FACTORS CONTRIBUTING TO DELAY IN SEEKING REFERRAL TREATMENT AMONG BREAST CANCER PATIENTS AT OCEAN ROAD CANCER INSTITUTE AND MUHIMBILI NATIONAL HOSPITAL DAR ES SALAAM, TANZANIA

Angelina Mtowa

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By

ANGELINA MTOWA

A Dissertation Submitted in Partial fulfillment for Dissertations of the Requirement for the degree of Master of Public Health of the Muhimbili University of Health and Allied Sciences

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CERTIFICATION

The undersigned certify that they have read and hereby recommends for acceptance by the Muhimbili University of Health and Allied Sciences a dissertation entitled ***Factors Contributing to Delay in Seeking Referral Treatment among Breast Cancer Patients at Ocean Road Cancer Institute and Muhimbili National Hospital,*** in partial fulfillment of the requirements for the degree of Master of Public Health of Muhimbili University of health and Allied Sciences.

Signature: _____

Dr. Joyce Masalu

(Supervisor)

Date: _____

DECLARATION

AND

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I, Angelina Mtowa, declare that this **dissertation** is my own original work and that it has not been presented and will not be presented to any other university for a similar or any other degree awards.

Signature …… Date …….…….

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DEDICATION

This study is dedicated to my lovely parents, my father the late Mr. Charles Mtowa and my mother Mrs. Blandina Mtowa, my loving and generous husband Gwamaka Tuntufye and my beloved sons, Nelwike and Lugano.

ABSTRACT

Cancer is reported to be the second-leading cause of death and disability in the world. Breast cancer is the second leading cause of cancer mortality among women in Tanzania. Delay in seeking treatment contributes in breast cancer patients' presentation at the tertiary hospitals when cancer is at an advanced stage and leads to poor prognosis. The general objective of this study was to explore factors which contribute to delay in seeking referral for cancer treatment among breast cancer patients at the Ocean Road Cancer Institute and Muhimbili National Hospitals.

Methods: This was a cross sectional study, done at the two tertiary hospitals; Ocean Road Cancer Institute and Muhimbili National Hospital in Dar es Salaam. All 142 breast cancer patients who attended clinics at the tertiary hospitals during the study period were included. A questionnaire was used to interview the respondents. Delay was measured in terms of the time from the diagnosis to the time of seeking treatment at the tertiary hospitals. Cross tabulations were done and Chi-square was used to compare proportions with $p \leq 0.05$ considered to be significant, Tables were used to summarize the findings.

Results: In total, 142 study participants were included with a mean age was 53 years and 82% were married, 30 employed. About 41% of the study participants delayed for more than three months, 48% reported at the tertiary hospitals when cancer is at stage III. Main reasons for delay in seeking treatment were; cost (34%), distance to ORCI/MNH 15%, receiving treatment at the traditional healers (37%) and misinformation about treatment offered at ORCI/MNH (14%). Martital status were signigicantly associated with delay in seeking health care (**OR=0.35 and 95%CI (0.15 , 081**).

Conclusions: Cost, use of traditional healers and distance to tertiary hospitals were associated with breast cancer patient delay in seeking care. This study provides very imperative information which will assist the Ministry of Health and Social Welfare to design strategies that will enable breast cancer patients to present early for treatment after being diagnosed.

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LIST OF ABBREVIATIONS

HSSP III,	Health Sector Strategic Plan
LMIC	Low and Middle Income Countries
MDGs	Millenium Development Goals
MEWATA	Medical Women Association of Tanzania
NSGRP	National Strategy for Growth and Reduction of Poverty
MNH	Muhimbili National Hospital
ORCI	Ocean Road Cancer Institute
PACT	Programme of Action for Cancer Therapy

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OPERATIONAL DEFINITIONS OF TERMS

Attitude: Attitude has been defined by Ribeaux and Poppleton (1978) as "a learned predisposition to think, feel and act in a particular way towards a given object or class of objects"

Breast cancer - Breast cancer is a malignant tumor that starts in the cells of the breast. A malignant tumor is a group of cancer cells that can grow into (invade) surrounding tissues or spread (metastasize) to distant areas of the body. The disease occurs almost entirely in women, but men can get it, too

Cancer stage - is based on the primary tumor's size and whether it has spread to other areas of the body. A number of different staging systems are used to classify tumors. The TNM staging system assesses tumors in three ways: extent of the primary tumor (T), absence or presence of regional lymph node involvement (N), and absence or presence of distant metastases (M). Once the T, N, and M are determined, a stage of I, II, III, or IV is assigned, with stage I being early and stage IV being advanced disease.

Cancer Treatment aims to cure disease, prolong life, and improve the quality of remaining life after the diagnosis of cancer is confirmed by the appropriate available procedures. There are four standard methods of treatment for cancer: surgery, chemotherapy, radiation therapy, immunotherapy and biologic therapy.

Diagnosis - refers both to the process of attempting to determine or identify a possible disease or disorder (and diagnosis in this sense can also be termed (medical) diagnostic procedure), and to the opinion reached by this process (also being termed (medical) diagnostic opinion).

Knowledge: is a familiarity with someone or something, which can include information, facts, descriptions, and/or skills acquired through experience or education. It can refer to the theoretical or practical understanding of a subject. It can be implicit (as with practical skill or expertise) or explicit (as with the theoretical understanding of a subject); and it can be more or less formal or systematic.

Mortality - Mortality is the number of deaths within a specific population during a given period of time. Mortality is expressed either as the actual number of deaths within a given period or as a rate—per 100,000 persons per year. As a rate, mortality measures the average risk of dying of cancer. Mortality is the product of incidence of and fatality for a cancer.

Perception: is the process of attaining awareness or understanding of the environment by organizing and interpreting sensory information. And it is what our senses feed to our consciousness.

Referral – In medicine, referral is the transfer of care for a patient from one clinician to another. Tertiary care is usually done by referral from primary or secondary medical care personnel

Survival—Survival is the probability of surviving. It is typically stated as a rate over a particular period of time since diagnosis with cancer.

Tertiary care – is specialized consultative health care, usually for inpatients and on referral from a primary or secondary health professional, in a facility that has personnel and facilities for advanced medical investigation and treatment, such as a tertiary referral hospital

Treatment - Cancer treatment has three primary modes: surgery, chemotherapy and radiotherapy each mode may be used separately or in some combination, depending on the cancer type and stage.

Treatment delay - is the interval between first detection of symptom and first medical consultation. This is a period of more than three months (Kumari et al 2011).

CHAPTER ONE

1.0 INTRODUCTION

1.1: Background to the Problem

Cancer is a group of diseases characterized by uncontrolled growth and spread of abnormal cells (American Cancer Society, 2010). Cancer reported to be the second-leading cause of death and disability in the world (The Economist Intelligence Unit, 2009). According to Ferlay et al., 2008, it was estimated that about 12.7 million cancer cases and 7.6 million cancer deaths to have occurred in 2008. In developing countries 50% of cancer occurs in individuals less than 65 years of age (International Atomic Energy Agency, 2011). It was reported that more than 70% of cancers in developing countries are diagnosed too late for cure (PACT, 2008).

The most frequently diagnosed cancer is the Breast cancer and is the leading cause of cancer death among females, accounting for 23% of the total cancer cases and 14% of the cancer deaths (Jemal et al., 2011). In 2002, breast cancer was the second leading cause of cancer death in America, with more than 1 million new cases (Angulo et al., 2007).

Cancer incidence is at increase in developing countries (Global Health council, 2010), in 2008 it was estimated that 64% of the cancer deaths occurred in the developing countries. This increase is attributable to changes in risk factors include unsafe sex, lack of physical activity, unhealthy diet, obesity, contaminants, ultraviolet or ionizing radiation, occupational or environmental exposure, aging, ethnicity or race, heredity and infectious diseases (Higman, 2010). The study done by Rees et al., (2004) mentioned that 5–10% of breast cancer cases are caused by hereditary factors.

In 2008, out of 100,000 women 19.3 were diagnosed with breast cancer in eastern Africa, which includes Kenya and Tanzania (A World Cancer Research Fund, 2010). In Kenya,

cancer death accounts for the 7% of total national morality every year (Kenya Cancer Control Strategy 2011 – 2016)

In Tanzania, cancer is recognized as a serious health care problem (ORCI, 2008) and is one of the major causes of mortality, morbidity, and disease burden. Tanzania with a population of 42.5 million people, it was estimated that 21,000 new cancer cases occur each year (Ferlay et al., 2008), out of this only 10% of these new cases manage to get proper care and treatment (MEWATA, 2008). Breast cancer is an issue of public health concern in Tanzania (MEWATA, 2008; Timothy et al., 2010). It ranks third after cancer of the cervix and kaposis sarcoma and it accounts 9.3% of all cancers seen at Ocean Road Cancer Institute (ORCI). In years 1974-1987 breast cancer accounted for 8.1% of all female cancers in Tanzania and most of the patients were less than 30 years of age (Amir and Parkin, 1994). In each year, it is estimated that 2,500 women with breast cancer register as patients in hospitals in Tanzania (Komen, 2008). Out of them only 300 were able to receive treatment at ORCI. Patient delay is an important health problem in Tanzania (Montazeri, 2003). The study done by Burson et., (2010) in Tanzania showed that majority of cancer cases (90.73%) are diagnosed at advanced stage 3 and 4 cases.

The Ocean Road Cancer Institute (ORCI) and Muhimbili National Hospital (MNH) are the health facilities which receive cancer patients from all over Tanzania. Resources to manage this significant burden of cancer are limited. For example, nation-wide, there is 1 medical oncologist, 4 radiation oncologists, 2 physicists and 7 pathologists (Barton, 2006). From the Newly diagnosed cancer, Less than 10% of patients are able to go for treatment at ORCI, and of this population 80% arrive when the cancer is too far advanced to treat effectively (Walker, 2007). Poor accessibility of cancer patients to diagnosis and treatment facilities on cancer prognosis reported as barriers for many people to seek treatment (Sloan, and Gelband, 2006).Delay in diagnosis is a substantial problem for cancer patients in Tanzania and majority of them die during the first year after being diagnosed. The World Cancer

Report showed that late detection and treatment of cancer plays a more important cause of low cancer cure rates in Tanzania.

Appropriate cancer management which include diagnosis and treatment can extend the lives of many, particularly if diagnosed early (Kelly et al., 2010; Sloan, and Gelband, 2006). However, according to the International Network for Cancer Treatment and research (International Atomic Energy Agency, 2011) many poor cancer patients never reach a center capable of providing appropriate treatment or without even the comfort of palliative care.

The World Health Organization described the four principal approaches of cancer control to be cancer prevention, early detection, diagnosis/treatment and palliation. Delay in breast cancer is defined as patient delay between first detection of symptom and first medical consultation (Montazeri, 2003 and Arndt et al., 2001). In an ideal world, after being diagnosed people would start treatment within a month (Cancer Research UK, 2009). However, this is not feasible to many cancer patients due to economic, social and cultural factors associated with the disease. Delay for treatment can be due to patients' side or health care delivery system. In patient side, costs for treatment, stigma and other social factors surrounding the cancer myth might cause the delay while for health care delivery system in terms of care providers; waiting time for diagnosis for cancer, referral systems can be a lengthy process. About 60-80% cancer patients with advanced staged disease are often quoted for patients in Low and Middle Income Countries (LMIC) because of late diagnosis (Magrath, 2010). One-third of the cancer burden might be decreased if cases were detected and treated earlier (WHO, 2011).

Hence this study aims to explore factors which contributing to the delay of breast cancer patients to seek treatment at the tertiary hospitals after being diagnosed.

1.2 Statement of the Problem

In Tanzania breast cancer it is relatively characterized with the advanced stage at presentation (Magandi, 2009; Burson et al., 2010), 90.73% of cancer patients are diagnosed as advanced stage 3 and 4 also the Cancer registry data in Tanzania reveal a high prevalence of late-stage disease at treatment. Data from Population-based registry for Eastern Zone Tanzania revealed that about 9.0% had breast cancer (Mwaselage et al., 2009). Kangolle, (2010) reported that at ORCI there is not a day you cannot find a patient with advanced breast cancer. Each year, it is estimated that 2,500 women with breast cancer register as patients in hospitals in Tanzania (Komen, 2008). Out of them only 300 were able to receive treatment at ORCI. Patient delay is an important health problem (Montazeri, 2003), and 80% of those who come for treatment at ORCI and MNH arrived when the cancer is far advanced and incurable (Sloan, and Gelband, 2006). This means that majority of the patients treated at ORCI and MNH receive palliative treatments rather than curative treatments.

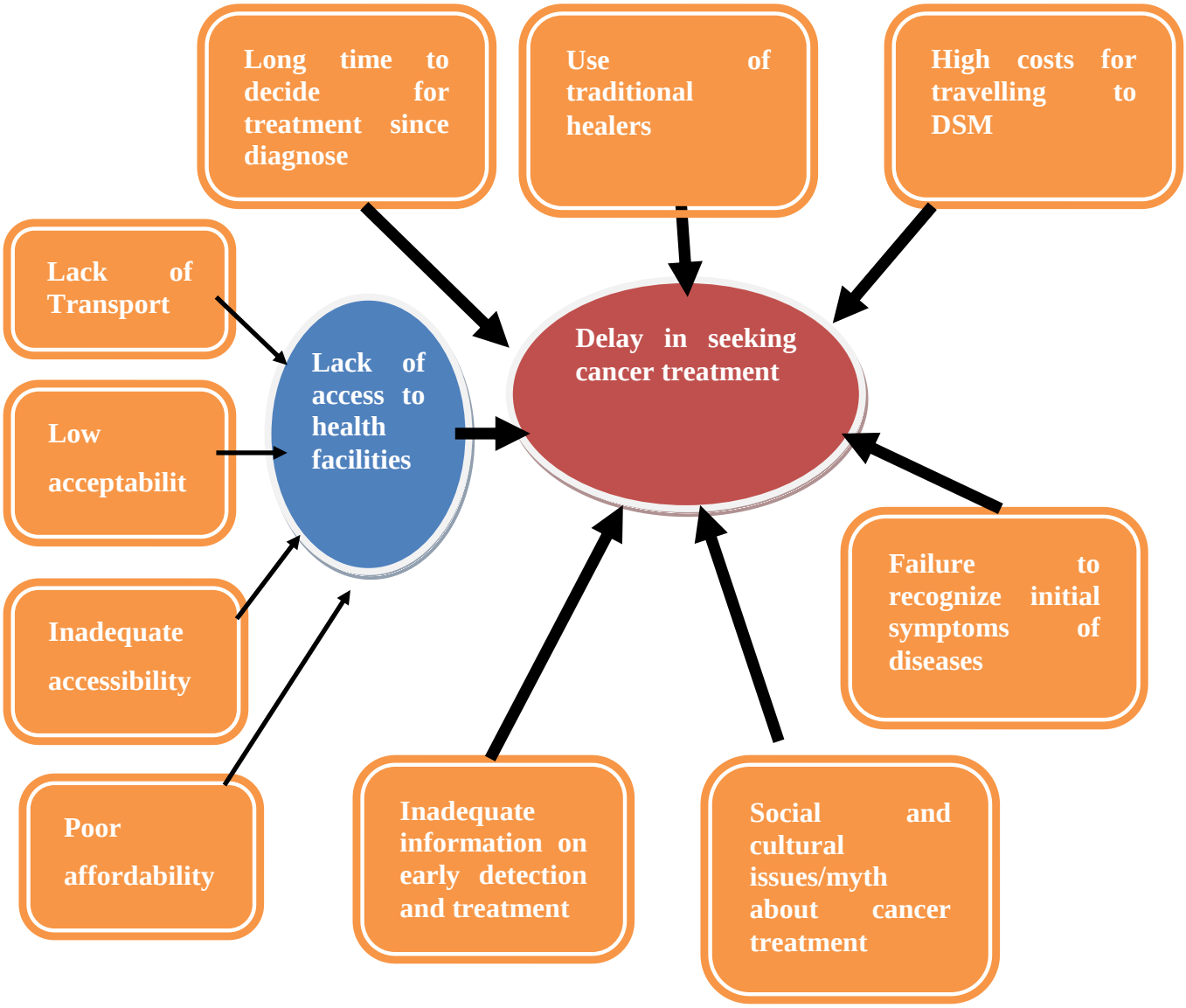
In Tanzania cancer treatment is only offered at the ORCI and Muhimbili National Hospital which are located in Dar es salaam, the capital and hence most of its patients come from different parts of the country after travelling long distances, thus, creates barriers to seek care in time. Health care costs, lack of information and lack of knowledge about prevention, diagnosis, and treatment create barriers for cancer patients to seek appropriate health care services in time. Social cultural issues also contribute to patients delay as they believe that they have been bewitched and hence resort to go to traditional healers because they are easily accessible and living in the same communities.

Various efforts have been taken to raise awareness on early diagnosis and early treatment of breast cancer by the Government, Non Governmental Organization (NGO) and other health implementers using various strategies which include dissemination of information about the breast cancer disease using radio programs, television, newspapers and posters. All these

initiatives have produced little impact in the community as patients continue reporting late at the tertiary hospital for treatment. Factors contributing to late reporting of patients with breast cancer for treatment at Ocean Road Cancer Institute are not clearly known.

1.3 Conceptual Framework

The conceptual framework below shows the various factors that will be conceptualized to independently affect the delay in seeking breast cancer treatment after diagnosis. These factors were categorized into socio-economical, Infrastructural and cultural factors.



1.4: Rationale of the Study

The results obtained will help in informing and promoting optimal early diagnosis and treatment among the breast cancer patients in Tanzania. It will generate insight that can assist programmes in developing effective strategies for addressing the challenges that hinder the early detection and treatment of breast cancer as well as inform future health care policy and practice that will increase the early diagnosis and optimal utilization of ORCI and MNH facilities. This study will generate general understanding of the factors associated with the delay for seeking cancer treatment which is important in order to increase overall cancer survival rate among the breast cancer patients. This study will be of value to public health professional, physicians and other health care providers as it will identify knowledge and perception towards occurrence, symptoms, risks, survival, transmission and treatment of breast cancer. Also the study will support the global and national efforts aiming at reducing premature deaths among the Tanzanians as it is stipulated in HSSP III, MDG number six and MKUKUTA.

1.5 Research Questions

What are the factors associated with the delay of seeking cancer treatment among breast cancer patients receiving treatment at the tertiary hospitals.

1.5.1 Subset of Research Questions:

- What are the reasons that make breast cancer patients delay to come for treatment?
- What proportions of the breast cancer patients come for treatment within one to three months after being diagnosed?
- What was the stage of cancer of breast cancer patients when reported at the tertiary hospitals?
- What is the knowledge of breast cancer patients on the symptoms of breast cancer?

- What are the perception of breast cancer patients on the prevention, diagnosis and treatment of breast cancer?

1.6 The Objectives of the Study

1.6.1 Broad Objective;

To explore factors associated with delay in seeking referral for cancer treatment among breast cancer patients at the Ocean Road Cancer Institute and Muhimbili National Hospitals

1.6.2 Specific Objectives;

1. To Identify the main reasons for delay in seeking health care among breast cancer patients
2. To determine the proportion of breast cancer patients who present at ORCI and MNH more than three month after diagnosis.
3. To determine the stage when the breast cancer patients come for treatment at ORCI and MNH
4. To assess knowledge of the breast cancer patients towards breast cancer prevention, diagnosis and treatment
5. To assess the perception of the breast cancer patients towards breast cancer prevention, diagnosis and treatment

CHAPTER TWO

2.0 LITERATURE REVIEW

2.1 Introduction

This chapter reviews various empirical studies and literatures on breast cancer especially those focusing on factors contributing to delay in seeking breast cancer treatment. This chapter will also explore on different literatures on cancer stages of patients at presentation for treatment. Other literatures will focus on the knowledge and perception of people on breast cancer prevention, diagnosis and treatment.

In recent years the burden of non-communicable diseases experienced in the low- and middle-income countries are on the increase (Ferlay et al., 2008). Despite the fact that cancer is not recognized as a high-priority health problem in most of the low- and middle-income countries (LMICs), about 5 million people die from cancer each year and 10 percent of the 50 million deaths occurred in those countries (Sloan et al., 2006). According to the most recent edition of the World Health Organization's (WHO, 2011) World Cancer Report, in the last thirty years the global cancer burden doubled and is estimated to double again between 2000 and 2020 and nearly triple by 2030).

The adoption of Western lifestyles and behaviours are among the many factors associated with the rising burden of cancer in the developing world, including increased tobacco consumption, higher-fat and lower-fiber diets, and reduced physical activity (The Economist Intelligence Unit, 2009). Cancer incidence is on the increase in developing countries (Global Health council, 2010) and the increase is attributable to changes in risk factors include lack of physical activity, unhealthy diet, obesity, contaminants, ultraviolet or ionizing radiation, occupational or environmental exposure, aging, ethnicity or race, heredity and infectious diseases (Higman, 2010). According to WHO (2011), tobacco use is reported as one of the major risk factors for cancer, as well as harmful alcohol use, poor diet and physical inactivity.

2.2 Factors Affecting Cancer Patients' Delay in Seeking Cancer Treatment at the Health Facilities:

Delay in diagnosis is one known reason for delayed seeking of cancer treatment, and may be due to either patient or health provider related factors. Some of these factors include socioeconomic, socio-cultural, demographic, infrastructure, Knowledge, attitudes and beliefs, access, time and cancer stage (Samur et al., 2002).

2.2.1 Social-economic Factors

Globally in 2008, the economic loss resulting from disability or death from cancer was estimated to be US$895 billion (Magrath, 2010). Worldwide cancer prevention programmes are implemented with varying effectiveness this is because of early detection and uneven distribution of resources (The Economist Intelligence Unit, 2009). Poverty continues to be linked to cancer, especially in the developing world and it has led to less cancer control, prevention and detection interventions to be established. The evidence shows that only 5% of global resources for cancer are spent in the developing world (WHO, 2002).

In a study done by Kimlin et al., 2010 for multiethnic groups revealed that therapeutic care, income, education, and ethnicity were mentioned as the significantly factors related to treatment delays for breast cancer survivors. In Uganda women have no control of their health care hence increased burden of the socioeconomic distress in the country (Cox, 2010).

Socioeconomic factors are among the factors that hinder or create barriers for utilization of cancer treatment at ORCI for most of the patients (The International Network for Cancer Treatment and Research, 2006). Travel distance for cancer patients (men, women, boys and

girls) from various regions in Tanzania to Dar es Salaam is long hence very costly for the majority of Tanzanians. Poverty, the bureaucracy of referral system, myths and misconceptions have led to cancer patients' presentation to health facilities at advanced stages of the disease (Magandi, 2009; The International Network for Cancer Treatment and Research, 2008).

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The socio-demographic factors such as age, education, marital status, economic status, history of breast disease, family history of breast cancer, the nature of the first symptom and many other factors are related to delay and late stage at diagnosis of breast cancer (Montazeri, 2003; Wright et al., 2010). Likewise, racial differences, location and the time period in which the diagnosis contributes to delay in seeking treatment (Gwyn et al., 2004).

2.2.2 Cultural and Infrastructure Factors

It is reported that inadequate health systems infrastructure, scarcity of necessary specialized skills, high diagnostic and treatment costs resulting inability to provide treatment regimens and follow-up care, as necessary (Axios, 2009).

Other studies indicated that lack of more accessible medical service and screening programs result into delay in seeking medical services (Rambau et al., 2011) hence many die at home with or without a diagnosis. Other reasons may keep people from being treated at a hospital like travelling to another place (e.g., an ancestral area) when they are sick (Sloan, and Gelband, 2006).

Also cancer is among the diseases that are stigmatized in many cultures, and patients may be rejected, even after cure (Sloan, and Gelband, 2006). The treatment for cancer also alters the body in visible ways; such as disfigurement caused by removal of affected body parts and infertility which may affect one's social interaction (Hanna et al., 2010). Culture may result into many cancer patients to consult a traditional healer and hence delaying formal

medical care until a cancer is far advanced. It is reported that in male-dominated societies, women may fear that they would lose their husband if they lost their breast (Yip et al., 2008)

It was noted by Rajaram and Rashidi (1999) that negative socio cultural perception of breast cancer, strong beliefs in traditional medicine and perhaps strong religious beliefs in developing countries were the main reasons for the delay in presentation.

Absence of cancer treatment infrastructures in other regions of Tanzania and shortage of trained oncologists in Tanzania contributes to low utilization of the ORCI facility (Sloan, and Gelband, 2006). The Ocean Road Cancer Institute (ORCI) and Muhimbili National Hospital (MNH) are the health facilities which receive cancer patients from all over Tanzania. Resources to manage this significant burden of cancer are limited. For example, nation-wide, there is 1 medical oncologist, 4 radiation oncologists, 2 physicists and 7 pathologists (Barton, 2006).

2.2.3 Access to Health Facilities and Services

Worldwide access to healthcare is considered basic human rights (The Economist Intelligence Unit, 2009). Also limited access to services is reported in developing countries (Timothy et al., 2010). Less than 25% of cancer patients in low income countries have access to radiation therapy, compared to more than 50% in high income countries (PACT, 2008). Study done by Porter, (2005) highlighted that barriers in access to care may delay diagnosis and/or treatment

The low status of women and poverty identified to be among the imposing challenges for women to seek health care (Cox, 2010). The study done in Hong Kong showed that inadequate access to public health care was an important contributing factor for delay (Yau et al., 2010).

According to the atomic energy agency, (2006), services for cancer diagnosis and clinical management are limited worldwide with approximately 5,000 functional cancer care centers. In Low and middle income countries (LMIC) another serious problem of human resource for health shortage hampers the access to cancer services.

ORCI and MNH benefit most of the patients who reside in Dar Es Salaam Township however those from rural areas and in the other regions cannot access these services easily (Mwaiselage, 2010, Denny et al., 2006).

2.3 Cancer Diagnosis and Delay for Treatment

Delay for treatment has been categorized as patient delay (that is the time from the first symptom until the time of presentation to the physician) or physician delay (that is time from the time of entry into the medical system until the time of treatment) (Burgess et al., 1998, and Afzelius et al., 1994). There is no significant time set for breast cancer patient to seeking treatment after diagnosis; however, several studies have recommended that treatment delays greater than 90 days may be associated with stage migration (Wright et al., 2010).

The International Network for Cancer Treatment and Research, (2011) reported that in low and middle income countries, approximately 72% of cancer deaths occurred in 2008 because of delays in diagnosis and presentation with advanced disease. It was estimated by Farmer et al., (2010) that every year in low-income and middle income countries about 4 million deaths from cancer can be averted through early detection and treatment. Delay in the treatment of breast cancer lowers the effectiveness of most treatments and considerable increase in the breast carcinoma death rate (James, 2010).

It was reported by Yau et al., (2010) that delay in presentation of cancer patients has a significant economic impact than treating patients with early-stage disease. (The principal

goal of physicians dealing with breast cancer is early diagnosis and prompts treatment (Samur et al. 2002). The earlier a cancer is diagnosed and treated the better the chance of it being cured (Wax, 2010, Angulo, 2007, Jamel et al., 2011). Late diagnosis and treatment contribute to low survival rate among cancer patients (IMA World Health, 2009; Cancer Health Center, 2010; Yip et al., 2008). Norsa'adah et al., (2011) reported that late stage presentation can result in ineffective curative efforts, which then contributes to a community perception that cancer is untreatable, and can lead to a vicious cycle of late presentation, high mortality rates, and distrust of orthodox medical establishments, which are then only utilized as a last resort. The Health Services Research, (2007) mentioned the association of treatment delay and reduced breast cancer survival. However, early signs are often missed by local village doctors, who can make incorrect diagnoses and are themselves usually not aware about early warning signs of cancer hence cannot inform the public of the same (Khimji, 2011).

Hanna et al., (2010) mentioned that there is very low awareness and knowledge of risk factors, symptoms or signs of breast cancer which contribute to delay for early diagnosis and treatment. Study done by Norsa'adah et al., (2011) for Malaysian women indicated that 43.3% delayed the consultation by more than 3 months. Also in Iran, widowed and divorced women reported to have a higher risk of delay (Montezeri et al., 2003)

In Tanzania, delay in diagnosis is a substantial problem for cancer patients and majority of them die during the first year after being diagnosed. In the country as whole, about 95% of cancer patients die at home and about 5% in hospital (WHO, 2002).

According to a study of breast cancer done by Urasa et al., (2011) in Tanzania, breast cancer treatment is dependent on the stage of the disease, age and medical state of the patient, tumor characteristics, patients' preferences and resources within the health sector of each country.

2.4. Cancer Stage and Timing for Seeking Health care

Cancer Stage is usually expressed as a number on a scale of 0 through IV — with stage 0 describing non-invasive cancers that remain within their original location and stage IV describing invasive cancers that have spread outside the breast to other parts of the body (Breast cancer organization 2012). Also stages of cancer have been categorized into two groups, Early Stage (I & II) and Late Stage (III & IV).

The clinical stage of the disease at presentation has been found to be important for the outcome of the patient with breast cancer (Parkin et al., 2002; Amir et al., 1996) and most of the young age patients present at an advanced stage.

Cancer diagnosis can be a lengthy process (Cancer Research UK, 2009). The cancer patients have to wait to have tests or to get the results and sometimes patients have to wait for appointments to begin their treatment. Others cancer patients are diagnosed only when their cancer is advanced such that curative therapy is no longer an option, or would be costly and of low efficacy but high toxicity. In Uganda, it was reported that 95% of the breast cancer patients presented at the hospitals when the cancer is at advanced stage hence resulted into increase in mortality rate (Im, 2011).

In Tanzania, 90.73% of breast cancer patients presented at the tertiary hospitals when the cancer is at advance stage and hence they receive palliative care only (MEWATA, 2008, Burson et al., 2010). It was reported that at ORCI about 80% of those who come for treatment they arrived when the cancer is at advance stage and incurable (Sloan and Gelband, 2006).

2.5 Knowledge and Beliefs toward Cancer Diagnosis and Treatment

Health beliefs and knowledge of breast cancer were mentioned by Nosarti et al., (2000) as the two important factors that influence health seeking behavior among breast cancer patients. The likelihood of patient delay has shown to be related more to behavioral factors and knowledge which are in turn linked with advanced breast cancer at diagnosis (Facione et al., 2002). It is reported by Magrath, (2010) that an unknown number of patients in LMIC with overt cancer remain undiagnosed and untreated for various reasons ranging from wrong beliefs about the causes of cancer (e.g., evil spirits) and consequent stigmata, especially with genital cancers, to fear of cities where treatment facilities are located, ignorance, poverty or wrong advice for example from traditional healers or local health workers.

Lack of knowledge about breast cancer was mentioned as an important factor delay in Iran (Montezeri et al., 2003). The study done on women's knowledge and belief on breast cancer revealed that majority of the study participants identified a painless breast lump as a symptom of breast cancer (Grunfed et al., 2002; Krombein and De Villiers, 2006). A study done in Nigeria population on cancer knowledge showed that 68% didn't know that breast lump was a warning sign of cancer (Oluwatosin, and Oladepo, 2006).

Cancer incidence and deaths may be related to silence and misinformation (The Economist Intelligence Unit, 2009). Illiteracy and a general lack of understanding alienate people from seeking treatment in the first place, and from completing treatment and follow-up (Cancer Health Center, 2010). Low awareness of the importance of screening, early detection, financial barriers, stigma associated with cancer and poverty reported to prevent many people from seeking preventive services or care at early stages (Farmer et al., 2010; Jones et al., 2010). Also the study done in Iran, revealed that Seventy-five percent of the women had knowledge on breast cancer, however only 27% knew that breast pain is not a symptom of breast cancer (Parsaa and Kandiahb, 2005). The study done by Hadi et al., (2010) among

women on various ethnic groups reported that in 3 knowledge domains, namely; general knowledge, breast cancer risk factors, symptoms and screening tests, the Indians had significantly less knowledge.

Ignorance about breast cancer, fear of mastectomy, use herbal treatment, attendance to prayer- camps, financial incapability and perceived hastening of death were reported as among the commonest causes of delay for breast cancer patients in Ghana (Lamptey et al., 2009). Other factors for delay for presentation at health facilities for treatment mentioned by Harrison et al., (2010) were low awareness levels of the breast cancer patients in Southern India and nonexistent screening practices. Moreover; shyness is another cause of delay in seeking treatment among breast cancer cases (Basu et al., 2010). The study done by Bish et al., (2005) indicated that Knowledge concerning the variation of symptoms in breast cancer enables patients to interpret the symptoms correctly and influences their assessment of symptoms as well as their decision to seek medical attention.

It was reported by Norsa'adah et al., (2011) that Perception of the seriousness of a symptom of breast cancer is dependent upon the first symptom and how fast the symptom changes and multiplies.

In Tanzania, a study done for women in Rombo by Vallentine, (2007), reported that there were no association between occupation and knowledge towards breast cancer. Also their knowledge towards breast cancer was little. Furthermore, lack of knowledge about the signs and symptoms of cancer accelerated the delay of seeking treatments for many cancer patients in Tanzania (Kazaura et al., 2007).

CHAPTER THREE

3.0 METHODOLOGY

3.1 Introduction

This chapter elucidates how data were collected using a well developed data collection tools. In general the chapter focuses on the study area, research design, research variables, study population, sample size and sampling procedure, data collection tools, inclusion and exclusion criteria, research assistants, instrument pretesting, ethical consideration, data processing and analysis and study limitation, etc.

3.2 The Study Area

This study was conducted at the Ocean Road Cancer Institute and Muhimbili National Hospital in Dar es Salaam. These hospitals were selected due to the facts that they are the only hospital which provides cancer treatment in Tanzania. The ORCI provides cancer diagnosis, chemotherapy and radiation treatment and MNH does histopathology and surgery for cancer.

3.3 Research Design

This was analytical cross-sectional study design conducted at the ORCI hospital and MNH (December 2011 to April 2012).

3.4 Study Variables

3.4.1 Dependent Variable;

The dependent variable for this study was the time taken before seeking treatment at the tertiary hospitals after diagnosis and given referrals in peripheral centers.

3.4.2 Independent Variables

The independent variables for this study were;

- Main reasons for delay in seeking health care (cultural, access, costs, distance, misinformation, affordability, accessibility, transport, referral system)
- Factors associated with delay for seeking referral treatment (age, education, marital status, occupation and cancer stage)
- Stage of cancer at presentation (I, II, II or IV)
- Patients cancer knowledge toward breast cancer prevention, diagnosis and treatment and
- Perception toward breast cancer prevention, diagnosis and treatment

3.5 The study population

The study population involved breast cancer patients who were receiving either in-patient or out-patient services at the only specialized cancer management facilities in the country which are ORCI and MNH.

3.6 Sampling Procedure and Sample Size

3.6.1 Sample Size Estimation

The minimum sample size n was obtained using the formula developed by Cochran (year 2006) was used in populations that are large:

$$n = \frac{Z^2P\ (100-P)}{\varepsilon^2}$$

Where:

P = Proportion of breast cancer patients, P = 42.5%, calculated from a proportion of breast cancer patients delayed for more than three months in a study done by Harirchi et al., (2005) in Iran

E= margin of error set at 5%

Z= standard normal deviate set at 1.96 for 95% confidence level

n= Population size = 162

According to the statistics of ORCI, in a month about 25 – 40 breast cancer patients are seen, hence a convenient sampling method was used to enroll breast cancer patients. Using Epi-info version 6 software, the sample size was calculated from a proportional of 42.5%, breast cancer patients who delayed seeking health care. Hence, because of short duration of research and availability of breast cancer patients at ORCI and MNH, all breast cancer patients (new and those attending clinic) in a four months of the study were involved and were able to reach a total of 142 breast cancer patients.

3.6.2 Sampling Techniques

The convenient sampling technique was chosen because at these tertiary hospitals only 25 – 40 breast cancer patients are seen in a month and also the time for the study was only four months to reach a total of 162 study participants. Consent for participation in the study for breast cancer patients was sought verbally or written. A total of 142 study participants were interviewed and those delayed in seeking health care were asked for the reasons for delay in seeking treatment at the tertiary hospital.

3.6 Data Collection Techniques and Tools

Data were collected by using the administered questionnaires. The questionnaire comprised of four parts which contained 40 questions. The first part consisted questions which covered demographic information, the second part contained breast cancer information of

the study participants include their cancer stages at arrival at the tertiary hospitals. The third part contained ten questions which assessed the knowledge of the study participants towards breast cancer prevention and treatment, the fourth part contained questions which assessed the perception of the study participants towards breast cancer prevention and treatment. The last part contained questions on factors contributing to delay in seeking referral treatment at tertiary hospitals. The data collection tool was translated in from English to Swahili languages then English.

3.7 Pre – testing of the Tool

To ensure the validity (if the tool collect the information we need) and reliability (if the tool collect the data in a precise way); the pretest of the tool was carried out by interviewing 5 (five) breast cancer patients attending clinic at Mama Ngoma Hospital in Mwenge Dar es salaam. Then the tool was refined incorporated the challenges/issues observed during pre-testing.

3.8 Inclusion Criteria

The eligibility criteria for the study includes; breast cancer patients aged 18 – 80 years who were receiving treatment at ORCI and MNH (radiation, chemotherapy, surgery and those attending clinics) during the research period.

3.9 Exclusion Criteria

Breast cancer patient who is not willing to participate in the study or tired in the middle of the interview. Also exclusion criteria involve men with breast cancer and other breast cancer patients who were attending treatment in other health facilities apart from ORCI and MNH.

3.10 Ethical Consideration

Ethical clearance obtained from Muhimbili University of Health and Allied Sciences Research and Publication Ethical Committee. The investigator sought permission from the management of the MNH and ORC before the study. Informed consent (verbal/written) from study participants obtained (appendix 1). Study objectives, methodology and benefits were explained to those who agreed to participate. Participants were assured of confidentiality by assigning them with numbers instead of names. Only those who consented were interviewed, and were free to withdraw from the study at any point in time. Two research assistants with background in social sciences were selected, trained for one day to acquaint with the data collection tool.

3.11 Data Procedure and Analysis

The breast cancer patients attending treatment at ORCI and MNH were recruited from December 2011 – April 2012, after obtaining written or oral informed consent from the study participants, a face-to-face structured interview was carried-out. The study participants were asked to recall the month and year of their first medical consultation due to breast cancer, the cancer stage of the patient on arrival were retrieved by the support of the doctors and nurses at ORCI and MNH. The Reasons for delay were asked for patients that had reported at MNH at ORCI more than three months after diagnosis.

Data cleaning was done at the end of each day, the questionnaires were given numbers for identification, data were entered into the EPI Data and analysed using STATA. Collected information was edited during and after collection, coded (sex, place of diagnosed, marital status, occupation, education, cancer stage, knowledge, perception and factors contributing to delay for treatment). Data were tabulated and then analyzed. Descriptive statistics were used to provide information on measure of central tendencies for the data. Frequency distribution tables and computation of proportions in percentage was used in analyzing the

socio demographic (categories) variables and main reasons for delay in seeking health care. Univariate and multivariate analysis were performed to calculate odds ratios (OR). Age, marital status, educational level, occupation and stage of cancer have been selected as potential explanatory factors contributing to delay in seeking health care. Strength of association was measured using P value and 95% confidence intervals. The cross tabulation was done for cancer stage and patient delay in seeking health care at ORCI and MNH.

Ordinal measurements scale was used to measure Knowledge (YES, NO and I don't know) and racket scale was used to measure the perception (Agree, Disagree, neutral and I don't know). The various aspects of breast cancer facts (occurrence, symptoms, survival, transmission and treatment) were scored one for each correct answer and added together to determine respondents' level of knowledge. The participants scored were grouped into three groups; good knowledge (scored 8 – 13 marks), fair knowledge (5 – 7 marks) and poor knowledge (0 – 4 marks).

Duration before receiving treatment was measured by dichotomous scale (less than three month and more than three month). In this study, patient delay was defined as the delay to seek for treatment after diagnosed for more than three months. Cancer stage was measured by ordinal scale (0, I, II, II IV).

The main reasons for causing delay that were measured; Cost for treatment (medicine, consultation, transport, food) and distance from a place of living to ORCI/MNH. Affordability of breast cancer patients to receive treatment at ORCI/MNH, cultural and traditional factors e.g. seeking treatment at the traditional healers, distance from diagnostic place to ORCI/MNH and Referral system from the health facility to ORCI/MNH.

3.13 Dissemination of Results

The study report is intended to be submitted to Muhimbili University of Health and Allied Sciences (MUHAS) as partial fulfilment of Master of Public Health. It is also planned to be submitted to the Ministry of Health and Social Welfare (MoHSW) as policy enforcers. Also the report will be disseminated to different stakeholders working in the health sectors as well as the community.

3.14 Limitation of the Study

The limitations of this study were;

- The study population was of the sick patients who some of them could not respond to the all questions or getting tired of long many questions led to exclude them in the study
- The strike of the health workers in April 2012 resulted to delay to reach the intended study participants in time.
- This study done on the patients who were attending at tertiary hospital, hence might not representing the Tanzanian women at large
- Some patients were diagnosed long time ago hence the possibility of recall bias, as most of the variables relied upon information given by patients

CHAPTER FOUR

4.0 RESULTS

4.1 Introduction

This chapter provides a detailed analysis of the data collected from the ORCI and MNH. It starts by analyzing data according to the research questions which guided this study. A mixture of analytical tests was used at various stages of data analysis.

4.2 Socio Demographic Characteristics

This study recruited 143 study participants (1 man and 142 women) 24 from MNH and 118 from ORCI; one man was recruited to show that breast cancer is not only the problem of women. However, in analysis only data for 142 women were used. Their mean age was 53 years and 62% were married, 21% employed. About 16% of the study participants were literate, 29% having completed at least a primary education. Among them 61% lived in urban area, 59 were Christians and 41 were Muslims and 91% had children (see table 1).

Table 1: Socio Demographic Characteristics of the Study Participants

Variables	Frequency	%
Marital status		
Single	7	5
Currently married	87	62
Living with partner/significant other	18	13
Widowed	23	16

Separated	3	2
Divorced	3	2
Total	**142**	**100**
Place of living at young stage		
Urban area	86	61
Rural area	56	39
Total	**142**	**100**
Religion		
Christian	83	58
Muslim	59	42
Total	**142**	**100**
Having children		
YES	129	92
NO	13	9
Total	**142**	**100**
Education achievement		
No formal education	31	22
Incomplete primary education	42	30
Complete primary education	46	32
Secondary and above	23	16
Total	**142**	**100**
Occupation		
Employed	30	21
Business Person	32	23
Peasant	47	33
Not employed	33	23
Total	**142**	**100**

4.3 Places of Diagnosis among Breast Cancer Patients Attending Treatment at Ocean Road Cancer Institute and Muhimbili National Hospital

The breast cancer reported various health facilities where they were diagnosed with the disease, however, Majority of the study participants 54% were diagnosed at the regional hospitals and 27% at the tertiary hospitals (table 2).

Table 2: Distribution of Patients According to Places Where Cancer Was Diagnosed

Place of diagnosed	**n**	**%**
Dispensary	4	4
Health Center	11	8
District hospital	10	7
Regional hospital	77	54
Other (MNH, Bugando)	40	27
Total	**142**	**100**

4.4 Main Reasons for Delay in Seeking Health Care at Ocean Road Cancer Institute and Muhimbili National Hospital

The breast cancer patients who delayed seeking treatment for more than three month were 41% of the study participants. Then those who delayed in seeking treatment for more than three months, were asked for the reasons for their delay for seeking health care after being diagonised with breast cancer (table 3). Among them, 34% said cost of treatment, 15% said distance to ORCI/MNH, 37% said they were receiving treatment at the traditional healers and 14% said misinformation about treatment offered at ORCI/MNH.

Table 3: **Main Reasons for Patient Delay Seeking Treatment at Ocean Road Cancer Institute and Muhimbili National Hospital**

Main reasons for delay	**Patient delay > 3 months**	
	n	**%**
Cost	20	34
Distance	9	15
Receiving treatment at the traditional healer	22	37
Misinformation about treatment offered at ORCI and MNH	8	14
Total	59	100

4.5 Cancer Stage of Beast Patients at Presentation at ORCI and MNH

Figure 1 below shows the cancer stages and ages ranges of the breast cancer patients when reported at the tertiary hospitals. About 69% and 46% of breast cancer patients with the age range of 50 – 69 reported at the tertiary hospitals when the cancer is at stage I and II respectively. Also about 59% and 43% of breast cancer patients reported when cancer is at stage III and IV respectively.

The highest proportional of breast cancer patients with age group ranged 50 – 69 presented when breast cancer stage is at advanced stage however; statistically cancer stages were not significantly associated with age of the breast cancer patient. (X^2 P = 0.316).

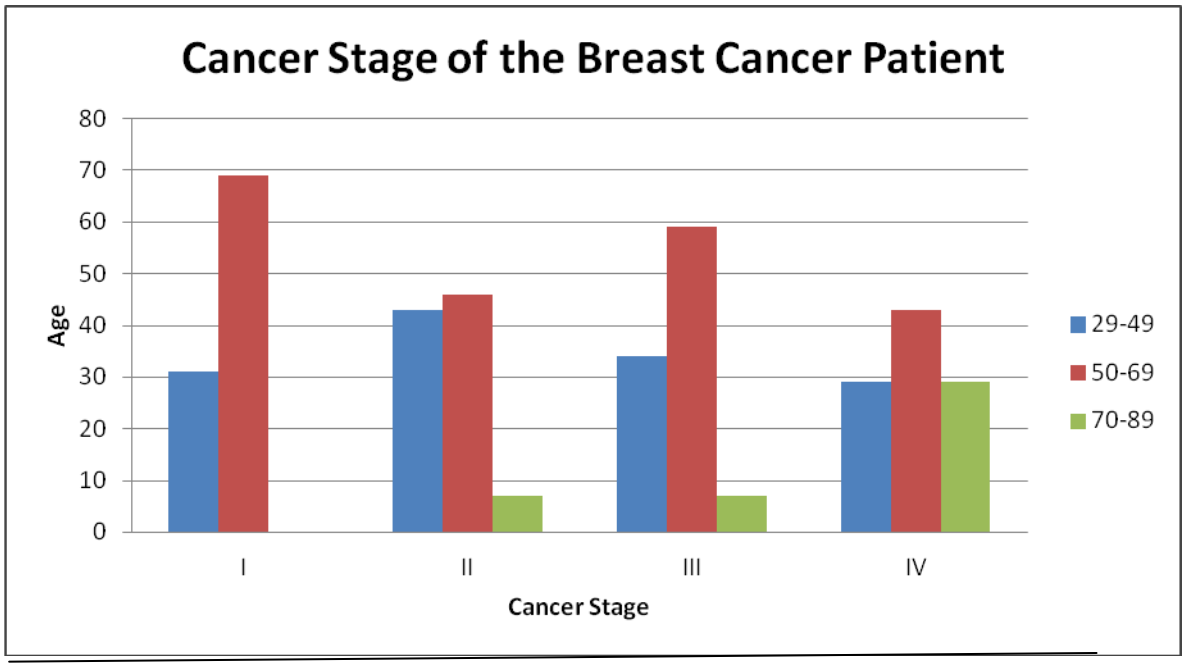


Fig. 1: cancer stage of the study participants when reported at the tertiary hospitals

4.6 Factors Contributing to Delay in Seeking Treatment

Univariate and multivariate analysis were done on socio demographic varibles for the patients who delayed in seeking treatment at ORCI and MNH.

Table 4 below showed that the marital status variable as stasticaly associated with patient delay OR = **0.34 95% CI (0 .16, 0 .75)**. Other factors such as age, education level and occupation were not statistically significant associated with treatment delay, however results reveal and increased odds of treatment delay for businesswomen and those who were not employed as compared to employed women.

Table 4: Results for Univarite Analysis on Factors Contributing to Delay in Seeking Treatment among Breast Cancer Patients

Factor/Characteristics	Univariate Analysis
	OR (95% CI)
Age groups	
(<50)	1
50-65	0.71 (0.34 , 1.48)
>65	0.98 (0.35 , 2.82)
Education level	
(No education)	1
At least Primary	0.67 (0.29 , 1.53)
Secondary and above	0.37 (0.12 , 1.21)
Marital Status	
(Single/living alone)	1
Currently married/living in union	**0.34(0 .16 , 0 .75)**
Cancer stage	
(Stage I)	1
Stage II	0.29(0.08 , 1.01)
Stage III	0.44(0.13 , 1.48)
Stage IV	0 .25(0.03 , 1.82)
Occupation	
(Employed)	1
Business person	1.97(0 .65 , 5.97)
Peasant/Not employed	2.69 (1.03 , 6.98)

Multivariate comparison (table 5) also indicated that the marital status were significant associated with treatment delay that women who were married or living in union were less likely to delay in seeking cancer treatment compared to those who were single or living alone (OR=0.35 and 95% CI (0.15 , 081).

In addition to that, the findings also indicated that women who went up to primary education , secondary level and above were less likely to delay treatment that those who doesn't have any formal education. The study also suggest an association between delay in seeking treatment with higher level of cancer stages, however the association were not significant at 0.05.

Table 5: Results for Multivariate Analysis on Factors Contributing to Delay in Seeking Treatment among Breast Cancer Patients

Factor/characteristics	**Multivariate Analysis** **OR(95% CI)**
Age groups	
(<50)	1
50-65	0.48(0.21 , 1.12)
>65	0.70(0.21 , 2.34)
Marital Status	
(Single/living alone)	1
Currently married/living in union	**0.35(0.15 , 081)**
Cancer stage	
(Stage I)	1
Stage II	0.25 (0.06 , 0.98)
Stage III	0.40 (0.10 , 0.35)
Stage IV	0.16 (0.02 , 1.49)
Occupation	
(Employed)	1
Business person	2.77(0.82 , 9.33)
Peasant/Not employed	3.19 1.08 , 9.39)

Cross tabulation was done on cancer stages and the study participants reported at the tertiary hospitals in less than three months and those who reported at the tertiary hospitals in more than three months (table 6). The results showed that patients delay was not statistically associated with the cancer stage, $X^2 = 0.743$.

Table 6: Comparison between Delay in Seeking Health Care and Cancer Stages

	<3 months	**> 3 months**	**Total**
	No. (%)	**No. (%)**	
Stage of Cancer			
I and II	42(62.7)	25(37.3)	67
III and IV	45(60)	30(40)	75
Total	87(61.3)	55(38.7)	142

$X^2 = 0.743$

4.7 Knowledge of Study Participants on Breast Cancer Occurrence, Examination Methods, Treatment and Transmission.

Knowledge of the study participants towards breast cancer occurrence, examination methods, treatment and transmission were assessed as shown in table 7 below.

4.7.1 Breast Cancer Occurrence

Less than half of the of the study participants (38%) reported correctly that breast cancer does not commonly occur in the old people, 88% said that breast cancer is the most common cancer for women and 78% reported correctly that breast cancer presents as a painless breast lump, 30 % of the study participants reported that breast cancer can be inherited.

4.7.2 Breast Cancer Examination Methods

Among the study participants, 89% said that breast self examinations were the methods of early detection of the breast cancer and 89% reported correctly that early diagnosis improves outcome of treatment. Of the study participants, 93% reported that routine examination of breast cancer is necessary.

4.7.3 Treatment of Breast Cancer

Majority of the study participants (80%) reported correctly that breast cancer is curable if early treated. 88% said that breast cancer cannot be cured by traditional medicine and 78% reported correctly that breast cancer is treatable in the hospital.

4.7.4 Breast Cancer Transmission

As shown in table 7 below, about 70% of the study participants didn't know that breast cancer can be inherited.

Table 7: Distribution of Participants by Knowledge on Breast Cancer Occurrence, Examination Methods, Treatment and Transmission (N=142)

Knowledge on breast cancer occurence	knowledgeable (n)	%	Not knowledeable (n)	%
Breast cancer occur more commonly in old people	88	62	54	38
Breast cancer is the most common cancer in women	87	61	55	39
Breast cancer usually presents as a painless breast lump	111	78	31	22
Knowledge on breast cancer examination methods				
Breast self examination is useful in early diagnosis	126	89	16	11
Knowledge on breast cancer transmission				
Breast cancer can be inherited	43	30	99	70
Knowledge on breast cancer treatment				
Early diagnosis improves outcome of treatment	126	89	16	11
Breast cancer is curable	17	12	126	88

by the traditional healers				
Breast cancer is treatable in the hospital	111	78	32	22

We grouped the knowledge into three groups, these were; good, fair and bad knowledge towards breast cancer according to their responses. One mark was given for each correct response for all 11 questions. Those who got 8 – 11 were marked as having good knowledge, 7 – 5 fair knowledge and 0- 4 poor knowledge. Among 142 study participant only 20% had a good knowledge, 64% had fair knowledge and 14% had poor knowledge on the breast cancer.

4.8 Perception towards Breast Cancer Occurrence, Symptoms, Survival, Examination, Risks and Treatment

Perception of the study participants towards breast cancer occurrence, symptoms, survival, examination, risks and treatment were assessed as shown in table 8.

4.8.1 Perception towards Breast Cancer Occurrence

About 58% of the study participants disagreed to the statement that breast cancer is more common in women with big breasts. Also 41 % perceived that if a woman's mother or sister had breast cancer, she is more likely to get breast cancer.

4.8.2 Perception towards Breast Cancer Symptoms

Of the study participants, 44 % disagreed to the statement that lumps in the breast that are cancerous are usually painful and 50% agreed that a change in the color or discharge of a women's nipple could be a sign of breast cancer.

4.8.3 Perception towards Breast Cancer Examination

Among the study participant, 53% agreed that the best time to check for lumps in the breast is just after the menstrual period end and 83% perceived that doctor and nurses are the only ones who could find a lump in the breast.

4.8.4 Perception towards Breast Cancer Treatment

More than half of the study participants (76%) agreed that after receiving treatment for breast cancer a woman can enjoy a good quality of life. Majority of the study participants (80%) agreed that the treatment for breast cancer is a long and painful process, 90% also agreed that treatments for breast cancer are more helpful to young people and 90% agreed that treatment for breast cancer is embarrassing and 87% agreed that treatment of breast cancer results in loss of physical beauty.

4.8.5 Perception toward Breast Cancer Survival

Of the 63% study participants concurred with the statement that women's chance of surviving breast cancer is very low, even if it is found early.

4.8.6 Perception toward Breast Cancer Risks

Among the participants, 62% agreed that woman who eats foods high in fat and little fruit and vegetable may be more likely to get breast cancer.

Table 8: Perception of the Study Participants towards Breast Cancer Occurrence, Risks, Symptoms, Survival, Examination and Treatment (N = 142)

Perceptions towards breast cancer occurence	**Agree (n)**	**%**	**Disagree (n)**	**%**	**Neutral (n)**	**%**	**I don't know (n)**	**%**
Breast cancer is more common in women with big breasts	60	42	82	58	25	17	4	3
Perceptions towards symptoms for breast cancer								
Lumps in the breast that are cancer are usually painful	94	66	48	34	7	5	1	1
Perceptions towards risks for breast cancer								
A woman who eats foods high in fat and little fruit and vegetable may be more likely to get breast cancer	87	62	55	38	15	10	14	10
Perceptions towards breast cancer examination								

The best time to check for lumps in the breast is just after the menstrual period end	75	53	67	47	16	11	26	18
Doctor and nurses are the only ones who could find a lump in the breast	118	83	24	17	1	1	2	1
Perceptions towards breast cancer survival								
A women's chance of surviving breast cancer is very low, even if it is found early	89	63	53	37	10	1	4	1
Perceptions towards breast cancer treatment								
A woman after receiving treatment for breast cancer can enjoy a good quality of life	108	76	34	24	7	1	3	2
The treatment for breast cancer is a long and painful process	115	80	24	17	1	1	3	2
Treatments for breast cancer are more helpful to young people	128	90	14	10	5	1	7	1
Treatment for breast cancer is embarrassing	129	90	13	9	3	1	2	1

Treatment of breast cancer results in loss of physical beauty	125	87	17	12	4	3	1	1

The perceptions towards breast cancer occurrence, symptoms, risks, survival and treatment were grouped into two groups; those with good perception and bad perception according to their responses. The good perceptions were those study participants who answered correct and scored from 6 to 13 marks and bad perception were those who scored 0 – 5 marks. Of the study participants 61% had good perception towards breast cancer, 39% had bad perception towards breast cancer.

CHAPTER FIVE

5.0 DISCUSSION

5.1 Main Reasons for Delay in Seeking Health Care

The reasons for breast cancer patient delay in seeking health care at ORCI and MNH were assessed in this study, these include; social demographic information, social economic, infrastructure, environment and social cultural.

The findings from this study suggest the main reasons for delay in seeking of treatment among the breast cancer patients were; cost for health care, distance, seeking treatment at traditional healer and misinformation about the treatment offered at ORCI and MNH.

5.1.1 Cost for Health Care

This study found that cost for health care was among the reasons for delay in seeking health care at the ORCI and MNH. In a study done by Kimlin et al., (2010) for multiethnic groups revealed that income, education, and ethnicity were mentioned as the significantly factors related to treatment delays for breast cancer survivors, in this study about 34% study participants delayed for the reason of cost, similar findings were reported in studies conducted by Lamptey et al., (2009) in a pilot study in Ghana, which reveled that 31.4% patients delayed seeking treatment due to financial issues. This findings also supports the study done by Kimlin et al., 2010 for multiethnic groups which revealed that therapeutic care, income, education, and ethnicity were mentioned as the significantly factors related to treatment delays for breast cancer survivors.

5.1.2 Distance

Travel distance to treatment facilities accounts for failure for cancer patients to comply with the treatment (Athas et al., 2000). The International Network for Cancer Treatment

and Research, (2008) also reported that transport constraint is one of the factors led to delay for treatment. In this study, about 15% of study participants who delayed seeking treatment said distance was the reason for their delay as the patients need to travel several kilometers to reach these tertiary hospitals in Dar es Salaam. These findings are supported by the study done by Yau et al., (2010) on Chinese women, whereby limited access to public health care was an important contributing factor for patient delay. The tertiary hospitals MNH/ORCI benefits most of the patients who reside in Dar Es Salaam Township however those from rural areas and in the other regions cannot access to this service easily (Mwaiselage, 2010).

5.1.3 Seeking Treatment at the Tradition Healer

This study demonstrated that seeking treatment at the tradition healer is among the reason for delay in seeking treatment at the ORCI and MNH. It was reported by Ekortarl et al., (2007) that poor information, beliefs and fears about cancer were among the factors that contribute to delay in seeking health treatment in developing countries. This is similar to the results of this study whereby 37% of the study participants delayed because they were seeking treatment from the traditional healers. These findings implies that patient spend more time seeking treatment at the traditional healers and resulted into presentation at the tertiary hospitals when cancer is at advanced stage and hence difficult to cure. The study done by Im, (2011) indicated that low survival rate of breast cancer patients is partly due to depending on traditional healers.

5.1.4 Misinformation on the Kind of Treatment Offered at ORCI and MNH

The patients were misinformed on the kind of treatment offered at ORCI and MNH, and this was reported by the study participants as a reason which caused delay in seeking treatment. It was mentioned by Hanna et al., (2010) that values surrounding loss of hair or fertility during chemotherapy or loss of organs due to surgery (e.g. mastectomy for breast

cancer may be limit the acceptability of treatment. In this study 14% breast cancer patients delayed due to misinformation about treatment offered at ORCI/MNH. These results also support the study done by Magandi, (2009) that revealed myths and misconceptions are the result of cancer patients' presentation at advanced stages of cancer diagnosis. Also the results of this study supports the study done by Norsa'adah et al., (2011) which reported that negative information, such as the side-effects of chemotherapy, led to fear and caused some patients to decline treatment. Some believed that the effects of chemotherapy were worse than breast cancer itself.

5.2 Factors Contributing to Delay in Seeking Health Care

Factors contributing to delay for seeking treatment at the tertiary hospitals (ORCI and MNH) were studied in this study. The significant association was observed between married or livings in union that they were less likely to delay in seeking cancer treatment and delay in seeking treatment. This means that those living married or living in union they have someone to insist/remind on early seeking health care. However, the study done by Montenzeri et al., (2003) showed that widowed and divorced women had a higher risk of delay. The findings from this study and other studies (Montazeri, 2003; Nosart et al., 2011) in patient delay showed that marital status was significant predictor of delay.

The study did not demonstrate any association between delay and cancer stage, however, delay for seeking health treatment might results into advanced cancer stage and hence reduce the survivals of the breast cancer patients. Delay for seeking treatment was not associated with education, but education plays good roles for people to seeking treatment especially those who are educated. Also this study did not demonstrate any association between age and patient delay, however, in other studies (Arndt et al., 2001) have shown that older age is a predictor for patient delay.

5.3 Seeking Health Care at ORCI and MNH

Several studies have been done on patient delay for seeking treatment after diagnosis in many parts of the world. The study done by Richards et al., (1999) on delay for presentation and treatment for symptomatic breast cancer, 52% of the patients experienced a delay for more than 3 months, the study done by Montenzeri et al., (2003) on Iranian women on delay presentation for treatment, 23% of women delayed for more than three months and their survival were very low. Also study done by Norsa'adah et al., (2011) on Malaysian women indicated that 43.3% delayed the consultation by more than 3 months, these findings supports the results in our study.

5.4 Cancer Stage at Presentation at Tertiary Hospitals

The presentation of breast cancer patients at referral hospitals when their cancer is already advanced has been shown in our study. Detecting breast cancer at earlier stages reported to have lower mortality rates (Yip et al., 2008). These findings corroborate the studies done by Rambau et al., (2011) on the northern part of the country were 64% presented with the advanced clinical stage III of breast cancer. There are other studies which also support the findings of this study; like study done for young women by Yeboa et al., (2012) reported that 85% of these young women had Stage III or IV disease at presentation to hospital also in a study done in Uganda by Gondos et al., (2007) for breast cancer patients showed that about 58% reported when cancer is at stage III. Also similar studies done by Burgess et al, (1998) and Thongsuksai, (2000) reported that delay in diagnosis and treatments of breast cancer were seen to the patient with late stage of disease and high mortality. The findings of this study also was in agreement with the study done by Magandi, (2009) and Burson et al., 2010 in Tanzania that breast cancer is relatively characterized with the advanced stage at presentation, it was reported that at ORCI 80% of those who come for treatment they arrived when the cancer is at advance stage. Cancer registry data in Tanzania reveal a high

prevalence of late-stage disease at treatment. The findings of this study did not show the association between cancer stage and delay in seeking health care, however, majority of the study participants delayed and presented with the advanced cancer stages.

5.5 Knowledge towards Breast Cancer Occurrence, symptoms, Treatment, Survival and Treatment

Lack of knowledge of facts about breast cancer is one important factor in delay (Kumari et al., 2011; Elsie et al., 2010). However, in this study more than half (54%) of those surveyed reported that breast cancer is common in old women, this finding is supported by the study done by Oluwatosin, and Oladepo, (2006) for women in Nigeria where about 80% agreed that breast cancer is common for old people. However, the study done by Amin, (2008), reported that only 17% knew that breast cancer is common in old people.

The study done by Grunfeld et al., (2002) revealed that most of the women surveyed recognized a painless breast lump as a symptom of breast cancer and study done by Okobi et al., (2006) also reported that 21.4% of respondent knew that painless breast lump as a symptom of cancer. The study done by Amin, (2008) among the Arabic Speaking Immigrant Women in Halifax, Nova Scotia reported that 77% answered correctly that most of the painless lumps are cancerous. These findings are in consistent with this study where 66% of the study participants agreed that painless lump is a symptom of breast cancer. However, the results of this study differ with that of Kumar et al., (2009) were 71% were not aware that painless lump is a symptom of breast cancer.

This study revealed that about 69% of the study participants knew that breast cancer can be inherited; these results differ with that of Amin et al., (2009) where only 33.1% knew that breast can be inherited. However, the study done by Okobi et al., (2006) indicated that over half (56%) didn't know that breast cancer can be inherited. The results of this study indicated that half of the study participants supported treatment of breast cancer at the

hospital, which is good predictor for early treatment and differ with the study participants concurred that breast cancer is treated by the traditional healers.

Cure of breast cancer depends on early detection and early treatment. The majority (80%) of respondents felt that breast cancer can be cured if detected early, this findings support the studies done by Kumar et al., (2009) and Boyd et al., (2006) where majority (80% and 96% respectively) consented that breast cancer is curable if detected early. Furthermore the study done by Okobi et al., (2006) also reported 41% agreed that cancer can be cured if detected early.

Breast cancer knowledge is very important to the patient survival, the study done by Muhammed et al., (2010) on female students in Malaysia revealed that more than two thirds of the students were aware of breast self examination (BSE), this findings is consistent with the results of this study where about 89% reported that breast self examination is useful for early diagnosis. These findings further support the idea of Parsa, and Kandiah, (2005) on knowledge, attitude and perception towards cancer among Iranian women and found out that almost half of the respondent had moderate knowledge towards breast cancer examination.

Hanna et al., (2010) mentioned that low awareness on knowledge of risk factors; symptoms or signs of breast cancer contribute to delay for early diagnosis and treatment. The results of this study indicated that only 20% of the study participants had good knowledge on breast cancer whilst 65% had fair knowledge. This findings support the study done by Salaudeen, (2009) where about 36.7% had good knowledge on breast cancer. However, these findings differ with other studies done by Sadler et al., (2007) on African American women which showed that majority lack the basic knowledge on breast cancer and the study done by Khokher et al., (2011) on Pakistan women also revealed that 59% had poor knowledge on breast cancer. In addition to this, studies done by Okobia et al., (2006),

Valentine, (2007) and Sait et al., (2010) also showed poor knowledge on breast cancer among the respondents.

5.6 Perception towards Breast Cancer Occurrence, Symptoms, Diagnosis, Transmission and Treatment

This study presents the perception of the study participants towards breast cancer occurrence, symptoms, diagnosis, transmission and treatment. Peoples' perception towards breast cancer is a good predictor for health seeking behaviour, people may choose to go to health facilities or not depend on how they perceive treatment for breast cancer.

In this study, 58% of the study participants disagreed that breast cancer is more common in women with big breasts; the results are inconsistent with the study done by Shaikha, (2011), were 82% agreed that breast cancer is common in women. A change in the color or discharge of a women's nipple could be a sign of breast cancer agreed by almost half (50%) of the study participants, these results support the study by Shaikha, (2011) about 68.5% had the same perception, however, it differ with the study done by Oluwatosin, and Oladepo, (2006) where on 0.5% agreed.

In this study, 41 % perceived that if a woman's mother or sister had breast cancer, she is more likely to get breast cancer; the results are consistent with a study of Shaikha, (2011), who 67.7% perceived that breast cancer related to family history on breast cancer.

Eating food with high fats and little fruit and vegetable are among the risk factors for breast cancer, this study over half (62%) of the study participants agreed with this statement, however, the result differ with the study done by Parsa, and Kandiah, (2005) for Iranian women where only 21% preserved the same. Almost half of the respondent (53%) agreed that the best time to check for lumps in the breast is just after the menstrual period end,

these findings tally with a study done by Parsa, and Kandiah, (2005) that reported 55% perceived the same.

Majority of the study participants (83%) perceived that doctor and nurses are the only ones who could find a lump in the breast, these results are differ from study done by Parsa, and Kandiah, (2005) only 12% agreed. Over half of study participants (63%) perceived that there is a very low chance of surviving breast cancer even if it is found early; however the study done by Parsa, and Kandiah (2005) concurred with this result, where 55% agreed.

Almost 76% of the study participants concurred with the fact that woman can enjoy a good quality of life after receiving treatment for breast cancer, these findings support the study done by Hadi et al., (2010) where 63% participants believed the same.

Breast cancer treatment is long and painful process, a breast cancer patient can spend more than three months receiving treatment. The findings for this study indicated that majority of the study participants support the statement, these findings support the study done by Wu et al, (2008) on women toward mammography screening, 19.0% of respondents perceived that mammogram procedure was embarrassing, shameful and uncomfortable if the mammogram was conducted by a male or strange health professional.

Breast cancer treatment is embarrassing; this embarrassment includes surgery, radiation and chemotherapy. The statement supported by the majority of the study participants in this study. However, these findings do not support the previous research done by Hadi et al., (2010) where 46% disagreed that breast cancer treatment is embarrassing and also two thirds of the respondents did not perceived that breast cancer treatment results in loss of physical beauty.

Good perceptions towards breast cancer treatment predict the good behaviour in seeking health treatment, in this study 39% of the study participants had bad perceptions towards

breast cancer; this might contribute to the delay in seeking treatment at ORCI/MNH. Although, study done by Muhammad et al., (2010) on students showed that majority of students had positive perceptions towards the treatment of breast cancer. Studies done by Norsa'adah et al., (2011) and Grunfeld, (2003) revealed that negative perception of breast cancer treatment prevented patients from receiving early diagnoses, similar to a study in Nigeria.

CHAPTER SIX

6.0 CONCLUSION AND RECOMMENDATIONS

6.1 Conclusion

The delay for seeking health care and patient presentation at the tertiary hospital with advanced cancer stage observed to the most of the study participants. The study provides the significant findings to support the government effort in planning and development of budget for health sector as well as development of strategies to address these factors.

The main reasons for delay in seeking health care at the ORCI and MNH among breast cancer patients were studied. Majority of the study participants delayed as they were seeking treatment at the traditional healers. The cost for health care was among the reasons contributing to the delay in seeking health care. Other reasons were misinformation about the treatment at ORCI and MNH and distance from the place diagnosed to these tertiary hospitals. These findings reveal the need of addressing these issues which made breast cancer patients delay in seeking health care at a prompt time.

Marital status was significantly associated with patient delay, however education was not significant associated with patient delay but education plays a crucial role in health seeking care. Also early breast cancer stage at presentation at tertiary hospitals predicts the survival of breast cancer. Hence this calls for deliberate effort to inform the community on early health seeking care after diagnosis.

The Breast cancer knowledge is imperative contributor for health seeking behaviour, however, in this study the knowledge of breast cancer among the study participants were fair and early seeking health care for breast cancer patients depends on how people perceive the prevention, risks factors, diagnosis and treatment of breast cancer. Good perception towards breast cancer is a vital factor for a patient to make a good judgement in seeking

health care. Hence deliberate efforts are needed to improve the knowledge of the community towards breast cancer prevention, diagnosis and treatment.

This study provides very vital information which will assist the Ministry of Health and Social Welfare to design strategies that will enable breast cancer patients to present early for treatment after being diagnosed. Also the government will use this information to develop policies which can address the factors contribute to delay for breast cancer treatment.

6.2 Recommendations

The following are recommended in response to the findings revealed by this study;

1. Delay for seeking treatment revealed as an important problem in this study hence, the Government, Non Governmental Organizations, private sectors and community at large should develop policies and strategies to inform the community on importance of early treatment for breast cancer and the effects of delay for seeking treatment. Also factors contributing to delay for treatment should be known and addressed to the community. This will led into reduction of the incidence, morbidity and mortality caused by breast cancer.
2. The government should also establish other cancer treatment hospitals in other regions to reduce the costs and distance for cancer patients and hence reduce delay for seeking treatment which in turn increases cancer patients' survivals.
3. From the study it is clear that majority of the breast cancer patients had fair knowledge about breast cancer, hence it calls for more public education on breast cancer. The effort done by MEWATA, Tanzania Breast Cancer Foundation and other actors should be leveraged to all part of the country and special breast cancer education should be given to the public. These efforts should include;
    a. Establishment of specially programs to educate school aging groups from primary, secondary schools and colleges.

b. Establishment of public educational campaign to educate the Tanzanians involving media groups and other implementers/actors. The target should include all Tanzanians with special focus to less educated women and rural areas where information for breast cancer prevention, diagnosis and treatment is inadequate.

4. The government should develop breast cancer screening policy to improve the diagnosis as well as early treatment for cancer patients.
5. Psychosocial factors could contribute to delay for seeking treatment; however, this study did not touch base with any psychosocial issues, hence open for more study in this area. More studies are needed to explore why breast cancer patients are seeking first treatment at traditional healers rather than in the hospitals. Also the study done only to the breast cancer patients but there is a need for more studies on the knowledge, attitude and perception on care takers, relatives and friends of the breast cancer patients to explore more factors contributing to delay in seeking treatment.
6. Risks for breast cancer was not included in this study, however, the community should be educated on the important risks for breast cancer and reduce the incidence, prevalence, mobility and mortality caused by breast cancer.
7. The study interviewed only women with breast cancer, but there are men who also suffer from breast cancer, other study on factors for delay should be done for men affected with breast cancer.

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APPENDICES

Appendix 1: Data collection Tool (English)

Questioner number…… Name of Tertiary Hospital……

Name of interviewer…….

A. Socio demographic Information

1. What is the sex of a patient? *Tick where appropriate*

- Male
- Female

2. When were you born? ----------

3. What is your age? ----------

4. Which one of the following best describes the patient marital status? (*Tick where appropriate*)

  - Single
  - Currently married
  - Living with partner/significant other
  - Widowed
  - Separated
  - Divorced
  - Other (specify_____)

5. What is your tribe? ----------

6. Where do you live? ----------

7. In what type of area did you live most of your childhood? (*Tick where appropriate*)

- Urban, large city
- Urban, small city
- Suburb of large city
- Suburb of small city
- Rural, farm
- Rural, non-farm
- Other (specify_____)

8. What is your religion? (*Tick where appropriate*)
    - Christian
    - Moslem
    - Other
9. Do you have any children?
    - Yes
    - No
10. What is the highest level of education you completed? (*Tick where appropriate*)
    - No formal education
    - Incomplete primary education
    - Complete primary education
    - Secondary and above
11. What is your occupation? (*Tick where appropriate*)
    - Employed
    - Business Person
    - Student
    - Not employed

B. Cancer information

12. When were you first diagonised with breast cancer? ----------
13. Where was it?

- Dispensary
- Health Center,
- district hospital
- regional hospital
- other (specify) ----------

14. When were you started treatment at ORCI/MNH? *If come after three month ask question (20)*

- Less than three months
- More than three months
- I don’t remember

15. what was the cancer stage on arrival? (this information will be collected from the patients files with support of Dr. Mwaisalage)

- 0
- I
- II
- III
- IV

C. Knowledge on common symptoms of breast cancer

16. Breast cancer is the most common cancer in women

- Yes
- No
- I don't know

17. Breast cancer cured

- Yes
- No
- I don’t know

18. Breast cancer occur more commonly in old people

- Yes

- No
- I don't know

19. Breast cancer can be inherited
    - Yes
    - No
    - I don't know
20. Breast cancer usually presents as a painless breast lump
    - Yes
    - No
    - I don't know
21. Early diagnosis improves outcome of treatment
    - Yes
    - No
    - I don't know
22. Breast self examination is useful in early diagnosis
    - Yes
    - No
    - I don't know
23. Breast cancer is curable when detected early
    - Yes
    - No
    - I don't know
24. Is routine examination of breast cancer necessaryly?
    - Yes
    - No
    - I don't know
25. Is breast cancer curable by traditional medicine?
    - Yes
    - No

- I don't know

26. Is breast cancer treatable in the hospital?
    - Yes
    - No
    - I don't know

D. Perception towards breast cancer

For the following questions tick where appropriate

27. Breast cancer is more common in women with big breasts
    - Agree
    - Disagree
    - Neutral
    - I don’t know
28. Lumps in the breast that are cancer are usually painful
    - Agree
    - Disagree
    - Neutral
    - I don’t know
29. A change in the color or discharge of a women's nipple could be a sign of breast cancer
    - Agree
    - Disagree
    - Neutral
    - I don’t know
30. If a woman's mother or sister had breast cancer, she is more likely to get breast cancer
    - Agree
    - Disagree
    - Neutral

- I don’t know

31. A woman who eats foods high in fat and little fruit and vegetable may be more likely to get breast cancer
    - Agree
    - Disagree
    - Neutral
    - I don’t know
32. The best time to check for lumps in the breast is just after the menstrual period ends
    - Agree
    - Disagree
    - Neutral
    - I don’t know
33. Doctor and nurses are the only ones who could find a lump in the breast
    - Agree
    - Disagree
    - Neutral
    - I don’t know
34. A women's chance of surviving breast cancer is very low, even if it is found early
    - Agree
    - Disagree
    - Neutral
    - I don’t know
35. A woman after receiving treatment for breast cancer can enjoy a good quality of life.
    - Agree
    - Disagree
    - Neutral
    - I don’t know
36. The treatment for breast cancer is a long and painful process.
    - Agree

- Disagree
- Neutral
- I don’t know

37. Treatments for breast cancer are more helpful to young people.
    - Agree
    - Disagree
    - Neutral
    - I don’t know
38. Treatment for breast cancer is embarrassing.
    - Agree
    - Disagree
    - Neutral
    - I don’t know
39. Treatment of breast cancer results in loss of physical beauty
    - Agree
    - Disagree
    - Neutral
    - I don’t know

F. Factors affecting treatment delay among breast cancer patients

For the following questions tick where appropriate

40. Since you were diagnosed and given a referral letter, how long did it take you to decide to honor the referral (month)?
    - Less than three months
    - More than three month
    - I don’t remember

41. What were the reasons for late to honor the referral? (*Ask this question for those who reported more than one month) tick where appropriate*

- I had no money
- The long distance to ORCI/MNH
- It was rainy season and roads were impassable
- I was receiving treatment at the traditional healer
- Misinformation about cancer treatment at ORCI/MNH
- Other (specify)

Appendix II: Dodoso la kukusanyia taarifa za wagonjwa wa saratani ya matiti

Namba ya dodoso…… Jina ya Hospitali ya rufaa……

Jina la Mhojaji…….

A. Taarifa binafsi

1. Nini jinsi ya mgonjwa? *Weka alama ya sawa kwenye jibu sahihi*
    - Mwanaume
    - Mwanamke
2. Je umezaliwa wapi? ----------
3. Je una umri gani? ----------
4. Kati ya vitu vilivyoorodhoshwa hapa chini, kipi kinaelezea hali ya ndoa ya (*Weka alama ya sawa kwenye jibu sahihi)*
    - Hajaolewa
    - Ameolewa
    - Wanaishi na mwenzake
    - Mjane
    - Wameachana
    - wametarakiana
    - sababu ingine (elezea_____)

5. Je kabila lako ni lipi? ----------
6. unaishi wapi? ----------
10. Katika maisha yako ya utoto, uliishi wapi? (*Weka alama ya sawa kwenye jibu sahihi*)
    - mjini, Mji mkubwa
    - mjini, mji mdogo

- pembezoni mwa mji mkubwa
- pembezoni mwa mji mdogo
- Kijijini, kwenye mashamba
- Kijijini, kusikokuwa na mashamba
- Sababu ingine (elezea_____)

11. je dini yako ni ipi? (*Weka alama ya sawa kwenye jibu sahihi*)
    - Mkristu
    - Muislam
    - Dini ingine
12. je una watoto?
    - Ndio
    - Hapana

10. Je ni kiwango kipi cha elimu ulichofikia? (*Weka alama ya sawa kwenye jibu sahihi*)
    - Elimu isiyo rasmi
    - Sijamaliza elimu ya msingi
    - Nimemaliza elimu ya msingi
    - Elimu ya upili na zaidi
11. Je ajira yako ni ipi? (*Weka alama ya sawa kwenye jibu sahihi*)
    - Nimeajiriwa
    - Mfanyabiashara
    - Mwanafunzi
    - sijaajiliwa

B. Taarifa za saratani

12. Je ni lini ulipogundulika kuwa na saratani ya matiti? ----------
13. Je ni wapi?
    - Zahanati
    - Kituo cha afya
    - Hospitali ya wilaya

- Hospitali ya mkoa
- Ingine (elezea) ----------

14. Je ni lini ulipoanza matibabu hapa ORCI/MNH?
    - Chini ya miezi mitatu
    - Zaidi ya miezi mitatu

- Sikumbuki (*angalia kwenye faili lake kwa msaada wa Dr. mwaiselage na wafanya kazi wengine)*

15. je saratani ilikuwa katika hatua gani? (*angalia kwenye faili lake kwa msaada wa Dr. mwaiselage na wafanya kazi wengine)*
    - 0
    - I
    - II
    - III
    - IV

B. ufahamu wa mgonjwa kuhusu dalili za kawadia za saratani ya matiti

kwa maswali yafuatayo, weka alama ya vema mahali panapohusika

16. saratani ya matiti ni ugonjwa wa kawaida kwa wanawake
    - Ndio
    - Hapana
    - sijafahamu

17. saratani ya matiti inatibika
    - Ndio
    - Hapana
    - sijafahamu

18. saratani ya matiti inatokea kwa kawaida kwa watu wazee
    - Ndio
    - Hapana
    - sijafahamu

19. saratani ya matiti inarisishwa

- Ndio
- Hapana
- sijafahamu

20 saratani ya matiti kwa kawaida inajitokeza kwa uvimbe usiouma kwenye titi

- Ndio
- Hapana
- sijafahamu

21. Ugunduzi wa mapema unasaidia katika matokeo ya matibabu

- Ndio
- Hapana
- sijafahamu

22. Upimaji wa matiti binafsi ni mzuri kwa ugunduzi wa mapema

- Ndio
- Hapana
- sijafahamu

23. saratani ya matiti inatibika kama itagunduliwa mapema

- Ndio
- Hapana
- sijafahamu

24. Je uchunguzi wa mara kwa mara wa saratani ya matiti ni muhimu?

- Ndio
- Hapana
- sijafahamu

26. Je saratani ya matiti inatibika hospitalini?

- Ndio
- Hapana
- sijafahamu

C. Mtazamo wa mgonjwa kuhusu saratani ya matiti

kwa maswali yafuatayo, weka alama ya vema mahali panapohusika

27. saratani ya matiti ni tatizo la kawaida kwa wanawake wenye matiti makubwa
    - Nakubali
    - Sikubali
    - Sina upande wowote
    - Sifahamu

28. uvimbe kwenye matiti wa saratani kwa kawaida una maumivu
    - Nakubali
    - Sikubali
    - Sina upande wowote
    - Sifahamu

29. kubadilikwa kwa rangi au majimaji ya kwenye chuchu ya mwanamke ni dalili ya saratani ya matiti
    - Nakubali
    - Sikubali
    - Sina upande wowote
    - Sifahamu

30. kama mama au dada ana saratani ya matiti, ni rahisi kwa mwingine kwenye familia kupata saratani ya matiti
    - Nakubali
    - Sikubali
    - Sina upande wowote
    - Sifahamu

31. Mwanamke anayekula vyakula vyenye mafuta sana, matunda na mbogamboga kiasi ana hatari kubwa ya kupata saratani ya matiti
    - Nakubali
    - Sikubali

- Sina upande wowote
- Sifahamu

32. Muda mzuri wa kuangalia uvimbe kwenye titi ni baada ya kumaliza siku zako za mwezi
    - Nakubali
    - Sikubali
    - Sina upande wowote
    - Sifahamu
33. Madaktari na manesi ndio wanaoweza kutafuta uvimbe kwenye titi
    - Nakubali
    - Sikubali
    - Sina upande wowote
    - Sifahamu
34. Mwanamke mwenye saratani ya matiti ana nafasi ndogo ya kuendelea kuishi hata kama akiwahi kuiona
    - Nakubali
    - Sikubali
    - Sina upande wowote
    - Sifahamu
35. Mwanamke baada ya kupata matibabu ya saratani ya matiti anaweza kufurahi maisha yake vema
    - Nakubali
    - Sikubali
    - Sina upande wowote
    - Sifahamu
36. matibabu ya saratani ya matitini ya muda mrefu na yenye mchakato unaouma sana.
    - Nakubali
    - Sikubali
    - Sina upande wowote
    - Sifahamu

37. Matibabu ya saratani ya matiti yana msaada mkubwa kwa vijana wadogo.

- Nakubali
- Sikubali
- Sina upande wowote
- Sifahamu

38. matibabu ya saratani ya matiti yanafedhehesha.

- Nakubali
- Sikubali
- Sina upande wowote
- Sifahamu

39. Matokeo ya matibabu ya saratani ya ni kupoteza uzuri wa mwili

- Nakubali
- Sikubali
- Sina upande wowote
- Sifahamu

F. Mambo yanayosabibisha kuchelewa kuanza matibabu kwa wagonjwa wa saratani ya matiti

kwa maswali yafuatayo, weka alama ya vema mahali panapohusika

40. Toka ulipogundulika kuwa na saratani ya matiti na kupewa rufaa, je ni muda gani umechukua kuamua kwenda kwenye hiyo rufaa (mwezi)?

- Chini ya miezi mitatu
- Zaidi ya miezi mitatu
- Sikumbuki

41. Ni nini sababu iliyokufanya kuchelewa kwenda kwenye hiyo rufaa uliyopewa? (*uliza swali hili kwa wagonjwa waliochelewa zaidi ya mwezi mmoja) weka alama ya vema mahali sahihi*

- Sikuwa na pesa

- Umbali wa kutoka hapa nilipo mpaka ORCI/MNH
- Ilikuwa ni kipindi cha mvua na barabara hazipitiki
- Nilikuwa napatiwa matibabu kwa mganga wa kienyeji
- Taarifa mbaya kuhusu matibabu yatolewayo ORCI/MNH
- Mengineyo (elezea)

_____

_____

_____

_____

_____

_____

Appendix III: Informed Consent, English Version

MUHIMBILI UNIVERSITY COLLEGE OF HEALTH SCIENCES DIRECTORATE OF RESEARCH AND PUBLICATIONS.

INFORMED CONSENT

ID-NO ☐☐☐

Consent to participate in this study

Greetings! My name is Angelina Charles Mtowa. I am working on this research project with the objective to determine the factors contributing to delay for seeking referral cancer treatment among the breast cancer patients at the ORCI and MNH

.

Purpose of the study

This study has the purpose of generating information on factors contributing to delay in seeking referral treatment among the breast cancer patients who are receiving treatment at the ocean Road Cancer Institute (ORCI) and Muhimbili National Hospital (MNH). You are being asked to participate in this study because you have particular knowledge and experiences that may be important to the study.

What Participation Involves

If you agree to participate in this study the following will occur:

1. You will sit with an interviewer and answer questions about your knowledge, attitude, perception towards breast cancer and factors contributing to delay in seeking referral treatment since diagnosis of breast cancer at the health facility. The interviewer will be recording your responses using a tape recorder.
2. No identifying information will be collected from you during this interview, except your age, level of education, employment and marital status.

3. You will be interviewed only once for approximately 45 minutes in a private setting. After the interview you will be given incentive of 5,000 Tshs for your participation.

Confidentiality

I assure you that all the information collected from you will be kept confidential. Only people working in this research study will have access to the information. We will be compiling a report, which will contain responses from several respondents without any reference to individuals. We will not put your name or other identifying information on the records of the information you provide.

Risks

You will be asked questions about your knowledge, attitude, perception towards breast cancer and factors contributing to delay in seeking referral treatment at tertiary hospital. Some questions could potentially make you feel uncomfortable. You may refuse to answer any particular question and may stop the interview at anytime.

Rights to Withdraw and Alternatives

Taking part in this study is completely your choice. If you choose not to participate in the study or if you decide to stop participating in the study you will not get any harm. You can stop participating in this study at any time, even if you have already given your consent. Refusal to participate or withdrawal from the study will not involve penalty or loss of any benefits to which you are otherwise entitled.

Benefits

The information you provide will help to increase our understanding on factors which contributing on delay for seeking referral treatment which made some of cancer patients came when the disease it is in advance stage and fewer chances for cure and this

information will be used to prepare effective interventions/programs or policy to mitigate the problems of delay for seeking referral treatment.

In Case of Injury

We do not anticipate that any harm will occur to you or your family as a result of participation in this study

Who to contact

If you ever have questions about this study, you should contact the study Coordinator or the **Principal Investigator, Angelina Charles Mtowa,** Muhimbili University of Health and Allied Sciences (MUHAS), P.O. Box 65001, Dar es Salaam (Tel. no. 0784 288807 or 0767 899003). If you ever have questions about your rights as a participant, you may call **Prof. M. Aboud, Chairman of the University Research and Publications Committee,** P. O. Box 65001, Dar es Salaam. Tel: 2150302-6 and **Dr. Joyce Masalu who is the supervisor** of this study (Mob no. 0754 757571)

Signature

Do you agree?

Participant Agrees [__]

Participant disagree [__]

I _____ have read/understood the contents in this form. My questions have been answered. I agree to participate in this study.

Signature of Participant _____

Signature of witness (if participant cannot read) _____

Signature of research assistant _____

Date of signed consent _____

Appendix IV: Informed Consent Swahili Version

FOMU YA RIDHAA

Namba ya Utambulisho ☐☐☐

Ridhaa ya Kushiriki katika utafiti huu

Habari! Jina langu naitwa Angelina Charles mtowa, nafanya kazi katika mradi huu wa utafiti wenye lengo la kukusanya maoni toka kwa wagonjwa wa saratani ya matiti kuhusu sababu zinazosababisha wagonjwa wa saratani ya matiti kuchelewa kufika kwenye matibabu rufaa ORCI and MNH.

Malengo ya Utafiti

Utafiti huu una lengo la kukusanya taarifa ya maoni kukusanya maoni kuhusu sababu zinazosababisha wagonjwa wa saratani ya matiti kuchelewa kufika kwenye matibabu rufaa ya ORCI/MNH. Unaombwa kushiriki katika utafiti huu kwa sababu una uelewa na ambao unaweza kuwa muhimu katika tafiti hii.

Ushiriki.

Ukikubali kushiriki katika utafiti huu yafuatayo yatatokea:

1. Utakaa mtafiti aliyepewa mafunzo ya jinsi ya kuhoji na kujibu maswali yahusuyo ufahamu wako kuhusu sababu zinazosababisha wagonjwa wa saratani ya matiti kuchelewa kufika kwenye matibabu rufaa ya ORCI and MNH. Msaili atakua anarekodi majibu yako katika kaseti ya kurekodia.

2. Hakuna taarifa zozote za utambulisho tutakazokusanya wakati wa usaili isipokua umri, kiwango cha elimu, ajira na hali yako ya ndoa.

3. Utahojiwa mara moja tu kwa takriban dakika 45. Kisha utapewa shilingi 5,000 kama motisha ya kushiriki katika utafiti huu.

Usiri

Nakuhakikishia kwamba taarifa zote zitakazokusanywa kutoka kwako zitakua ni siri, ni watu wanaofanya kazi katika utafiti huu tu ndio wanaweza kuziona taarifa hizi. Hatutaweka jina lako au taarifa yoyote ya utambulisho kwenye kumbukumbu za taarifa utakazotupa.

Madhara

Utaulizwa maswali juu ya ufahamu wako kuhusu sababu zinazosababisha wagonjwa wa saratani ya matiti kuchelewa kufika kwenye matibabu rufaa ya ORCI/MNH. Baadhi ya maswali yanaweza kukufanya usijiskie vizuri. Unaweza kukataa kujibu swali lolote na unaweza kusimamisha usaili wakati wowote.

Haki ya kujitoa na mbadala wowote

Kushiriki katika utafiti huu ni uchaguzi wako, kama utachagua kutokushiriki au utaamua kusimamisha kushiriki hutapata madhara yoyote. Unaweza kusimamisha kushiriki katika tafiti hii muda wowote hata kama ulisharidhia kushiriki. Kukataa kushiiriki au kujitoa katika utafiti hakutasababisha adhabu yoyote au upotevu wa faida yoyote unayotakiwa kupata.

Faida

Taarifa utakayotupatia itasaidia kuongeza uelewa wetu kuhusu kuhusu sababu zinazosababisha wagonjwa wa saratani ya matiti kuchelwa kufika kwenye matibabu rufaa ya ORCI/MNH na kufika wakati saratani iko kwenye ahtua ambayo ni vigumu kutibika, pia taarifa hizi zitasaidia katika kutayarisha mipango, mikakati na sera kwa wagonjwa wa saratani ya matiti.

Endapo Utadhurika

Hatutegemi madhara yoyote kutokea kwa kushiriki kwako katika tafiti hii.

Watu wa kuwasiliana nao

Kama una maswaIi katika utafiti huu unaweza kuwasiliana na **mratibu mkuu wa mradi, Angelina Charles Mtowa** Chuo Kikuu cha Muhimbili, S.L. P 65001, Dar es Salaam (Simu. no. 0784 288807 au 0767 899003). Kama utakua na maswali yoyote kuhusu haki zako kama mshitriki unaweza kupiga simu kwa **Prof. M.Abou ,** ambaye ni **Mwenyekiti wa kamati ya chuo ya utafiti na machapisho,** S.L.P 65001, Dar es Salaam. Simu namba: 2150302-6 na **Dr. Joyce Masalu** ambaye ni **msimamizi wa utafiti huu** (Simu nambari. 0754 757571)

Sahihi

Unakubali?

Mshiriki amekubali [__]

Mshiriki amekataa [__]

Mimi _____ nimesoma/nimeielewa hii fomu, maswali yangu yamejibiwa. Nakubali kushiriki katika utafiti huu.

Sahihi ya mshiriki _____

Sahihi ya shahidi (kama hawezi kusoma na kuandika) _____

Sahihi ya mtafiti mwandamizi _____

Tarehe ya makubaliano _____