

**DELAYED HEALTH-SEEKING AMONG WOMEN WITH ADVANCED BREAST
CANCER AT THE CANCER TREATMENT CENTRE AT KENYATTA NATIONAL
HOSPITAL**

BY

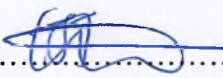
**JOY ANYIRA
H56/11401/2018**

**A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE AWARD OF THE DEGREE OF MASTER OF SCIENCE IN NURSING
(ONCOLOGY) IN THE SCHOOL OF NURSING SCIENCES OF THE UNIVERSITY OF
NAIROBI**

DECEMBER 2020

DECLARATION

I, Joy Anyira declare that this thesis is my original work and has not been submitted for the award of degree or diploma in any university.

Signature 

Date 01/12/2020

Reg No: H56/11401/2018

CERTIFICATE OF APPROVAL

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DEDICATION

I dedicate this work to my loving and supportive husband, Amani Katana Menza and our daughter Wema, you made the process worthwhile.

To my mum, you have always been an inspiration.

To all the women braving breast cancer, you are strong.

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LIST OF ABBREVIATIONS

ABC	:	Advanced Breast Cancer.
BC	:	Breast cancer
BSE	:	Breast Self-Examination
CAM	:	Complementary Alternative Medicine
CTC	:	Cancer treatment centre
ERC	:	Ethics and Review Committee
GP	:	General practitioner
KNH	:	Kenyatta National Hospital
NHIF	:	National Hospital Insurance Fund
UHC	:	Universal Health Coverage
UK	:	United Kingdom
UON	:	University of Nairobi
USA	:	United States of America
WHO	:	World Health Organization

OPERATIONAL DEFINITIONS

Appraisal interval is time from noticing a bodily change to perceiving a reason to discuss symptoms with a health-care professional.

Hospital delay is the time from the referral to the beginning of definitive treatment

Staging is a way of describing cancer, such as the depth of the tumor and where it has spread.

Health-seeking is any action undertaken by individuals who perceive themselves to have a health problem or to be ill for the purpose of finding an appropriate remedy

Delay time is the period from the recognition of the first symptom by the patient to initial medical consultation, usually spanning a period of more than three months

Knowledge is defined as familiarity, awareness or understanding of bodily sensations acquired through experience or education.

Advanced breast cancer is metastatic breast cancer including Stages 3 and 4. Stage 3 is locally advanced breast cancer, which means the cancer has spread to lymph nodes and/or other tissue in the breast, but not to further sites in the body. Stage 4 is metastatic breast cancer. At this stage, cancer has spread to other sites of the body, such as the liver, lungs, bones, brain, and/or others.

ABSTRACT

Background:

Eighty percent of women with breast cancer in Sub-Saharan Africa are diagnosed at an advanced stage (stage III and IV) of the disease. The stage at diagnosis is critical in determining survival rates with better prognosis among those diagnosed at earlier stages. In Kenya, the prevalence of breast cancer is estimated at 7% with most being diagnosed in advanced stages. Despite the various campaigns carried out to improve knowledge about breast cancer, diagnosis of the disease at late stages is still problematic.

Objective:

This research aimed to determine the reasons for delayed health-seeking among women with advanced breast cancer at the Cancer Treatment centre at Kenyatta National Hospital (KNH).

Methodology:

This was a cross-sectional descriptive study that employed a generic qualitative approach carried out among women with advanced breast cancer. The sample size was determined by saturation of data which was achieved. Purposive sampling was used to select the study participants. An interview guide was used to collect data. Pretesting of the study tools was done in the female oncology wards of KNH. Findings obtained from the study were analyzed into themes and presented in narration format. Poignant quotes were selected and presented in italics to support the themes. Ethical approval was sought from Kenyatta National Hospital-University of Nairobi Ethics and Research Committee and permission to conduct the study from the hospital management. The study findings will be shared with hospital management, the university and published in peer-reviewed journals.

Results:

Fourteen women were interviewed with an age range of 28 – 65 years. Out of the fourteen, twelve were diagnosed at stage III while two were diagnosed at stage IV. Delay time ranged from 3 - 12 months. Breast lump was the first symptom identified by most women. Since these symptoms did not affect their daily functions they were labeled as not serious and not requiring medical attention. Misdiagnosis, poor communication about the required investigations led delay in seeking medical care. The trigger to seek medical help was the worsening of their symptoms such that their daily functions were affected. At this stage, the women were willing to do whatever was required to access healthcare.

Conclusion:

Women considered their breast symptoms as not requiring medical attention until they got worse despite having been exposed to breast cancer health messages. The distress brought about by these worsening symptoms provoked them to urgently seek care and this is what set the women on the health-seeking journey. As the women sought medical help, their experiences and engagement with health care providers influenced the time taken to arrive at the Cancer Treatment center for treatment.

Recommendation:

Opportunities at any point these women present in the hospital need to be explored to educate women with an emphasis on screening and early presentation of symptoms.

CHAPTER 1: INTRODUCTION

This chapter includes the study background, problem statement, study justification and the research question.

1.1 Background of the Study

Breast cancer(BC) is responsible for the death of at least 627,000 women in the world annually (WHO, 2018). One of the major contributors to the high mortality rates is the late diagnosis which is associated with low levels of knowledge and awareness on the risk factors associated with breast cancer (Akhtari-Zavare et al, 2015). At least 58% of all deaths related to breast cancer in the world occur in Africa. African countries have an established burden of late diagnosis with women presenting with advanced breast disease (Adwoa and Busisiwe 2019). The incidence of breast cancer is estimated at 40 per 100,000 (WHO, 2019). It is, however, critical to note that breast cancer diagnosis in Africa happens in the late stages hence these values do not accurately capture the incidence of breast cancer (Bambidele, et al, 2017). The prevalence of breast cancer in Kenya is estimated at 7% with most of the women presenting in advanced stages (Orindi, 2016). According to a research done by Macheneri in Kisii County, the uptake of screening services was low. Most of the women with breast cancer seen had discovered their symptoms by chance.

The delay between individuals' first discovery of breast abnormality and initial consultation with a physician is a common determinant of late detection of breast cancer. Approximately twenty to thirty percent of women with breast cancer symptoms take three months before seeking care. Studies on breast and cervical cancer awareness in Africa suggest low levels of knowledge among women (Pamaa et al 2017). This affects their attitude towards the uptake of screening services resulting in late diagnosis of breast cancer in many women. Other barriers to early presentation include; fear, denial, distrust in health services and fatalism (Pamaa et al 2017). According to a

study done in Ghana, women take about 8 to 14 months between symptom discovery and health-seeking (Agbeeko, 2017). In a Kenyan setup where BC incidence is rising and more women presenting with advanced-stage disease, qualitative studies on this phenomenon are scanty. This study, therefore, seeks to find out why women seek help at an advanced stage of the disease.

1.2 Problem Statement

Eighty percent of women with cancer of the breast in Sub-Saharan Africa are diagnosed at an advanced stage (stage III and IV) disease (Eleanor and Robyn, 2019). Late diagnosis of breast cancer has decreased chances of survival as compared to diagnosis at an early stage with resultant low quality of life. Postponing to seek care for three or more months significantly contributes to the late diagnosis of breast cancer. (Richards et al, 2016). Globally, the occurrence, mortality and prognosis for breast cancer vary because of the disparities in health care systems, risk factors and effective screening programs in place. High fatality rates are noted in lower and middle-income countries due to diagnosis in the advanced stages of the disease.

Regionally, breast cancer in Africa is characterized by the delayed presentation of breast cancer which is attributed to low levels of awareness high cost of screening and inaccessibility of screening facilities (Ibid, 2014). Other determinants of delayed health-seeking include delays in obtaining diagnostic results, dreading the disease and its management, economic implications, inaccessible health care, poor detection methods, preference for alternative medicine, postponed referrals or failure to refer, wrong diagnosis and false reassurances.

In Kenya, breast cancer has the highest occurrence with a total of 5,985 new cases which is 12.5% of all new cancer cases. It is also the third top cause of mortality among patients with cancer in the country accounting for 9.2% of all deaths from cancer (GLOBOCAN, 2018). From other studies,

most of the breast cancer patients present in an advanced stage, resulting in higher mortality and low overall 5- year survival.

At Kenyatta National Hospital (KNH), 50.7% of the women presented at the late stages of the illness (stage III and IV) while 7.4% and 33.7% were diagnosed in tumor stage I, and stage II respectively (Abinya et al, 2018). Despite the many cancer awareness campaigns being carried out, late-stage presentation is still a problem. This study, therefore, sought to determine the reasons why women seek help in advanced stages of breast cancer at the Cancer Treatment Centre (CTC) at KNH.

1.3 Study Justification

Determining the reasons for late presentation of breast cancer is significant in planning targeted interventions that will help to decrease the mortality rates of breast cancer in Kenya. The choice of a qualitative research method will be help obtain contextualized information from the respondents' perspectives, feelings and thoughts.

This study conforms with the implementation of Pillar 1 of the National Cancer Control Strategy 2017-2022, with particular attention to the timely diagnosis of cancer. Early detection is an important intervention in cancer control.

Addressing the reasons for delayed health-seeking will strengthen Kenya's primary health care system and will contribute to the realization of Universal Health Coverage

Results from this research may aid in coming up with measures to improve the health-seeking behavior among Kenyan women. This will help to structure appropriate community-based programs that can address barriers and enable early presentation, diagnosis and treatment of breast cancer.

1.4 Objectives

1.41 Broad objective

To determine the reasons for delayed health-seeking among women with advanced breast cancer at the Cancer Treatment centre at Kenyatta National Hospital.

1.42 Specific Objectives

1. To determine the socio-demographic characteristics that contribute to delay in health-seeking among women with advanced breast cancer at the Cancer Treatment centre at Kenyatta National Hospital.
2. To determine the psychosocial factors influencing health-seeking behavior among women with advanced breast cancer at the Cancer Treatment centre at Kenyatta National Hospital.
3. To establish the influence of social-cultural factors on health-seeking behavior among women with advanced breast cancer at the Cancer Treatment centre at Kenyatta National Hospital.
4. To determine healthcare system factors that contribute to delay in health-seeking among women with advanced breast cancer at the Cancer Treatment centre at Kenyatta National Hospital.

1.5 Research questions

1. What are the socio-demographic characteristics that contribute to delay in health-seeking among women with advanced breast cancer at the Cancer Treatment centre at Kenyatta National Hospital?
2. What are the psychosocial factors influencing health-seeking behavior among women with advanced breast cancer at the Cancer Treatment centre at Kenyatta National Hospital?

3. What is the influence of socio-cultural factors on health-seeking behavior among women with advanced breast cancer at the Cancer Treatment centre at Kenyatta National Hospital?
4. What are the healthcare system factors that contribute to delay in health-seeking among women with advanced breast cancer at the Cancer Treatment centre at Kenyatta National Hospital?

1.6 Research hypothesis

There is no relationship between socio-cultural factors and delay in health-seeking among women with advanced breast cancer at the Cancer Treatment centre at Kenyatta National Hospital

1.7 Expected benefits

Breast cancer is treatable. With the increasing incidence of breast cancer and poor patient outcomes due to advanced disease at presentation, there is need to understand the reasons for delayed health-seeking among patients within this setting. The findings of this study will help structure appropriate community-based programs that can address patient barriers to improve early presentation for diagnosis and treatment of breast cancer. The government and other stakeholders can also use the results in planning breast cancer awareness programs that can address the barriers to early health-seeking and improve timely diagnosis and referral.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

This chapter comprises a review of the various journals, books, reports, guidelines and scholarly articles read in about this study. Literature search was done using Google Scholar, PubMed and Hinari. The keywords used were “health-seeking behavior “delayed health-seeking”,” advanced breast cancer”, “and late diagnosis of breast cancer” and “health service accessibility”. The relevant articles containing the needed information were downloaded and saved. Several studies have been done on delayed health-seeking in breast cancer. This review of literature contains some of the reasons for delayed health-seeking among breast cancer patients in conjunction with a theoretical framework to explain the phenomenon.

2.2 Reasons for delayed health-seeking among women with advanced breast cancer

The factors discussed here were summarized as symptom appraisal, socio-demographic factors, psychological factors, health system factors, and sociocultural and spiritual factors.

2.2.1 Symptom appraisal

Symptom appraisal is critical in the health-seeking process. Most of the women self- discovered their breast symptoms. In a study done in Ireland, women learned of their breast problems in the course of their daily routines such as taking a bath, dressing up or breastfeeding. Breast self-examination (BSE) is an important practice for making women ‘breast aware’ which in turn enhances early detection of breast cancer. However, some women do not know how to do it (O’Mahoney et al, 2015). Among Malaysian women, symptom appraisal is the initial step in the course of help-seeking. At this point, they determine whether the identified symptoms are normal, severe, or need medical attention (Taib et al, 2018). Some of the women appraised their symptoms

as not serious hence did not need medical attention which consequently led to delays in seeking help (Memon et al, 2013). Some symptoms identified were attributed to hormonal changes and breastfeeding. (Taib et al, 2018).

Different cultural backgrounds influence women's experiences of breast symptoms. Symptoms can be evaluated as not serious if they do not meet these cultural expectations. In Chicago, women from the minor ethnic groups thought that breast lumps became malignant only if they were touched or pressed hence did not go for medical check-up. They would eventually seek help if the lump increased in size (Rauscher et al, 2014). Contrary to this, women studied in Ireland were cognizant that a swelling in the breast was a serious symptom that required medical review. More than 50% of these women from a study in Ireland were not certain about other symptoms of breast cancer apart from breast lumps. This poor knowledge about other symptoms led to their delay in help-seeking. (O'Mahony et al, 2015)

Despite the delay in help-seeking, women eventually sought care when they were triggered by the perceived seriousness of the symptoms (Taib et al 2018). Some of the triggers included the onset of pain (Khakbazan et al, 2014), the persistence of the symptoms to interfere with one's activities of daily living or unusual discharge (Memon et al, 2013)

In the African setup, low levels of awareness about breast cancer and self-examination of breast contributed to delay in care-seeking (Adwoa, 2017). Several misconceptions about breast cancer symptoms include plugged milk ducts, pregnancy symptoms, trauma and aging (Kohler et al, 2017). These misconceptions led to delayed diagnosis.

The finding above show that symptom appraisal is the most critical step in the help-seeking process for the diagnosis of cancer. It accounts for sixty to eighty percent of the process of seeking help (Andersen et al, 2013).

2.2.2 Socio-demographic factors

Socio-demographic factors had varied effects on women's health-seeking behaviour. For example, living in rural areas delayed help-seeking among women due to the inaccessibility of health facilities, reluctance to seek a doctor's consultation and preference for social customs (Malik et al, 2014). Women who were advanced in age had a higher percentage of delayed help-seeking (Innos et al, 2013). Contrary to these findings was a research carried out in the United States of America (USA) where age did not influence their tendency to seek help (Ruddy et al, 2014).

From a qualitative study, women who had income or had employment benefits like health insurance and sick leave allowance tend to seek for care in time. In the same study women with a low income had to find other sources of income to fund the increase in expenditure on medical services and this meant that they would not create time to schedule check-ups. If the women were self-employed, they were concerned about the loss of income as they sought medical help (Angus et al, 2017).

On marital status, women who were not married were reported to have delays in health-seeking. This is because they expressed a lack of financial and moral support (Memon et al, 2013). Contrary to this is a study among Iranian women which highlighted being married as a determinant of delayed health-seeking because they were held up by traditional duties of taking care of children, house chores and other family duties thus lacked time to attend to their health needs (Harirchi et al, 2015). In a different study, there was no relationship between delayed health-seeking and marital status (Sharma et al, 2013).

In the African setup, socio-demographic factors such as place of residence, age, income, education and marital status did not influence patient delay in health-seeking (Ezeome, 2016). A study done in the same country found out that being single and younger age influenced health-seeking (Ibrahim and Oludara 2014). In Egypt low levels of education, advanced age and being married led to a delay in health-seeking (Abdelaziz et al, 2018). From the studies above there is no unanimity on how socio-demographic factors affect health-seeking behaviour. This implies that these aspects affect health-seeking within a context of other factors which can be best determined using a qualitative study method.

2.2.3 Psychological factors

Several studies also reported the different psychological factors and how they affected women's tendencies to seek care. Fear was expressed in varied ways by the women who participated in the studies. For example, some of the women in Iran opted for alternative medicine because they feared confirmation of breast cancer diagnosis by conventional medicine. This consequently contributed to delays in looking for help from conventional medicine (Rastad et al, 2014). Some women were uncertain about the ability of conventional medicine to cure the deadly outcomes of breast cancer (Taib et al, 2014). Fatalism caused early help-seeking among breast cancer women yet in some it caused delay because of the perceived futility of treatment using conventional medicine (Taib et al, 2014).

Denial is another psychological factor that led to delays in health-seeking. Regarding breast cancer symptoms, denial is not negating the existence but a reaction to diminishing mental distress related to cancer diagnosis (Granek and Fergus, 2014). The researchers proposed that cultural and socio-political factors have a part in this course thus making denial insufficient to explain why women seemingly ignore their breast symptoms (Granek and Fergus, 2014). Despite the variations, these

results propose that there is a multifarious psychological reaction to the appraisal of breast cancer symptoms.

In the African setup, the most reported psychological factor that led to the delayed presentation was fear. Women reported fear of the social and financial implications of cancer diagnosis, mastectomy, death, disfigurement and of seeking conventional medicine care (Oludara, 2014; Ismail et al, 2015 and Kohler et al, 2017). On denial, some women simply hoped that the symptoms would wane on their own which led to delay in health-seeking (Ismail et al, 2015), and (Kohler et al, 2017).

2.2.4 Health System factors

Several health system-related factors determined the care-seeking behaviour among women with cancer of the breast. Most of them depend on the experiences women had as they sought care as well as the institutional factors.

In Mexico, Malaysia and the USA, women cited undesirable experiences as a cause of delayed health-seeking. These experiences include: being despised, ridicule and fear of being judged as petty (Unger-Saldaña & Infante Castañeda, 2017; Taib et al, 2014; Facione & Facione, 2016).

In another study, women did not have confidence in the medical team because of ineffective communication skills which led to confusion as they communicated the diagnosis and management of their medical conditions (Taib et al, 2014). In Mexico, women reported that they had to visit many health facilities to be attended to by a physician or have investigations done. For some, the referral trajectory led to delays in care-seeking (Unger-Saldaña and Infante-Casteñeda, 2017).

In Iran, a study found that long admission periods in public hospitals before being referred led to delays in health-seeking among women with breast cancer (Khakbazan et al, 2014). In comparison

to this were studies done in the United Kingdom (UK) and Ireland where the referral process is shorter; they are first reviewed by a general practitioner (GP) who in turn refers them directly to specialized care. Despite this, some of the women reported delay because of misdiagnosis by the medical team. ((Burgess et al, 2016 and O'Mahony et al, 2015).

The utilization of complementary and alternative medicine significantly led to delays in health-seeking. Some women preferred complementary medicine because they were oblivious to other forms of treatment. Others preferred complementary medicine because of the belief that it gives a better quality of life. To some, it is a means to avoid surgical interventions (Taib et al, 2014). It was also noted that some women would opt for alternative medicine out of the existing trust they have for the people who offered the services. Seeking this kind of care also met their emotional and psychological needs.

Financial constraints majorly affected how women with cancer of the breast sought care in health facilities in the developing countries (Iskandarsyah et al, 2014 and Ruddy et al, 2014). However, a study in the USA found out that it is the co-pay insurance cost and hidden costs that lead to delays in seeking care. These costs comprise lost incomes and child care expenses which is a common challenge for women who are not financially stable (Ruddy et al, 2014). Among Indonesian women, the hidden costs entailed transport and accommodation cost for them and their caregivers. (Iskandarsyah et al, 2014).

The use of public means to the hospital is reported to contribute to delays in health-seeking. This is compounded by longer distances to the health facilities among women in Sri Lanka (Kumari & Goonewardena, 2016) and Thailand (Poum et al, 2014). In Kuwait, a study reported no significant influence of the means of transport and the time taken to get to hospital on delayed health-seeking (Sharma et al, 2013). Since these countries are not in the same infrastructural and economic status,

it is not possible to conclude on the means of transport and distance from the hospital as determinants of delayed health-seeking.

In the African setup, two studies showed that the women delayed in seeking medical care because of false assurance from the medical team who attended to them (Ezeome 2016 and Adwoa 2017). In Malawi, poor communication skills led to confusion and misunderstandings in the diagnosis of breast cancer since some thought biopsy was a form of treatment (Kohler et al, 2017). Poverty was also reported to be a determinant of delays in health-seeking among women in developing countries (Sharma et al, 2014). In Ethiopia and Egypt, studies showed longer referral trajectory leading to delays in health-seeking. Most of the women got to the cancer treatment centres at their third or fourth point of care-seeking (Dye et al, 2019) and (Mousa et al, 2016)

Studies in the African setup site traditional and complementary medicine as a reason for delayed presentation among women with breast cancer. It was alleged that this was the most effective way of treating their disease. Some of the women did not think the symptoms they had were related to breast cancer. Those who knew did not believe it can be treated in the hospital effectively (Kohler et al, 2017).

2.2.5 Cultural and spiritual factors.

Health-seeking behaviour among women were influenced by their social and cultural links. For example, in some settings, social disclosure hastened women's health-seeking (Taib et al, 2014). On the other hand, nondisclosure also led to delays in health-seeking. These women did not disclose because they didn't want to be a nuisance. (Li et al, 2018). Disclosure influenced delay in seeking help because the misconceptions the women had were strengthened. (Poum et al, 2014) Cultural perceptions about breast cancer in a certain setup therefore influence health-seeking behaviour.

In Malaysia, the women's lived experiences and views about the fatal aftermaths of breast cancer resulted in a social custom of hopelessness. In another setup, conventional medicine used in the treatment of breast cancer was considered futile and this formed part of the cultural customs their women believed (Taib et al, 2014). Parallel opinions occurred among women with breast cancer in the UK where women who had friends or relatives with cancer had delayed seeking help because by sharing their experiences, they made them lose hope. (Burgess et al, 2016).

Cultural responsibilities played by women in society also influenced their health-seeking behaviour. A lot of women postponed health-seeking because of duties at work and in their homes (Burgess et al, 2016 and Khakbazan et al, 2014).

Religiosity and spirituality have varied influences on health-seeking behavior. According to a study in the USA, despite their high levels of religious beliefs, their health-seeking behaviour was not influenced by them (Gullatte et al 2018). Nevertheless, they stated how helpful these beliefs and fellowship were to the overall outcome of their medical conditions (Taib et al, 2014). Other women believe that breast cancer was a divine test of their convictions and that they were destined to go through such seasons (Iskandarsyah et al, 2014).

2.3 Conceptual framework

The conceptual framework below shows the relationship between the different variables. The independent variables are socio-demographic factors, symptom appraisal & psychosocial factors, cultural factors and health system factors. The dependent variable is the delay in health-seeking.

These variables indicate that health-seeking behavior is affected by several factors. Sociodemographic factors such as age can influence a person's health-seeking behavior. There is a high possibility of younger persons seeking health care as compared to older persons. Education level will also influence in that, the more the person is educated, the higher the chances of seeking care owing to the level of understanding of the need to seek care.

Psychological factors such as fear, fatalism and denial can lead to delay in health-seeking among women with breast cancer. Lack of awareness and inaccurate symptom appraisal can also delay health-seeking among these women

Cultural factors also influence health-seeking behaviour among women. These include beliefs about traditional medicine/medical treatment, counter culture and self-medication. Belief in self-medication and traditional medicine may cause women to delay in seeking conventional medicine.

Health care system factors such as misdiagnosis, symptomatic management and delay in referral system are likely to contribute to the diagnosis of breast cancer at late stages. Women may also delay in seeking medical care if the facilities are not easily accessible.

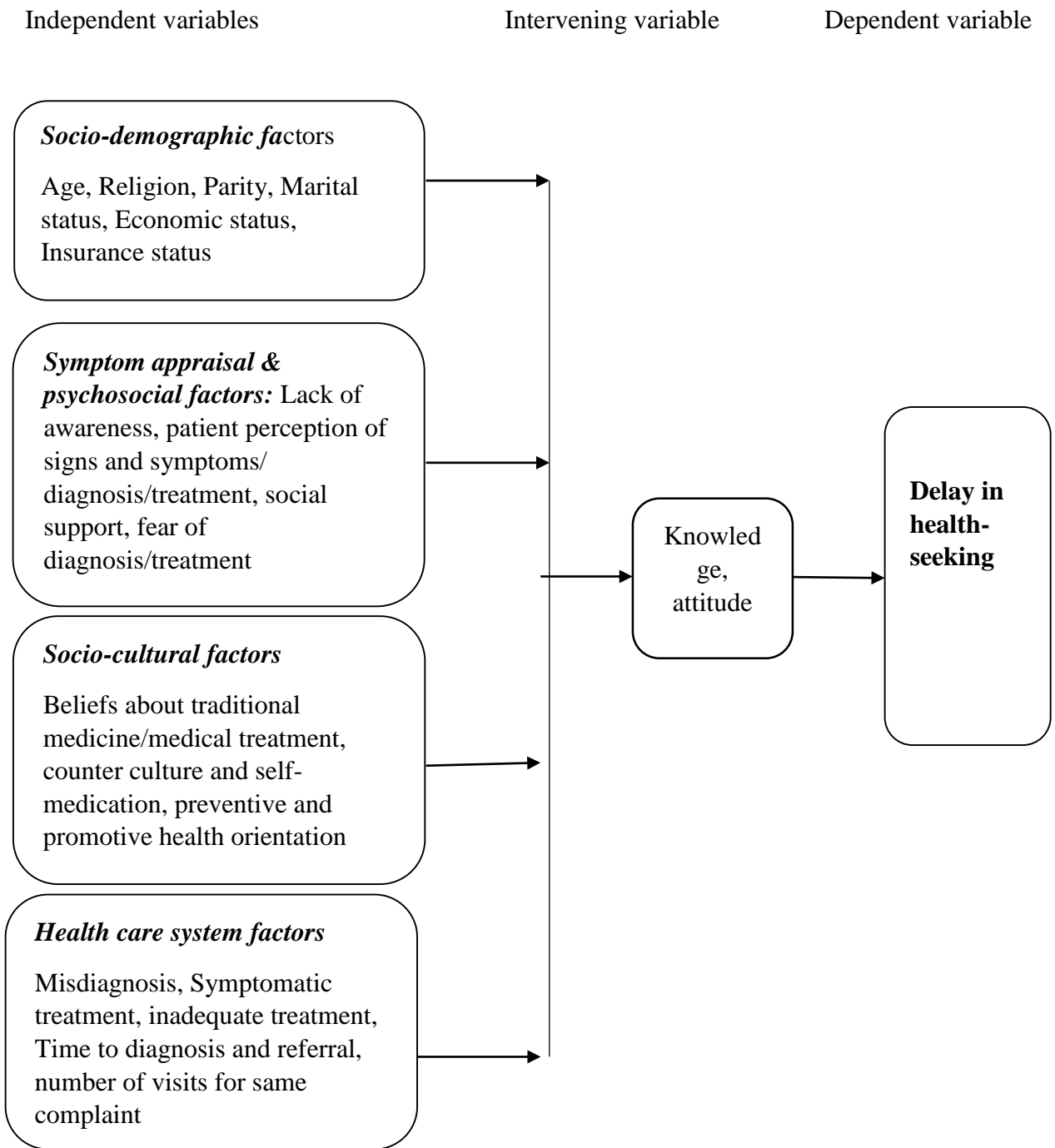


Figure 2. 1 Conceptual framework of help-seeking among women with breast cancer. (Source: Modified from Dwivedi, 2015)

2.3 Theoretical framework

The Andersen behavioral model for health care utilization will be used in this study to determine the health-seeking behavior of women with cancer of the breast. The model proposes that the choice to seek health care is a product of one's tendency to use the health service, the elements that aid or impede the use and the necessity for the care.

This model was developed in the 1960s but has been modified over time given emergent issues in health service delivery and policies. Research in health-seeking behaviour has also contributed to modifications to this model. The basic components of the model did not change despite the modifications done.

According to the model, the factors determining utilization of health services are contextual characteristics; individual characteristics; health behavior and health outcomes. The contextual and individual elements comprise predisposing factors, enabling factors and the need for care. The predisposing factors at an individual level comprise demographic factors (i.e. age and gender), social factors (i.e. ethnicity, cultural customs, level of education, occupation, and social relationships), health beliefs (attitudes, values, beliefs and knowledge about health) and genetic predisposition to illnesses. Individual enabling resources include financial resources and factors that enhance health service use such as knowledge of the services provided, cost of care, nature, source and quality of care, ease of access (means of traveling, time taken to and from the health facility) and care given as perceived by the patient. The individual needs factors include perceived and evaluated need. Perceived need is the subjective assessment of the women's health position. The evaluated need is health as assessed by the physician.

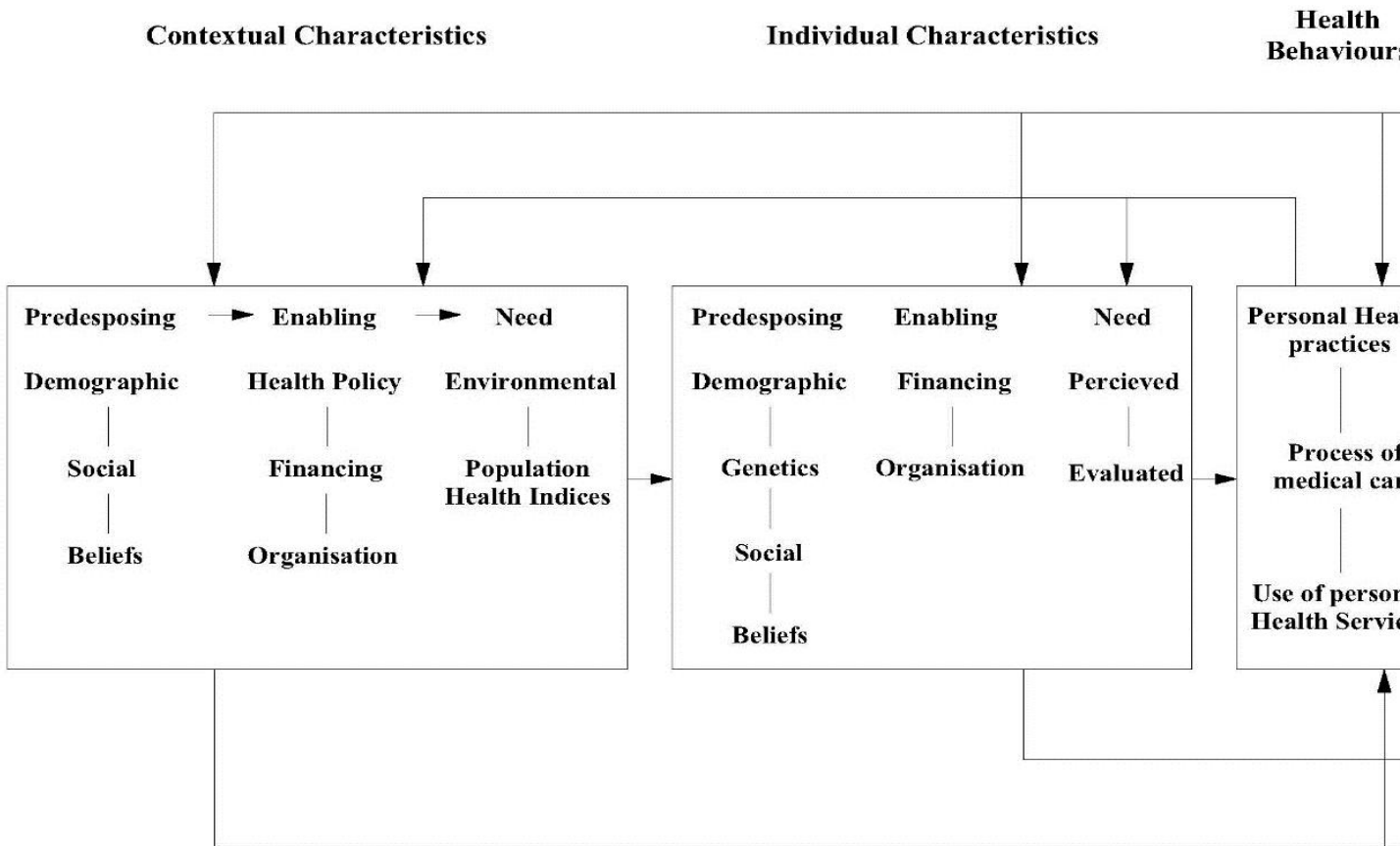


Figure 2. 2 The Andersen Behavioral model for health care utilization (Ronald Andersen et al, 2013)

Adopted from the US health care system policy and management (2013)

An essential characteristic of the model is feedback. This model has feedback arrows that reflect the several interdependent effects the constituents have on the utilization of health services.

This model will be utilized to explore the health-seeking behaviour among women with cancer of the breast in the Kenyan context using a qualitative study method.

CHAPTER THREE: METHODOLOGY

3.0 Introduction

This chapter contains the research methodology which includes the research design, study area, study population, sample size, sampling technique, research tool, reliability and validity, pre-testing, data collection procedure, data management plan, data entry and cleaning, data analysis, data storage, ethical considerations, limitations and delimitations and data dissemination plan.

3.1 Study Design

This was a cross-sectional study that employed a generic qualitative approach to explore the reasons for delay in the health-seeking behavior among women with advanced breast cancer at the cancer treatment Centre at Kenyatta National Hospital (KNH). The generic qualitative approach was used since it enabled the researcher to get more details about how the factors interacted and contributed to delay from the participants lived experiences.

3.2 Study area

The study was done at the cancer treatment Centre (CTC). This centre was set up to address the increasing number of patients seeking cancer treatment at Kenyatta National Hospital (KNH). The CTC provides comprehensive cancer management representative of the country generally. The cancer treatment centre is situated on the first floor of the old hospital building. It offers outpatient services to both new and revisiting patients. This department has a client flow of approximately 100 patients per day. Approximately 30 patients with breast cancer are seen in this unit per month. A total of 25 nurses work in this unit. At least 3 consultants and 6 medical officers attend to patients with cancer who come to seek care in this unit daily.

3.3 Study population

The population studied comprised of patients diagnosed with advanced breast cancer and were undergoing treatment at the cancer treatment centre at KNH.

3.3.1 Inclusion criteria

The study participants met the following characteristics:

- i. Patients who gave consent to participate in the study.
- ii. Patients diagnosed with stage III and IV breast cancer in KNH cancer treatment centre.
- iii. Patients who were psychologically stable to partake in the study.

3.3.2 Exclusion criteria

Participants were not included in the study if they had any of the following characteristics:

1. Patients who declined to consent to participate as well as the mentally confused at the time of collecting data.
2. Very sick patients.

3.4 Sample size

The sample size was determined by the principle of data saturation, where data was collected until redundancy was achieved.

3.5 Sampling technique

The researcher used purposive sampling to select women who were diagnosed with either stage III or IV breast cancer. These women were enlisted into the study to share their lived experiences on the phenomenon of interest. The researcher chose the participants based on her judgment. This judgment was based on whether the patient was psychologically stable for the interview, with

advanced stage of the disease and as recommended by the nurse on duty or the patients who had been interviewed before.

3.6 Trustworthiness/Rigor

Credibility, dependability, confirmability and authenticity were used to ensure the trustworthiness of the study.

Credibility is the precise and forthright representation of a participant's lived experience. This was achieved in this study through a lengthy engagement with the participants. This enabled the researcher to probe more about the phenomenon.

Transferability was enhanced by providing a comprehensive description and robust data with a wide possible variety of information through the detailed and accurate descriptions of the patients.

Confirmability was achieved by maintaining a reflexive journal during the research process to keep notes and document reflections daily that would be helpful and relevant during the study.

Dependability was met by having 2 knowledgeable qualitative nursing researchers read the transcribed document to confirm the themes and subthemes identified. Member checks were also done involving the participants.

Qualitative research is generally known to score highly in terms of internal validity, because it documents the “natural” behaviour of participants in their situations and examines, in detail, what people mean when they describe their experiences, feelings and attitudes. The internal validity of the study was also achieved through a pre-test. A pre-test allowed studying the data collected and recorded during the interviews.

3.8 Pre-testing

Pre-testing was done in the female wards where women diagnosed with breast cancer are admitted at Kenyatta National Hospital until the data achieved was consistent. Only women who gave written consent were recruited for the pretesting. Adjustments to the tool were done accordingly after the pretesting.

3.9 Data collection procedure

The enrollment of study participants was carried out at the start of every clinic day. This was done at the registration desk where all patients report before being reviewed. The researcher went through the patients' files and with the help of the unit nurse in-charge purposively recruited a specific number of study participants each day depending on the patient turnout. Participants were informed about the need to participate in the study before being involved in the study.

Sampled participants were interviewed after being reviewed by the clinicians. This was done after assessing their eligibility and obtaining informed consent to take part in the study. The data was collected by conducting in-depth interviews using an interview guide, and the conversation was recorded. The interviews took approximately 30-45 minutes each. The questions in the interview guide were used flexibly to suite the context and promote dialogue. The researcher had a backup of all the recorded audios.

Measures to handle clients who became emotionally overwhelmed were put in place. This included allowing them to express their emotions, sitting silently with them and some were referred the unit counselor.

3.10 Data management plan

This section described the data entry and cleaning, data analysis and data storage.

3.10.1 Data entry and cleaning

The recorded audio responses were transcribed verbatim. A translator was involved in translating data from Kiswahili to English depending on the language used during the interviews. To ensure accuracy, the transcriptions were translated back to the original data. All printouts of the transcripts, any field notes or documents and the patient's demographic data were collected and sorted.

3.10.2 Data analysis and presentation

The study population was described by summarizing the socio-demographic data and clinical characteristics using measures of central tendency and dispersion.

The transcribed data was reviewed several times to make sense of what they contained and the highlights were noted down. As the transcripts were read many times, coding was done manually using a priori based on the Andersen Behavioral Model of Health care utilization (Ronald M Andersen et al, 2013) and the research questions. The first level of coding helped to organize segments of the data into broad codes. The second cycle of coding was more focused. Summaries from circle one coding were analyzed for similarities. Any similar or recurring categories were then combined. The different categories were filed in different folders for proper organization. The relationship between the categories was analyzed through constant comparison and then linked into themes. Then themes were identified from the words used or the phrases most commonly used and presented from the codes, either from the language, beliefs or opinions of the participants. Finally, the findings from the themes were linked to the study objectives to find meaning and to interpret the study results.

Data was presented in narration format with poignant quotes in italics to support the themes and subthemes.

3.10.2 Data storage

All audio recordings and typed field notes were encrypted and saved on the researcher's laptop with a password. The typed data from transcriptions were stored on the researcher's computer and were locked with a password. This data will be stored for 10 years after which the hardcopy papers will be shredded into pieces and the soft copy data will be deleted.

3.11 Ethical consideration

Permission to carry out the study was sought from the Kenyatta National Hospital- University of Nairobi (KNH-UON) ethics and research committee (ERC). After approval, the researcher further sought permission from KNH management to conduct the study. Permission was also sought from the In-charge-CTC to be able to conduct research in this department. These three steps were to ensure that there was no harm done to the participants in fulfillment of the principle of beneficence.

Informed consent from the participants was gotten by sufficiently explaining to them the purpose of the study and completing a consent form thus fulfilling the principle of respect for persons. The women were assured of discretion with all the information they had provided during the study.

3.11.1 Covid-19 Prevention measures

Due to COVID 19 pandemic, preventive measures were observed by the researcher and participants. The measures included hand washing using alcohol-based sanitizers before and after data collection, social distancing of at least one meter between researcher and participants was maintained. In addition, face masks were used during data collection and minimum timelines were observed to collect data as well as taking the participants' temperature before the commencement of data collection.

3.12 Limitations and delimitations

1. **Recall bias:** Some of the patients may not have had accuracy or completeness of recall to the memory of past events or experiences. To reduce recall bias, women with the most recent diagnosis were recruited for the study.
2. **Interviewer bias:** An interviewer's knowledge may have affected the framing of questions and presentation. To mitigate this, simple and easy to understand questions were used in the interview guide.
3. **Information bias:** The respondents may have given information that the researcher may have wanted to hear. This was mitigated by asking them to answer the questions based on their day to day practice.

3.13 Data dissemination plan

The results obtained from this study will be availed to the relevant policymakers, clinical and academic audiences through different outlets. The results will be presented to The University of Nairobi (UoN) School of Nursing Sciences where the final copy will be made available in the University repository for future references. The findings will also be published in peer-reviewed journals and presented in conferences.

CHAPTER FOUR: RESULTS

4.0 Introduction

This chapter gives details of the findings of the study based on qualitative data obtained from women with advanced breast cancer. During the study, the participants were purposively sampled and referred to as ‘Respondent’ (Resp.1-Resp.14). The chapter begins with an account of study participants then the different themes brought out during the interviews. A total of three themes were derived with six subthemes described under the respective themes.

4.1 The study participants

The study sample included 14 women after data saturation was achieved. They had a mean age of 45.5 years (SD=9.1) within the range of 28 to 65 years. The average number of children among the women was 2.8 (SD=1.7) within the range of 0 to 7 children. The sample comprised of 12(85.7%) married women and two single women. One woman did not have formal education while 6, 3, and 4 women had primary, secondary and tertiary education respectively. A section of 8(57.1%) women resided in Nairobi County while the rest resided outside Nairobi County. Majority 9(64.3%) of the women were unemployed and did not have a regular income. They received remittances from their relatives when they had needs or as frequently as the supporters could afford to do so.

The socio-demographic characteristics of the participants are presented in Table 1.1 below.

Table 4. 1 The socio-demographic description of the study participants

ID	Age	Residence	Level of Education	Marital status	Occupation	Income	Stage at diagnosis
Resp. 1	44	Nairobi	Form 4	Married	Business woman	12,000-15,000	III
Resp. 2	51	Murang’a	Form 4	Married	H/wife	Irregular	III

Resp. 3	65	Embu	-	Married	Farmer	Irregular	IV
Resp. 4	49	Murang'a	Std.6	Married	H/Wife	Irregular	III
Resp. 5	51	Kiambu	College	Married	Secretary	40,000	III
Resp. 6	35	Kiambu	Std.8	Married	H/wife	Irregular	III
Resp. 7	39	Kiambu	Std. 8	Married	H/ wife	Irregular	III
Resp. 8	28	Nairobi	College	Married	H/wife	Irregular	IV
Resp. 9	46	Muranga	Std.8	Single	H/wife	Irregular	III
Resp. 10	53	Kirinyaga	Std. 7	Married	Farmer	Irregular	III
Resp. 11	51	Nairobi	Std.8	Married	Vegetable Vendor	30,000	III
Resp. 12	42	Nyeri	Form 4	Married	H/wife	Irregular	III
Resp. 13	38	Nairobi	College	Married	Waiter(Hotel)	35,000	III
Resp. 14	45	Nairobi	College	Single	Teacher	38,000	III

4.2 Factors influencing health-seeking behaviour.

The factors which influenced the health-seeking behavior of the women in this study are discussed under the following themes: symptom experience, decision to seek help and the health-seeking journey.

4.2.1 Theme 1: Symptom experience

Most of the women in this study self-discovered the symptoms they identified apart from one who did not have any symptoms related to the breast tissue. Twelve out of the fourteen women in this study had a graphic imprint of the exact period they discovered the symptom as well as the nature of the symptom. While taking a bath, when grooming, and sometimes just touching the breast unconsciously were some of the activities they were doing when they discovered the symptoms. None of the fourteen women interviewed learnt her breast symptom through a structured or deliberate breast self-examination.

“I was just walking in the house, then I touched my breast and felt a lump. At that point I just assumed.”(Resp.5)

“I was taking a shower and in the process, I felt the lump. Because of the discomfort I felt whenever I could put on a bra, I got concerned.”(Resp.12)

“One day as I was dressing up to go to work, I felt a lump in my right breast. Since I was in a hurry I didn’t give it much attention” (Resp.14)

Most (10 out of 14) of the women did not seek healthcare immediately upon sighting symptoms. These women delayed testing for breast cancer despite having identified the symptoms mostly lump, swollen breast, ‘burning sensation’/ irritation, ‘womb bleeding, ‘drainage from the nipple’, ‘some very dirty milk’ and pain, redness, ‘pain at the shoulder blades’ , pain in the same breast which went all the way to the back, pain in the chest. Some of the reasons they gave for this delay were the fact that they didn’t think these symptoms were serious to require medical attention. One of the women mentioned that she had the same symptom (lump) while breastfeeding her second-born but it resolved without medical intervention.

“According to what I know, when a woman delivers and her child is nursing, the breast can swell, even for 3 days but resolves on its own.”(Resp.6)

“I was in pain but took painkillers. I stayed home for 2-3 months and didn’t go to the hospital. But when the swollen breast persisted to the point that I couldn’t sleep, I sought help from a nearby clinic.”(Resp.3)

“...it began with a lump then a burning sensation on my right breast. This pricking sensation was made worse when I put on a bra. I stayed for 3 months hoping that it would go away but it didn’t.” (Resp.4)

The essence of the changes that these women noticed was related to their thoughts and feelings. Reactions such as worry and scare influenced the women to seek help thus reducing the delay. However, the lack of worry delayed symptom appraisal.

“Upon discovering a lump in the breast, I proceeded to work and didn't think so much about it. I was not in pain so I decided that I would go for check-up when I find time. I did not manage to get someday off from work. Six months later I discovered the lump had grown and there was another small one at the side. That's when I got really scared and went for check-up”. (Resp.13)

As expressed by the interviewees, views from their significant others were sought after to understand the bodily changes they experienced. Some of the people these women shared their symptoms with downplayed the seriousness of these symptoms, which led to a delay in help-seeking.

“My husband thought it was just a small thing like I had when breastfeeding my firstborn”
(Resp.4)

“Like for me, when I discovered the lump, I was with my husband. I asked him about it but he didn't think it was serious. I even asked him to touch the lump but he ignored the whole thing. Until I just decided to go to the hospital after encouraging myself to. You see that kind of delay. Who knows If I came earlier it would have been a different thing altogether. Some people say when one gets sick of cancer, they get healed, and that's when you go immediately.”(Resp.2)

“I didn’t have money to do the required tests in time. I also had to convince my husband that I needed to seek help since he didn’t think it was anything serious. If I was working I would not have waited.”(Resp.12)

Some of the women were directed to seek alternative therapies causing additional delays. Upon identification of a lump in the breast, one of the women was introduced to herbs by her mother-in-law thus delaying breast cancer diagnosis.

“It began with a lump, in 2016. It was not painful. I told my husband about it after which he told his mother about it. His mother gave me herb to crush and apply at the site. She also asked me to boil some and drink for a week. In 2017 January I felt some pain in the same breast which went all the way to the back. This time around I went for check-up in the hospital” (Resp.12)

Three of the respondents regretted having ignored the signs and symptoms of breast cancer.

“If I knew when I saw the drainage, I should have come immediately” (Resp.6)

“I was so afraid especially at stage III. I wish I came earlier” (Resp.12)

“My challenge was getting time to go to the hospital. I wish I went earlier”. (Resp.13)

A respondent indicated that there was no justifiable reason for not seeking healthcare after discovering the symptoms.

“I honestly don’t know why one would stay with a headache for a whole month and not come to the hospital at all. I can’t explain at all” (Resp.10)

The delay period varied from 1 month, 2 months, 3 months, 6 months, and 1 year. During this period of delay, these women were preoccupied with other activities. Some of these activities

included watchful waiting, monitoring of the lump and self-medication until there reached a point they could no longer wait. They eventually had to seek help.

“I was in pain but took painkillers. I stayed home for 2-3 months and didn’t go to the hospital. But when the swollen breast persisted to the point that I couldn’t sleep, I sought help from a nearby clinic.”(Resp.3)

“I stayed for 3 months hoping that it would go away but it didn’t. When it became very painful, I decided to seek help from one of the clinics in my neighborhood.”(Resp.4)

4.2.2 Theme 2: Decision to seek help ‘tipping point’

In due course, there came a point where the women decided to seek medical help. This decision was provoked by the observed progression of the symptoms. This worsening was marked by an increase in size and number of swellings, associated pain, and discharge from the breast or a combination of all these. Some were also triggered by their inability to carry out their daily duties.

“When I was unable to work, that’s when I went to the hospital. It began in 2007. I stayed with it because I didn’t know it was a problem until 2008. That is when I went to the hospital.” (Resp.10)

“The pain was so much that I Could not even stand. That’s when I went to the hospital.” (Resp.11)

“Upon discovering a lump in the breast, I proceeded to work and didn't think so much about it. I was not in pain so I decided that I would go for check-up when I find time. I did not manage to get a day off from work. Six months later I discovered the lump had grown and there was another small one at the side. That’s when I got really scared.” (Resp.13)

Regrettably, this happened later in the development of breast cancer which resulted in late-stage diagnosis and related poor outcomes.

4.2.3 Theme 3: Health-seeking journey

Under this theme, there are four subthemes. These are level of awareness, financial challenges, and psychological factors, socio-cultural factors and health system-related factors.

4.2.3.1 Subtheme 1: Level of Awareness

Five out of fourteen women were aware of the existence of breast cancer disease before they were diagnosed. Breast cancer was viewed as ‘a very bad disease’. Ten of the women had been exposed to information on breast cancer. Two women aged above 50 years reported having gone for screening before the presentation of the lump.

“I used to go for tests but they would find nothing unusual in the tests”. (Resp.3)

“I have been doing the screening throughout and nothing was seen. I just realized there was pain, yet have never skipped a screening”. (Resp.5)

Most of the women interviewed had not done breast cancer screening before their diagnosis (8 out of 14). Reasons cited for failure to go for breast cancer screening was ‘no family member’ was diagnosed with cancer before and lack of time to go for screening. Some of the women believed that it’s only those who had a history of breast cancer in the family who were likely to get breast cancer. This led to a delay in their health-seeking journey.

“I heard about breast cancer screening but I had never gone for any. There is no one with a history of breast cancer in our family” (Resp.11)

“I had heard about it, but didn’t manage to go for any. My challenge was getting time to go to the hospital. I wish I went earlier” (Resp. 13)

The main sources of information about breast cancer included radio, church, television, social media, word of mouth (people's discussions), and workmates. Some of the messages they had learnt were how to perform a self-breast examination and report to the hospital if they found any lumps. However, this information was not used in the process of appraising their symptoms.

“When I listened to the radio they told us when you get a breast lump as you shower you need to go for check-up. That’s what the doctors would tell us.” (Resp. 2)

“We were told that when a doctor does it, they can tell what’s wrong. When I do it myself I can easily convince myself that is normal, or its breast milk. The doctor can clear the doubts.” (Resp.5)

Patients with secondary and tertiary education, with income, aged below 40 years, and residing in Nairobi County were more aware of breast cancer and screening.

Most of the women emphasized the need to create more awareness of breast cancer. One of the women also recommended breast cancer to be declared a ‘national disaster’.

“You need to create more awareness and advertisements because when they see those adverts they will take action. Those posters you hang in the hospital should be hanged outside there for people to read.”(Resp.1)

“At the community level, the radio notices and advertisements will be really helpful. Like in our village, the free education given by the doctors in our churches is helpful.”(Resp.2)

“I think it should be taken as seriously as COVID is being taken.” Resp.5

“(Pops her eyes out) you guys just need to declare cancer a national disaster.” (Resp.8)

Recommended modes of awareness creation included schools and colleges, different forms of communication advertisements, radio, and TV. They also suggested that awareness creation messages should include ‘breast cancer can be managed’, ‘allay the fear surrounding breast cancer’, routine check-up, ‘seriousness of breast cancer irrespective of painless lumps’ and early signs of breast cancer. Awareness can also be done when women ‘come to the hospitals whether for clinics or to deliver’

“I think what you are supposed to do, in case a woman goes to the hospital, for any other issue that they have, the doctors can try and check. Not only the specific part which is sick, but they should also check the breasts and teach the women how to test on their own.”
(Resp.5)

“Now you know, the way people talk about this illness, you even get scared to go to the hospital. Most of the women will end up saying they are fine. The fear surrounding the whole thing should be allayed first.” (Resp.3)

4.2.3.2 Subtheme 2: Financial challenges

Financial challenges also contributed to a delay in health-seeking among the women interviewed in this study. Nearly all the women mentioned that they had financial challenges (13 out of 14). Most of the women interviewed were housewives and did not have stable sources of income. Depending on how serious they thought their condition was, they waited until they had finances to go for a medical check-up and diagnostic procedures.

“I was in a lot of pain but I didn’t know what to do because I didn’t have money. I may have wanted it removed but I didn’t know where to get money because my children were in school.”(Resp.7)

“For many women, money is a challenge because you think about a hospital, money comes first. So you keep postponing the issue. The more you stay the more the disease advances.”

(Resp.8)

“The cost of the tests was high yet NHIF refused to cater for these costs.” (Resp.14)

A breast cancer diagnosis is believed to lead to catastrophic expenditure. This brings a lot of hopelessness and a lack of motivation to go for a medical check-up to confirm the diagnosis.

“You become so hopeless even before you begin treatment. The bad thing with this disease you spend everything you have on this earth, then you eventually die” (Resp.3)

“We spend a lot of money, sell our property and still some don’t survive” (13)

Social-economic challenges including losing a job and lack of basic needs were prominent among these women, especially during treatment.

“Most of the problems came after my diagnosis. This because I lost my job since I could not report to work as expected when I began chemotherapy treatment. My husband does not have a stable job and our children are in school. The cost of treatment is also very high. (13)

“I even had to stop working.”(Resp.12)

Women with regular sources of income were more positive than counterparts. Patients aged below 42 years were more negative.

When asked for recommendations, some of the women recommended chemotherapy and other diagnostic expenses to be made free.

“The government should just come in and give free treatment to patients. The same way they give HIV drugs for free, this one is even worse than HIV. Because if we get treatment as early as required, we will get well” (Resp.9)

“Chemotherapy to be made free, other diagnostic expenses to be made free as well. People will definitely come because mostly its money that keeps them at home. People are dying because they can’t get enough money for check-up and treatment” (Resp.8)

4.2.3.3 Subtheme 3: Psychological factors

Fatalism caused delayed help-seeking among breast cancer women because of the perceived futility of treatment using conventional medicine.

“The bad thing with this disease you spend everything you have on this earth, and then you eventually die”. (Resp.3)

Fear of being diagnosed with breast cancer was reported to affect health-seeking behavior. Women reported fear of the social and financial implications of a cancer diagnosis.

“Fear is another reason. Because if you are told that you have cancer, it breaks your heart. By the way, I don’t usually like to mention that word...chuckles...Because of the kind of results you will get. So one just decides to stay at home”. (Resp.7)

Stigmatization instilled fear to seek medical attention and open disclosure of disease status. Stigmatization was associated with the departure of spouses, relatives and friends.

“Do you know where I come from when you are sick people really fear you?” (Resp.2)

“My landlord wanted to chase me away, when I told my husband about the condition, he ran away from me”. (Resp.6)

Misconceptions about the diagnostic procedures were also noted during the interviews. One of the women interviewed regretted having gone for an FNA test that caused the lump to grow very big.

“FNA was done. But this test made the lump to become very big. Until I regretted why I went for that test” (Resp.6)

4.2.3.4 Subtheme 4: Socio-cultural factors

Most of the women in this study stated that they were Christians. They shared about their symptoms and diagnosis with their religious groups. In some instances, they received reassurance messages from these groups. Consequently, some women did not follow up on medical care based on the assurance messages they received from others. They believed that God has the supernatural power to extraordinarily heal the disease. One of the respondents believed that prayers were sufficient to fully heal a lump in the breast.

“In our next prayer meeting, the prophet prayed for me and I believed I was healed. . . A year later I woke up with a lot of pain in my chest. The doctor then told me that I had breast cancer and that it was advanced- I am a firm believer that it is God who heals people. Once we repent our sins he heals us”. (Resp.14)

The women in this study felt that seeking spiritual support especially prayer was important in allaying their anxiety which was related to the breast cancer diagnosis.

“I talked to my church members about it and they prayed for me. That gave me a bit of relief”. (Resp.12)

Some women got encouragement from the belief that it's God who knows why the disease came and was in full control of their uncertainties.

“I read my Bible. Then I decided that I will just persevere because no one knows about tomorrow apart from God”. (Resp.10)

Most of the women received support/advice from friends, pastor, husband, mother, other family members, their children, sisters, brother, and church members. This support was either financial, physical or sometimes material support to enable them to seek the necessary medical care.

“I told my parents and siblings about it and they gave me money for the tests” (Resp.6)

During disclosure, the women only shared with trusted individuals. Three of the women interviewed restricted themselves from sharing breast cancer information with other people. From the interviews, two women were restricted to share their breast cancer status with other people and her children by pastor and doctor. The reasons for restriction were to avoid social consequences such as rejections, gossip, disgrace, negative comments and uncontrolled spread of news.

“...because you know people can be weird. Because whenever I could leave home for treatment, they would say I have gone to do my own things. So whenever I went for admissions I didn't tell them. When they see me carry a bag they imagine I have gone to do my own things.”(Resp. 10)

“My pastor told me to proceed with treatment and should not talk about it to many people because they would gossip about me” (Resp. 4)

“Then we didn't want to tell our parents first because when they hear the word cancer being mentioned they think it's the end of your life.”(Resp.7)

“I have not told them yet. You know some things you just keep to yourself.”(Resp.2)

Community beliefs and views about breast cancer influenced the women's reaction to the possibility of being diagnosed with this condition. Some chose not to seek help immediately as they feared confirmation of this diagnosis despite having identified the symptoms. In some communities, breast cancer is believed to be 'a very bad disease' and 'relate it to death itself,' a very dangerous disease'

"About treatment, I don't know much, though I heard it can't be treated", (Resp. 6)

"When they (community) hear the word cancer being mentioned they think it's the end of your life" (Resp.7)

"It is a very dangerous disease, most people really fear it." (Resp. 12)

In this study, one of the women postponed seeking medical help because of work and another because of the need to keep her business running. For some other women, the ability to go about their normal tasks was considered more important than seeking help for their breast symptoms.

"I proceeded to work and didn't think so much about it. I was not in pain so I decided that I would go for check-up when I find time. I did not manage to get a day off from work. At our workplace, when you miss work on a particular day, you don't get paid". (Resp.13)

The use of alternative medicine offered by a relative delayed one of the women interviewed in this study. She opted for this treatment because she had trusted her mother-in-law who had treated her earlier for a different ailment and was relieved. She believed that these herbs would heal the lump in her breast.

"... in 2016 my mother-in-law gave me herb to crush and apply at the site (breast with the lump). She also asked me to boil some and drink for a week. In 2017 January I felt some

pain in the same breast which went all the way to the back. This time around I decided to go for check-up in the hospital (Resp.12)”

4.2.3.5 Subtheme 5: Health system factors

Several health system factors led to a delay in the health-seeking process. Some of the frequent appointments could be missed due to industrial actions in the public hospitals. Resp. 1 who had reported her breast symptoms in time missed a surgical procedure because of this reason.

“I had to wait until the following year March 2018 for the procedure to be done. Doctors were on strike then” (Resp.1)

Poor communication between patients and medics was reported. Most of the time, instructions were given without proper explanation. The women had little understanding of the required investigations.

“They kept sending me back and forth, for things I didn’t understand”. (Resp.2)

“I was checked, and then was told to go to the hospital for removal of something; I am not sure what they usually remove”. (Resp.10)

In this study, the women had to breakdown the information on their own. This process of decoding things for themselves led to misconceptions, evoked fear and eventually caused them not to attend the subsequent visits. For example, Resp. 6 did not see the need to do a breast biopsy yet she had done an FNA earlier on. She believed that the FNA has led to further growth of the small lump she had. As such, she left the hospital and didn’t return until several months later.

“FNA was done. But this test made the lump to become very big. Until I regretted why I went for that test. Being told to do another test similar to this one wasn’t easy for me”

(Resp.6)

Long inter-facility testing procedures contributed to delayed diagnosis. Some of the women had to travel to other centres for diagnostic procedures which contributed to delays in the health-seeking process. For some, the whole process of being referred from one point to another led to a delay in diagnosis and initiation of treatment.

“They kept on sending me from one point to another until one year got over”. (Resp.2)

“You know how government hospitals can take you round in circles. I took another one year being referred from one department to another” (Resp.3)

Most of the women had registered for the national health insurance medical insurance. They expected that this insurance fund would cater for the cost of diagnostic investigations yet this was not the case. This led to a delay since most had to wait for financial support from relatives and friends to be able to do these tests.

“Money is also another reason they (women) would come late (for breast cancer treatment). Some of the tests are very expensive yet NHIF does not cater for these tests”.

(Resp.12)

Some of the women interviewed reported to a health facility at the onset of their symptoms but were misdiagnosed and given false assurance. Resp. 8 reported to the hospital immediately she noted that she had a breast lump. She was diagnosed with fibroadenoma which she was told that she could live with it only to come back when the disease had spread and was at stage 4. Resp. 11

was misdiagnosed and treated for a different ailment all together only to be told later on that she had breast cancer.

“I have gone to so many hospitals and was given treatment for the pain. There is one time I was told it is cholesterol so I was given treatment for cholesterol for three months but the pain did not disappear.” (Resp.11)

“I noticed a lump on my left breast and I went to the hospital immediately. I was misdiagnosed. I was told it was a normal lump that is supposed to be operated on and removed. It has a name, I forget the name....Fibro... Fibroadenoma. That was Mama Lucy hospital. I noticed that the lump got bigger, that’s when I came to Kenyatta” (Resp.8)

CHAPTER 5: DISCUSSION, CONCLUSION AND RECOMMENDATIONS

5.1: Introduction

This chapter presents a comparison of my study findings with other studies on the same phenomenon, study conclusion, recommendations based on the findings and study limitations.

5.2: Demographic characteristics.

The demographic factors in this study had varied effects on health-seeking behaviour among the women who were interviewed. The variability of how these demographic characteristics affected health-seeking behavior proposes that it is not the factors themselves, but are applied via other mechanisms. For instance, the ability to seek help is determined by how these factors are utilized. The way a woman manages her economic factors may enable or impede her access to medical care. In this study, the worsening symptoms resulting in pain and distress was a strong driving force for the women to overcome their challenges in seeking care.

The demographic characteristics of the participants in this study are comparable to those of women in other studies who were purposively selected. Their age range was between 24 years old (Resp.8, Stage IV) and 65 years (Resp. 3, Stage IV). This is similar to other patients with breast cancer studied in Ghana (25 – 67 years) (Asoogo & Duma, 2015), Iran (26 – 71 years) (Khakbazan et al, 2016), Malaysia (26 – 67years) (Norsa'adah et al, 2012) and China (20 – 81 years) (Lam et al, 2015).

Twelve of the fourteen participants (85.7%) in my study were married, 2 were single. One woman did not have formal education while 6, 3, and 4 women had primary, secondary and tertiary education respectively. In a study done in Ghana by Agbeko (2017), secondary level of education was the highest among the women who participated in the study. In Iran, among the women who

delayed health-seeking, half of them had a minimum of secondary education (Rastad et al, 2018). Likewise, in a study done in Nigeria, most of the women interviewed had secondary, graduate and postgraduate level of education with 45.3% of them having a delay time of more than 3 months (Ezeome, 2016)

In terms of place of residence, the women interviewed in this study were similar in distribution. Eight out of fourteen lived in Nairobi County while 6 resided outside Nairobi County. In a study done in Ghana, four of the women lived the rural areas, while 5 and 6 lived in semi-urban and urban areas respectively (Agbeko 2017. In a study done in Iran, all the 19 women interviewed lived in urban areas (Taib et al, 2017) while in Egypt most of the participants lived in rural areas, (Mousa et al, 2017).

Regardless of their residential areas, most of the participants in this study did not have a regular source of income. Most of them depended on their family members for financial support. In Nigeria, it was reported that 58.8% of the women interviewed belonged to a low socioeconomic class and 1.2% in a high socioeconomic class (Ezeome et al, 2016). In Pakistan, approximately 70% of the women with advanced breast cancer had yearly domestic earnings less than \$500 (£382.45) and were considered to be in the lower socioeconomic group (Talpur et al, 2017). Poverty has a significant influence on delayed care-seeking among women with breast cancer particularly in developing countries (Sharma et al, 2018). Inadequate finances are reflected in their inability to cater for their basic needs, inability to pay for quality care in private hospitals and access to public health insurance. (Unger-Saldaña & Infante-Castañeda, 2017). In this study, most of the women mentioned the lack of money as the reason why they delayed in seeking medical care. In Ghana, Asoogo and Duma (2015) reported some women who managed to save money over some time to seek help in the hospital. Elsewhere, women of middle and high socioeconomic

status (Talpur et al, 2015) and high family income (Poum et al, 2016) have delayed seeking help for other reasons such as the fear of confirmation of a breast cancer diagnosis. From the studies above although financial status is very important in health-seeking behavior, it may not be just mere financial ability that guarantees access to medical care.

5.3: Delay Time

This is the period from the recognition of the first symptom by the patient to initial medical consultation. Most of the women took between 3 - 12 months before presenting to the hospital. Depending on the type of breast cancer, a delay time of more than 3 months is associated with bigger tumor size, positive lymph node involvement, and metastatic disease. It is this progression in the disease that eventually triggers help-seeking among these women. A previous study of breast cancer patients at Kenyatta National Hospital reported a symptom duration of more than 3 months (Otieno et al, 2016). Delay time among women interviewed in Nigeria ranged from 1 – 96 months, (Ibrahim and Oludara (2017)). Delay time of 4 – 36.5 months was reported from qualitative studies in Malaysia (Taib et al, 2016) and Mexico (Unger-Saldaña & Infante-Castañeda, 2017).

5.4: Factors influencing health-seeking behaviour.

The factors that influence the health-seeking behavior of the women in this study are discussed under the following themes: symptom experience, decision to seek help and the health-seeking journey.

5.4.1: Symptom experience

Most of the women in this study self- discovered their breast symptoms. Although most of them had heard about breast cancer screening they did not go for any. These findings are similar to other studies carried out among women with breast cancer. In a study done in Ireland, women learned

of their breast problems in the course of their daily routines such as taking a bath, dressing up, or breastfeeding (O'Mahoney et al, 2015).

A breast lump was the most common first symptom that was experienced by the women in my study (13 out of 14). The other woman's first symptom was pain at the shoulder blades which was not directly related to the breast tissue. The shortest delay (1month) was in a woman whose initial symptom was a breast lump and the longest delay (1 year) in one whose initial symptom was a breast lump. The women's interpretation of their symptoms influenced care-seeking behaviour as opposed to the nature of the initial symptom. They initially interpreted their symptoms as not being serious. This because the lumps were small painless, and did not interrupt their daily activities. These findings are attributable to the subtlety of the initial symptoms of breast cancer. The early symptoms of breast cancer are usually not debilitating and can be ignored until the symptoms worsen. This may infer that the seriousness of the symptoms is qualified by the effects on a woman's functionality.

In other studies, the nature of the first symptom influenced health-seeking behaviour. Women who experienced breast pain delayed in seeking care (Meechan, Collins, & Petrie, 2016). Those who did not have breast lump were also found to delay longer (Burgess et al, 2018). Elsewhere, women whose initial symptom was a breast lump have also been found to delay (Taib et al, 2017). Women studied in other diverse backgrounds are reported to have interpreted their symptoms as not being serious to require medical care. This includes Pakistan (Malik & Gopalan, 2016; Memon et al, 2018), Columbia (Piñeros et al, 2016), Germany (Arndt et al, 2017), and Malaysia (Taib et al, 2017). However, since these were quantitative designs, the reasons for such conclusions could not be elicited. Burgess et al, (2017) in their study reported that the presence of pain was considered not serious but rather reassuring since these women appraised a painless lump as being cancerous.

Among Chinese women studied by Lam et al, 2018), breast pain rather than the lump pointed to an abnormality. Some of the women attributed their symptoms to trauma (Unger-Saldaña & Infante-Castañeda, 2017) and hormonal changes (Lam et al, 2016). It therefore appears, that, the psychological interpretation of their symptoms significantly influenced the appraisal of the symptoms and differs across cultures.

5.4.2: Decision to seek help “Tipping point”

This is the point at which a series of small changes in their breast symptoms became significant enough to cause the women to seek medical help. In this study decision to seek help was triggered by worsening of the symptoms. This worsening was marked by an increase in size and number of swellings, associated pain, and discharge from the breast or a combination of all these. For most of the women, this decision was triggered by their inability to carry out their activities of daily living. Unfortunately, this took place later in the late stages of the disease which is associated with poor outcomes. There remains some incongruence in what health education on breast cancer expects women to do and what they do. What these women interpret as being serious and needing medical attention is very different from what the health educators anticipate. These findings are similar to a study done in Ghana by Agbeko (2017) where the most common trigger was the worsening of symptoms to the point of affecting their quality of life and daily activities Pain has been broadly reported as a trigger to seeking any form of help (Ezeome, 2016; Lam et al, 2018; Taib et al. 2016). Contrary to these findings, Burgess et al(2017) reported that the appearance of breast lump was the most common trigger to seeking medical care because the women interviewed in the UK believed that breast cancer was not painful.

5.4.3 Health-seeking journey

Under this theme, four subthemes were discussed. They include the level of awareness, financial challenges, psychological factors, sociocultural factors and healthcare system-related factors

5.4.3.1 Subtheme 1: Level of Awareness.

Most of the women interviewed in this study had been exposed to breast cancer campaign messages. Some of the sources included radio, television, posters and in their church groups. Their level of exposure did not translate to the expected knowledge base in appraising their breast symptoms. Regardless of the source of information that informed the woman's knowledge base, the responsibility lied on her to consider her symptoms serious and needing medical care. Most of the women studied by (O'Mahony et al, 2017) in Ireland did not delay in seeking help since they were highly educated. Their sources of information were reading and accessing websites to interpret their symptoms. Highly educated women can access and utilize reading materials (print, web) with ease which eventually enhances their appraisal process. Contrary to this, women who are not educated such as some of those in the developing countries, may not easily access this information apart from that which is aired on audio/visual media. Nonetheless, it is worth noting that having the information does not guarantee prompt health-seeking. In their study, Barg and Grier (2015) attribute these findings to women's previous experiences and cultural orientation. Consequently, the information given during health education is utilized depending on how the women interpret it. Conversely, even where there was congruence between the intended and actual meaning, Granek and Fergus (2016) affirm that women who did not intend to seek medical help for their symptoms intentionally ignored their symptoms since they had other things that needed their attention.

5.4.3.2: Financial challenges

The high cost of care also contributed to delay in health-seeking among patients with breast cancer in developing countries. Most of the women in this study had financial challenges. The little finances they had could only cater for their daily and domestic expenses. Extra costs like health care costs could not be afforded by these women. The costs of diagnostic investigations are particularly very high in developing countries. Although most of the women had registered for the national health insurance which is expected to cover the cost of care for cancer patients, the insurance did not pay for the cost of diagnostic investigations they undertook. This led to a delay since most had to wait for financial support from relatives and friends to be able to do these tests, thus the National Health Insurance Fund (NHIF) policy on cancer needs to be reviewed to allow women access care more easily.

In other studies, the high cost of care led to delays in health-seeking (Iskandarsyah et al, 2016; Lam et al, 2016; Ruddy et al, 2016; Sharma et al, 2016). (Ruddy et al, 2017) proposes that it is the extra costs like child care, co-payments and hidden costs like lost wages that delays health-seeking among women who are financially challenged.

5.4.3.3: Psychological factors

Discussed below are some of the psychological factors that affected the health-seeking behaviour among women with breast cancer. In this study, the fear of being diagnosed with breast cancer affected health-seeking behavior. Women reported fear of the social and financial implications of a breast cancer diagnosis which led to delay in health-seeking. Fatalism also caused delayed help-seeking among breast cancer women because of the perceived futility in the treatment of cancer in this study. These findings are attributable to the cultural orientation and socialization of these women. Most of them are a result of the different beliefs in the different communities these

women come from. However, as the symptoms worsened, these women overcame these barriers and were forced to seek medical care. In two studies done in Ghana, women reported fear of the outcomes of breast cancer treatment which included death (Asoogo and Duma, 2015; Agbokey, 2014). Similar findings were reported by women in Ireland (O'Mahony et al, 2017), the UK (Burgess et al, 2016), Pakistan (Malik & Gopalan, 2016) and Malaysia (Taib et al, 2014). Fear was expressed in varied ways by the women who participated in other studies. For example, some of the women in Iran opted for alternative medicine because they feared confirmation of breast cancer by conventional medicine. This consequently contributed to delays in looking for help from conventional medicine (Rastad et al, 2016). Some women were uncertain about the ability of conventional medicine to deal with the deadly outcomes of breast cancer (Taib et al, 2016).

Fatalism hastened help-seeking among women with breast cancer (O'Mahony et al, 2016) yet in some, it caused delay because of the perceived futility of treatment using conventional medicine (Taib et al, 2014).

5.4.3.4: Socio-cultural factors

Social and cultural backgrounds also influenced the women's health-seeking behaviour in diverse ways. In this study use of alternative medicine led to a delay in seeking medical help. The use of alternative medicine offered by a relative delayed one of the women interviewed in this study. She opted for this treatment because she had trusted her mother-in-law who had treated her earlier for a different ailment and was relieved. She believed that these herbs would heal the lump in her breast. This attributable to the easy accessibility of the treatment option and the trust given that it had worked before for a different ailment. Similar findings were reported in Ghana by Asoogo and

Duma (2015) and Agbokey (2017). Surveys done in Nigeria and Pakistan also reported the use of alternative medicine. Some of the women visited prayer houses, traditional healers and alternative practitioners before seeking care in the hospital (Ezeome, 2016; Ibrahim & Oludara, 2015). In this study, the influence of religiosity and spirituality on health-seeking behaviour was equivocal. In this study, most of the women were Christians. Some of the women felt that seeking spiritual support especially prayer was important in allaying their anxiety related to the breast cancer diagnosis. In some instances, reassurance messages from women's social networks were religiously related. Hence, some women did not follow up based on the assured messages they received from others that God has the supernatural power to miraculously heal the disease. One of the respondents believed that prayers were sufficient to fully heal a lump in the breast. In Ghana, some women prayed to ensure the success of their hospital visits. One woman reported that prayer is what gave her the courage to seeking care in a hospital, (Agbeko, 2017). In other studies women reported that religious beliefs as well as membership in religious organizations led to better outcomes of their breast cancer diagnosis (O'Mahony et al, 2017; Taib et al, 2016).

Social roles played by these women also influenced their health-seeking behaviour. In this study, one of the women postponed seeking medical help because of work and another because of the need to keep her business running. To be able to continue with their duties as usual, they did not infer illness in appraising their breast symptoms. It appears that these women were determined to maintain their daily routines of work. This is attributable to the tendency of women to prioritize their social and cultural roles above their health. In other studies, many women deferred seeking medical care because of their jobs, domestic and social roles (Angus et al, 2017; Burgess et al, 2016; Khakbazan et al, 2016; Lam et al, 2016).

Social disclosure about their symptoms had varied effects on health-seeking behaviour. In this study, most of the women received support from family members and friends. This support was either financial, physical or sometimes material support to enable them to seek medical care. It is also noted that their decision-making process was influenced by other members of the society like husbands, religious leaders, other family members and friends. From the expressions of these women, opinions of their significant others were sought to understand the noticed bodily changes. Some of the people these women disclosed their symptoms to downplayed the seriousness of the symptoms and this led to a delay in help-seeking. This is attributable to the traditional view that women could not make decisions with finality. In other settings, social disclosure hastened women's health-seeking (Taib et al, 2016). On the other hand, nondisclosure also led to delays in health-seeking. These women did not disclose because they didn't want to be a nuisance. (Liam et al, 2018). Disclosure influenced delay in seeking help because the misconceptions the women had were strengthened. (Poum et al, 2016).

5.4.3.2: Health system-related factors

The quality of care offered in the health care facilities influences health-seeking behaviour. In this study, two of the women reported their breast symptoms to a health facility immediately after they discovered them. However, misdiagnosis and false reassurance from the health practitioners led to delays in the diagnosis of breast cancer. One of the women reported to the hospital immediately she noted that she had a breast lump. She was diagnosed with fibroadenoma which she was told that she could live with it only to come back when the disease had spread and was at stage 4. Another one was misdiagnosed and treated for a different ailment all together only to be told later on that she had breast cancer. These findings can be attributed to the shortage of staff in our public

hospitals where the few staff on duty may not pay keen attention to the overwhelming numbers of patients seeking medical care at the facility thus may make errors in diagnosis. Elsewhere, Unger-Saldaña and Infante-Castañeda (2017) reported that medical errors in diagnosis led to delays since the women were given false assurance that the disease was benign.

In this study, some of the repeated visits and appointments were missed due to industrial actions at the health facility. Ezeome (2016) also reports hospital industrial actions and inadequate facilities carry out diagnostic investigations in Nigeria as a cause of delays. One of the women who initially reported to the hospital missed a surgical procedure because of this reason.

Long inter-facility testing procedures contributed to delayed diagnosis. In my study, some of the women had to travel to other centres for diagnostic procedures which contributed to delays in the health-seeking process. For some, the whole process of being referred from one point to another led to a delay in diagnosis and initiation of treatment. These findings are attributable to the unavailability of enough diagnostic equipment in the public hospitals. They are forced to refer patients to private setups which further lengthens the trajectory thus leading to delay in diagnosis and initiation of treatment. In Mexico, women reported that they had to visit many health facilities to be attended to by a physician or have investigations done. For some, the referral trajectory led to delays in care-seeking (Unger-Saldaña and Infante-Casteñeda, 2017). Comparatively, the care-seeking trajectory for women studied in the UK (Burgess et al, 2018) and Ireland (O'Mahony et al, 2017) was reported to be shorter.

The health care workers' communication skills also influenced health-seeking behaviour among women with breast cancer. In this study, poor communication between patients and medics was reported. Most of the time, instructions were given without proper explanation. The women had little understanding of the required investigations. The process of decoding things for themselves

led to misconceptions, evoked fear which eventually caused them not to attend the subsequent visits. This is attributable to insufficient training in communication skills among the healthcare and shortage of staff in the public healthcare facilities. In another study, women did not have confidence in the medical team because of ineffective communication skills which led to confusion as they communicated the diagnosis and management of their medical conditions (Taib et al, 2016).

5.5: Conclusion

There were several levels of decision making in the women's health-seeking behaviour. The ability to make these decisions and when they were made determined the timing and course of the health-seeking process. This process was further hastened when the women began to feel that their lives were threatened by the worsening of symptoms. When they got to this point, they were determined to do whatever it could take for them to access care in the hospital. Nevertheless, their socioeconomic status made them rely on financial support from their friends and family and this consequently delayed their health-seeking process.

5.6: Recommendations

Based on the findings, this study recommends the following:

5.6.1: The women

There is need to design educational messages to help women to understand they do not need to wait until they are incapacitated to seek medical care as this can be too late where breast cancer is concerned.

5.6.2: The Institution

There is need for health care workers to utilize opportunities when women first report to the hospital to educate them about the importance of following through with referrals and investigations as this can potentially improve their health-seeking behaviour.

Health care workers need to be encouraged to include breast health education in their regular women's clinics such as ante-natal, post-natal, and other health promotion activities.

5.6.3: Ministry of health

To enhance early detection and diagnosis of breast cancer, there is need to have a national policy that provides free screening and diagnostic services under the National Health Insurance Fund.

There is need to acknowledge spiritual leaders and traditional herbalists and involve them when initiating educational interventions to improve early detection of breast cancer in Kenya since they are significant stakeholders in BC diagnosis.

5.7: Further research

A subject for further research could be the role of husbands in women's health-seeking behaviors.

Further studies to explore the cultural phenomena that defines breast disease and thus improve the health-seeking behaviour among women with breast symptoms.

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APPENDICES

Appendix I: KNH/UON Ethics and Research Committee approval letter



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Website: <http://www.erc.uonbi.ac.ke>
Facebook: <https://www.facebook.com/uonknh.erc>
Twitter: @UONKNH_ERC https://twitter.com/UONKNH_ERC



KENYATTA NATIONAL HOSPITAL
P O BOX 20723 Code 00202
Tel: 726300-9
Fax: 725272
Telegrams: MEDSUP, Nairobi

Ref: KNH-ERC/A/148

15th May 2020

Anyira Joy
Reg. No.H56/11401/2018
School of Nursing Sciences
College of Health Sciences
University of Nairobi

Dear Joy

RESEARCH PROPOSAL – DETERMINING THE HEALTH SEEKING BEHAVIOUR AMONG WOMEN WITH ADVANCED BREAST CANCER AT THE CANCER TREATMENT CENTRE AT KENYATTA NATIONAL HOSPITAL(P75/02/2020)

This is to inform you that the KNH- UoN Ethics & Research Committee (KNH- UoN ERC) has reviewed and **approved** your above research proposal. The approval period is 15th May 2020 – 14th May 2021.

This approval is subject to compliance with the following requirements:


- Only approved documents (informed consents, study instruments, advertising materials etc) will be used.
- All changes (amendments, deviations, violations etc.) are submitted for review and approval by KNH-UoN ERC before implementation.
- Death and life threatening problems and serious adverse events (SAEs) or unexpected adverse events whether related or unrelated to the study must be reported to the KNH-UoN ERC within 72 hours of notification.
- Any changes, anticipated or otherwise that may increase the risks or affect safety or welfare of study participants and others or affect the integrity of the research must be reported to KNH- UoN ERC within 72 hours.
- Clearance for export of biological specimens must be obtained from KNH- UoN ERC for each batch of shipment.
- Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. (*Attach a comprehensive progress report to support the renewal*).
- Submission of an *executive summary* report within 90 days upon completion of the study. This information will form part of the data base that will be consulted in future when processing related research studies so as to minimize chances of study duplication and/ or plagiarism.

For more details consult the KNH- UoN ERC website <http://www.erc.uonbi.ac.ke>

Protect to discover

Appendix II: KNH study Registration certificate.

KNH/R&P/FORM/01



KENYATTA NATIONAL HOSPITAL
P.O. Box 20723-00202 Nairobi

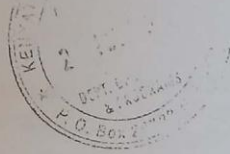
Tel.: 2726300/2726450/2726565
Research & Programs: Ext. 44705
Fax: 2725272
Email: knhresearch@gmail.com

Study Registration Certificate

- Name of the Principal Investigator/Researcher
ANJIRA JOY
- Email address: anjira.joy@gmail.com Tel No. 0724440138
- Contact person (if different from PI) DR. JEBET JOICE
- Email address: Jjebet@gmail.com Tel No. 0721475165
- Study Title
Determining the health seeking behaviour among women with breast cancer at the Cancer Treatment Center at Kenyatta National Hospital
- Department where the study will be conducted No Cancer Treatment Center
(Please attach copy of Abstract)
- Endorsed by Research Coordinator of the KNH Department where the study will be conducted.
Name: _____ Signature _____ Date _____
- Endorsed by KNH Head of Department where study will be conducted.
Name: DR C Mwangi Signature [Signature] Date 12/6/20
- KNH UoN Ethics Research Committee approved study number P75/02/2020
(Please attach copy of ERC approval)
- I Joy Anjira commit to submit a report of my study findings to the Department where the study will be conducted and to the Department of Research and Programs.
Signature [Signature] Date 16/06/2020
- Study Registration number (Dept/Number/Year) C70/181/2020
(To be completed by Research and Programs Department)
- Research and Program Stamp [Stamp]

All studies conducted at Kenyatta National Hospital **must** be registered with the Department of Research and Programs and investigators **must commit** to share results with the hospital.

Appendix III: KNH Research and programs approval.



Joy Tsindoli Anyira
The University of Nairobi.
School of Nursing Sciences.
P.O BOX 66177-00800
Nairobi
27/05/2018.

The Head of Department,
Research and Programs,
Kenyatta National Hospital.

Dear Sir,

RE: REQUEST TO CONDUCT A RESEARCH STUDY INVOLVING BREAST CANCER PATIENTS AT THE CANCER TREATMENT CENTER.

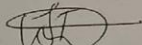
I am a second year student at The School of Nursing sciences, University of Nairobi pursuing a Master's degree in Nursing Oncology. I am conducting a study titled: Determining health seeking behaviour among women with breast cancer at the cancer treatment center at Kenyatta National Hospital. I write to request to conduct the above mentioned exercise at the hospital from the month of June until I achieve data saturation. I will conduct in depth interviews to the participants who will give consent. The study is purely for academic purposes.

In the context of covid-19 pandemic, I commit to adhere to ethical guidelines governing research on human subjects and measures put in place by the hospital in mitigating cross transmission of covid-19 among other unit infection prevention regulations. I will apply the following measures in prevention of cross transmission between the principal investigator and the study subjects.

- I. I will provide surgical face masks for all the study participants.
- II. Data will only be collected by the principal investigator (me) thus minimizing interaction with the participants.
- III. I will ensure proper hand wash or use of sanitizers by both parties.
- IV. Social distancing of 1.5 meters will be maintained between the principal investigator and the participants.

Thank you for the assistance.

Yours faithfully


Anyira Joy

Mobile no:0724440138

Email: anyirajoy@gmail.com

*2/6/2018
Please register
[Signature]*

Appendix IV: Informed consent information for respondent.

Title of the study: **Determining health-seeking among women with advanced breast cancer at The Cancer Treatment Centre at Kenyatta National Hospital**

Researcher: **Joy Anyira**

Institution of Study: **The University of Nairobi.**

Introduction

I am a student at the School of Nursing Sciences, University of Nairobi pursuing a Master of Science Degree in Nursing. I am conducting a study titled: **Determining health-seeking behaviour among women with breast cancer at The Cancer Treatment Centre at Kenyatta National Hospital**

This consent form gives you information about the study, the risks and benefits, and the process will be explained to you. Once you understand the study, and if you agree to take part, you will be asked to sign or use your thumb finger to put a mark (thumb print) on the consent form. I will also ask you questions regarding the study before you sign the consent form to ascertain your comprehension of the information provided.

Purpose of the study

This study will determine the reason for delayed health-seeking among women with advanced breast cancer at the Cancer Treatment Centre at KNH.

Time

The interview will take approximately 30-45 minutes.

Risks

There will be no economic or physical risks to participating in the study. However, you will take some time off your schedule to respond to questions from the researcher. Also, during the interview, some questions will require you to disclose some personal information that might trigger some negative feelings and possibly anxiety. If this happens, the researcher will refer you to the hospital counselor.

Benefits

There is no direct monetary benefit in participating in this study. However, the results of the study will be useful in planning and facilitating early diagnosis and treatment of breast cancer. The findings will be availed to the hospital, other relevant decision makers and stakeholders to aid in putting in place measures that will improve the care given to patients with breast cancer.

Confidentiality

Confidentiality will be maintained and the information you provide will only be used for the intended purpose of the study. In addition, your name will not be required on any forms or used during publication of the final report thus ensuring your anonymity. All materials used during the study will be under lock and key and only the personnel involved in this study will have access to them. Electronic files will be saved on password and fire-wall protected computers.

Interview procedure

The interview will be done by the researcher and the research assistant. We will record this interview to make sure that we listen to your responses correctly. We will write down your responses verbatim or base on the meaning of your comments. Your name will not be associated with the recording or on the transcript. We will assign you a number as your study code. If your name or any identifiable information comes on the transcript, we will delete it before sharing it with other individuals who may have access to the study data.

Voluntary participation

Participation in this study is voluntary. Refusal to take part will not attract any penalty. You retain the right to withdraw from the study without any consequences. You are free not to answer any question during the interview.

Sharing the results

Contact person:

1. Principal Investigator

Name: Joy Anyira

Phone No. +254 724440138

Email: anyirajoy@gmail.com

Physical Address: School of Nursing Sciences
University of Nairobi, College of Health Sciences
Kenyatta National Hospital Campus

2. Supervisors

Name: Dr. Joyce Jebet

Phone No. +254 721 475 165

Email: jjcheptum@gmail.com

Physical Address: School of Nursing Sciences
University of Nairobi, College of Health Sciences
Kenyatta National Hospital Campus

Name: Dr. Emmah Matheka

Phone No. +254 710105771

Email: emmahmatheka@yahoo.com

Physical Address: School of Nursing Sciences
University of Nairobi, College of Health Sciences
Kenyatta National Hospital Campus

3. Ethics Committee

Prof. M.L. Chindia,

The Secretary,

KNH/UON Ethics and Research Committee

Tel No. +254 726300-9

Email: uonknh_erc@uonbi.ac.ke

Physical Address: School of Pharmacy Grounds
University of Nairobi, College of Health Sciences
Kenyatta National Hospital Campus

Appendix V: Fomu ya Idhini (Kiswahili version)

Kichwa cha utafiti: Kutathmini tabia ya utafutaji wa huduma za matibabu kati ya wanawake walio na saratani ya titi katika kituo cha matibabu ya saratani katika hospitali ya kitaifa ya Kenyatta.

Mtafiti: Joy Anyira (Mwanafunzi wa Shahada ya Masomo ya Saratani, Mwaka wa Pili)

Taasisi ya Utafiti: Chuo Kikuu cha Nairobi

Utangulizi wa utafiti

Umealikwa kushiriki mahojiano kama sehemu ya utafiti, unaofanywa na Joy Anyira ambaye ni mwanafunzi wa shahada ya Uuguzi (Masomo ya Saratani) (Master of Science in Nursing (Oncology), katika Chuo Kikuu cha Nairobi.

Fomu hii ya idhini inakupa habari juu ya utafiti, hatari na faida, na mchakato huo utaelezwa kwako. Mara tu ukielewa uchunguzi, na ikiwa unakubali kushiriki, utaulizwa kutia saini au utumie kidole chako kuweka alama (kuchapishwa kwa kidole) kwenye fomu ya idhini.

Lengo la Utafiti:

Kusudi kuu la utafiti huu ni Kutathmini sababu zinazocheleweshwa utafutaji wa huduma za matibabu kati ya wanawake walio na saratani ya titi katika kituo cha matibabu ya saratani katika hospitali ya kitaifa ya Kenyatta.

Muda

Mahojiano yatachukua takriban dakika 30-45 ambapo yatafanywa na mtafiti.

Faida za utafiti:

Hakuna faida ya moja kwa moja kwako kama mshiriki wa mtu binafsi. Walakini, matokeo ya utafiti huu yanaweza kutumiwa na taasisi kupata sera/miongozo au matibabu ya wanawake walio na saratani ya titi.

Hatari

Hakuna hatari za moja kwa moja zinzotarajiwa kwako unaposhiriki katika utafiti huu. Ikiwa kuna maswali ambayo hutaki kujibu, unayaruka. Kwa kuongezea, una haki ya kukataa kutoa habari.

Usiri

Data yako haitakuwa na lebo na nambari yako ya kusoma sio jina lako. Kitambulisho chako kitakuwa siri. Maelezo yoyote muhimu ambayo utajitolea kumpa mtafiti itabaki kuwa ya siri na itafunuliwa tu kwa idhini.

Ushiriki wa Hiari na Kujiandoa

Kumbuka, ushiriki wako ni hiari kabisa. Utakapobadilisha kubadilisha mawazo yako, unayo haki ya kuacha kushiriki katika mahojiano wakati wowote bila kukabiliwa na matokeo yoyote.

Kushiriki Matokeo

Matokeo ya utafiti huu yanaweza kuwasilishwa wakati wa vikao vya kisayansi na kitaaluma na inaweza kuchapishwa katika majarida ya kisayansi na karatasi za kitaaluma.

Watu wa Mawasiliano

Ikiwa una maswali yoyote wakati wa au baada ya utafiti jisikie huru kuwasiliana na mpelelezi, msimamizi au Kamati ya Maadili na Utafiti ya KN/UON kwenye anwani zilizopewa hapa chini.

1. Mtafiti Mkuu

Jina: Joy Anyira
Nambari ya Simu. +254 724 440 138
Barua Pepe: anyirajoy@gmail.com
Anwani: Shule ya Kisayansi ya Uuguzi
Chuo Kikuu cha Nairobi, College of Health Sciences
Bewa la Hospitali kuu ya Kenyatta

2. Msimamizi

Jina: Dkt.Joyce Jebet
Nambari ya Simu. +254 721 475 165
Barua Pepe: jjcheptum@gmail.com
Anwani: Shule ya Kisayansi ya Uuguzi
Chuo Kikuu cha Nairobi, College of Health Sciences
Bewa la Hospitali kuu ya Kenyatta

Jina: Dkt. Emmah Matheka
Nambari ya Simu. +254 710105771
Barua pepe: emmahmatheka@yahoo.com
Anwani: Chuo Kikuu cha Nairobi,
Bewa la Hospitali kuu ya Kenyatta

3. Kamati ya Maadili

Jina: Prof. M.L. Chindia,
Katibu, Kamati ya Maadili Na Utafiti ya KNH/UON
Nambari ya Simu. +254 726300-9
Barua Pepe: uonknh_erc@uonbi.ac.ke
Anwani: School of Pharmacy Grounds
Chuo Kikuu cha Nairobi,
Bewa la Hospitali kuu ya Kenyatta

Appendix VI: Consent form

If you Consent to Participate in this study please sign below:

I hereby consent to participate in this study. I have been informed of the nature of the study being undertaken and potential risks explained to me. I also understand that my participation in the study is voluntary and the decision to participate or not to participate will not affect my treatment schedule in this facility in any way whatsoever. I may also choose to discontinue my involvement in the study at any stage without any consequences. I have also been reassured that my personal details and the information I will relay will be kept confidential. I confirm that all my concerns about my participation in the study have been adequately addressed by the investigator and the investigator have asked me questions to ascertain my comprehension of the information provided.

Participants Signature (or thumbprint)**Date**.....

I confirm that I have clearly explained to the participant the nature of the study and the contents of this consent form in detail and the participant has decided to participate voluntarily without any coercion or undue pressure.

Investigator

Signature.....**Date**.....

Appendix VII: Interview guide.

Thank you for consenting for participation. Before I start to record, I will ask some general questions about you.

Demographics

1. Age(years)
2. What is your marital status? -----
3. What is your highest level of education? -----
4. Residence-----
5. What is your occupation? -----
6. About how much do you earn monthly? ----- (Ksh.)
7. Do you have children? -----

If yes, how many-----

Thank you for sharing your background with me. Now, do I have your permission to start the recording?

[If No, thank participant for time and end the session] [If yes, continue with the interview]

Now that the recording has started, please say “Yes” to confirm that you approve of me recording the interview.

1. What is known about breast cancer in the community?

Probe:

- causes
- Symptoms
- screening
- Treatments

2. Had you ever heard of breast cancer before you recognized the first symptom of your illness?

(When, how)

3. Tell me about your experience with breast cancer from the first symptom recognition to diagnosis

Probe:

- Who noticed the problem with your breast?
- How did you notice the problem with your breast?
- What did you feel when you noticed it?
- What action did you take after noticing the problem? (Before and after diagnosis)
- When did you seek medical care?
- Why did you seek medical care? (Appearance of symptoms/persistence of symptoms/worsening of symptoms)
- When you were told you had breast cancer, who was the first person you told about your diagnosis? Why?
- What stage was the cancer diagnosed?
- Tell me about activities that helped you during your diagnosis?

4. What are the major challenges you have faced during diagnosis?

5. Why do think breast cancer patients seek medical care late?

Probe:

- Socioeconomic factors (age, education, income)
- Individual factors (do not know where to go, carelessness/neglect, and fear, financial, underestimate the severity of the problem)
- Cultural factors (traditional medicine, community beliefs)
- Health care system (access, referral)

6. What measures do you suggest to make sure breast cancer diagnosis happens early?

Probe:

- At individual level
- Community level
- Health facility level
- Government level

7. Do you have any questions for us or something you want to add?

Thank you for your time and information, have a good day!!!

Appendix VIII: Interview guide.-Kiswahili version

Asante Kwa kukubali kushiriki mahojiano haya.Kabla nianze kurekodi ningemba kukuuliza maswali ya jumla kukuhusu.

Demografia

1. Umri.....
2. Hali yako ya ndoa.....
3. Kiwango cha elimu.....
4. Makaazi yako.....
5. Unafanya kazi gani?
6. Kiwango cha mapato yako kila mwezi.....
7. Una watoto?

Kama ndio, ni wangapi?

Asante kwa kutoa habari kuhusu demografia yako.Je utaniruhusu nianze kurekodi mahojiano haya kuanzia sasa?

(Kama la, shukuru muhusika kwa muda wake ili kukamilisha mahojiano) kama ndio, endelea na mahojiano)

Kwa vile rekodi imeanza, tafadhali sema ndio kuhakikisha kwamba umekubali nirekodi mahojiano haya.

1. Ni nini kinachojulikana kuhusu saratani ya matiti katika jamii yenu?

Peleleza;

Inasababishwa na nini?

Dalili zake

Uchunguzi

Matibabu.

2. Ulikuwa umewahi kusiskia kuhusu saratani ya matiti kabla uanze kuona dalili za kwa za ugonjwa huu?(lini na vipi)
3. Hebu niambie mstakabali wa maisha yako tangu ulipoona dalili ya kwanza hadi ulipobaini kuwa uko na saratani ya matiti?

Peleleza:

Nani aliyetambua shida ya matiti hii

Ulijuaje kuwa titi lako liko na shida

Ulihisis vipi ulipotambua shida hii

Ulichukua hatua gani baada ya kutambua hiyo shida (kabla na baada uhakiki)

Ni wakati gani ulianza kutafuta huduma ya matibabu?

Kwa nini ulitafuta huduma ya matibabu? (kuonekana kwa dalili/dalili kuendelea kwa muda/dalili kuwa mbaya Zaidi.

Ulipoambiwa kwamba uko na saratani ya matiti, ni yupi uliyemwambia kwanza kuhusu ugonjwa huu? Na ni kwa nini?

Saratani ilikuwa imefika kiwango gani lilipobainika?

Niambie kuhusu shughuli zilizokusaidia wakati wa utambuzi wa ugonjwa.

4. Ni zipi ulizopitia wakati wa utambuzi?
5. Unafikiria ni kwa nini wagonjwa wa saratani hutafuta matibabu kuchelewa?za kijamii

Peleleza:

Sababu za kijamii na kiuchumi (Umri, elimu, mapato)

Sababu za kibinafsi (sijui kwa kuenda, kutojali, hofu, uchumi, kupuuza ukali wa ugonjwa)

Sababu za kitamaduni (dawa za kiasili, Imani za jamii)

Miundo ya afya (upatikanaji, rufaa)

6. Ni mikakati ipi ungependekeza ili kuhakikisha kwamba saratani ya matiti inagunduliwa mapema?

Peleleza:

Kiwango cha kibinafsi

Kiwango cha kijamii

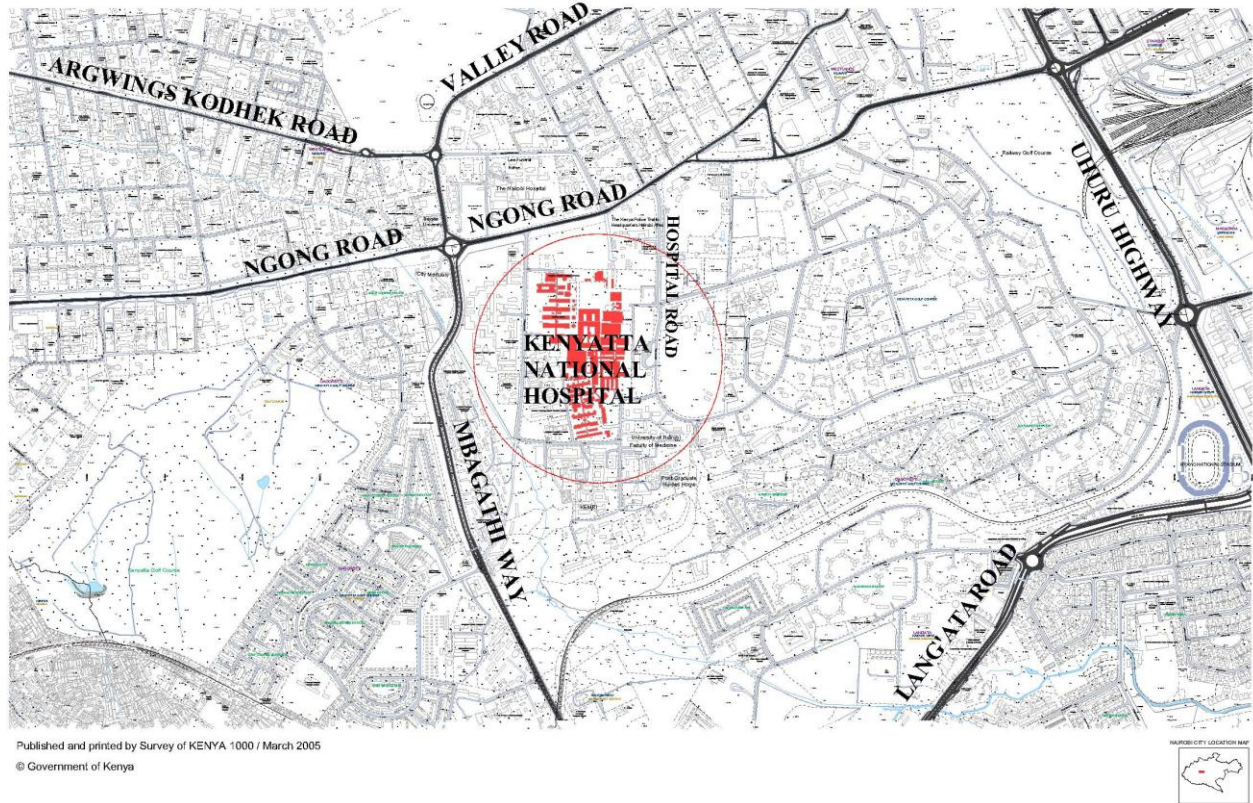
Vituo vya afya

Kiwango cha serikali.

7. Je una swali/maswali y/maswali yoyote/jambo ambalo ungependa kuongezea?

Asante sana kwa muda wako na kwa kukubali kutoa habari.Uwe na siku njema.

Appendix VIX: Map of the study area



Adapted from JICA maps (2015)

Originality Report

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- Word Count: 14209
- Submitted: 1

DELAYED HEALTH-SEEKING AMONG WOMEN
WITH ADVANCED BREAST CANCER AT THE
CANCER TREATMENT CENTRE AT KENYATTA
NATIONAL HOSPITAL By Joy Anyira

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Joy Anyira
21/12/20

[Signature] 1/12/2020