2019

All Medical Superintendents
All SCMOHs
Kisumu County

RE: PERMISSION TO CONDUCT FIELD STUDY IN KISUMU COUNTY
The following students are hereby authorized to conduct their internships and/or independent study projects within the County Government of Kisumu, its health facilities and surrounding communities. Their topics will contribute towards the implementation and review plans for the County as the SIT partners with us under its program theme: Urbanization, Health and Human Rights.

<table>
<thead>
<tr>
<th>Name</th>
<th>Passport Number</th>
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</thead>
<tbody>
<tr>
<td>Amaya Jade</td>
<td>548489488</td>
</tr>
<tr>
<td>Ashley Nmoh</td>
<td>564909258</td>
</tr>
<tr>
<td>Emily Pender</td>
<td>521240215</td>
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<tr>
<td>Emma Martin</td>
<td>556022107</td>
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<tr>
<td>Eva Nelson</td>
<td>543038647</td>
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<tr>
<td>Hunter Corbett</td>
<td>575615126</td>
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<tr>
<td>Jocelyn Dorney</td>
<td>579399557</td>
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<tr>
<td>Madison Shaffer</td>
<td>576850140</td>
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<tr>
<td>Paprika Berry</td>
<td>594356532</td>
</tr>
<tr>
<td>Rowan Pochler</td>
<td>517389950</td>
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</tbody>
</table>

Any assistance you accord them in the process of conducting their field work will go a long way in promoting intercultural learning.

Dr. Onyango D.
County Director of Health
Kisumu County.