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FACTORS ASSOCIATED WITH DELAY IN PRESENTATION OF CANCER PATIENTS FOR TREATMENT: A PATIENTS' PERSPECTIVE

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DECLARATION

I declare that this work has not been previously submitted and approved for the award of a degree by this or any other university. To the best of my knowledge and belief, the dissertation contains no material previously published or written by another person except where due reference is made in the thesis itself.

Njambi Ann Kabura

June 2018

Approval

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ABSTRACT

The global burden and threat of non-communicable diseases constitute one of the major challenges for development in the twenty-first century which undermines social and economic development throughout the world. A huge proportion of deaths due to non-communicable diseases, including cancer, occur in the low and middle income countries. Cancer is among the top five causes of mortality in Kenya. Its estimated annual incidence is close to 37000 and unfortunately close to 80% of the patients is diagnosed at an advanced stage. The economic impact of cancer is felt at an individual and most importantly a population level. Shortening the interval between onset of symptoms and initiation of treatment would greatly improve patient outcomes and also reduce the cost of more aggressive treatment. Understanding the pathways to care is critical for interventions to be made in a timely manner. An assessment of patients' perspectives guides strategic decision making to meet expectations and effectively manage health care performance.

The main aim of this study was to identify the factors associated with late cancer diagnosis among patients presenting for treatment at Kenyatta National Hospital.

A descriptive cross-sectional design was used for this study. The study was undertaken at Kenyatta National Hospital's Cancer Treatment Center. Standardized questionnaires were administered to all eligible and consenting patients with either stage three or four of cancer presenting for treatment at the cancer treatment center. Patients' records were also reviewed to ascertain the diagnosis, stage and type of cancer. The data collected was summarized and analyzed using Microsoft Excel and MINITAB 14.

Female respondents were more than the male respondents. The mean age of the respondents was 49 years; 87% of the respondents were below 65 years old. 71% had attained only primary education, 10% had attained tertiary education. Most of the respondents (74%) resided in rural areas and 84% of them were in the informal sector. 87% had no pre-existing illnesses and only 23% were smokers. 65% of them had no prior knowledge on cancer, 71% were unaware of measures to reduce the risk of cancer and only 19% had been previously screened for cancer.

78% of the participants had experienced their symptoms for more than 6 months before the diagnosis of cancer was made. 58% of the participants initially sought help for their symptoms in private hospitals and 45% had their diagnosis made in private hospitals. 55% had their diagnosis made in secondary and tertiary public hospitals. 61% waited for more than 6 months before

getting their diagnosis of cancer and a similar proportion had to wait for more than 3 months before initiation of treatment. Long waiting time for specialized treatment was identified as the main reason for delay.

The findings of this study corroborate those of other similar studies. The success of any cancer control programs will require well-coordinated demand-side and supply-side efforts to address the barriers to early detection and treatment of cancer.
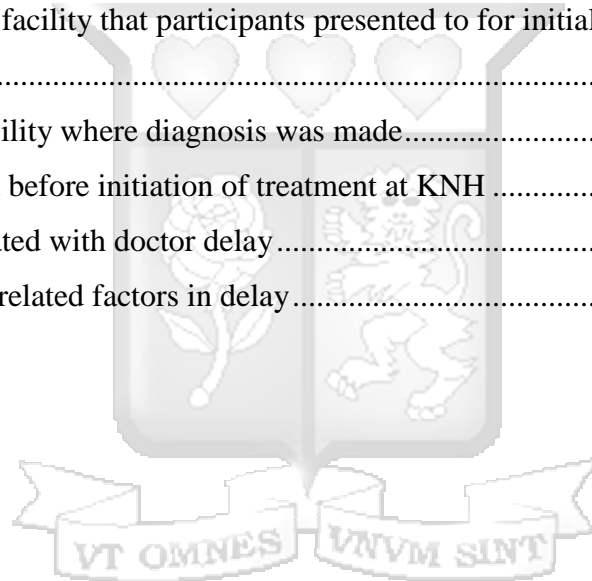
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OPERATIONAL DEFINITIONS

Patient delay is the interval from the onset of symptoms to the initial consultation or presentation to a healthcare practitioner.

Doctor delay will refer to delay in primary healthcare facilities where patients first present, where the health care practitioner fails to correctly identify and act upon possible symptoms of cancer.

A healthcare practitioner refers to any healthcare worker that may interact in a treatment setup with patients such as doctors, dentists, nurses, pharmacists and clinical officers.

System delay is the delay occurring from the patient's interaction with the health care system; at the point where the patient's symptoms begin to be investigated (after the initial consultation with a provider), to appropriate referral for further investigations and initiation of treatment. This can occur at any level of care within the healthcare system.

Advanced cancer refers to cancer that has spread to other places in the body and usually cannot be cured or controlled with treatment.
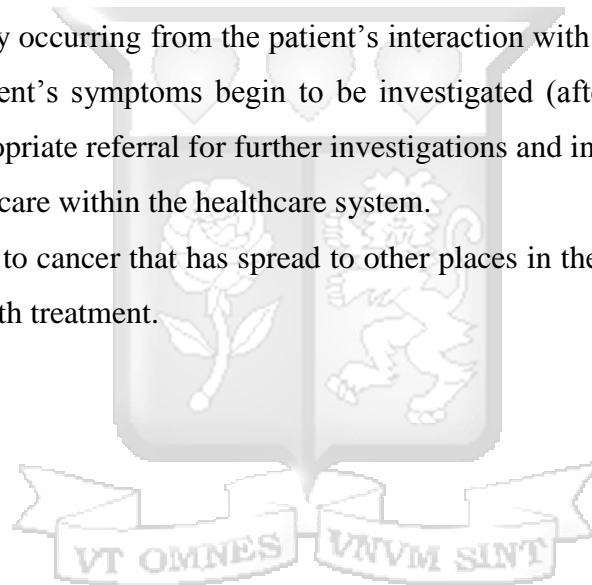
LIST OF ABBREVIATIONS

A&E –   Accident and Emergency

CTC –   Cancer Treatment Center

CAM –   Complementary and Alternative Medicine

GP-   General Practitioner

HPV –   Human Papillomavirus

HIV –   Human Immunodeficiency Virus

KNH –   Kenyatta National Hospital

LMIC –   Low and Middle Income Countries

MoH –   Ministry of Health

MTRH-   Moi Teaching and Referral Hospital

NCD -   Non-communicable Diseases

NHS –   National Health Service (UK)

OECD -   Organization for Economic Co-operation and Development

UN –   United Nations

WHO –   World Health Organization

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CHAPTER ONE
INTRODUCTION

1.1 Background to the study

The increasing global burden of non-communicable diseases (NCDs) has become one of the major challenges for development in the twenty-first century. NCDs undermine social and economic development throughout the world and threaten the achievement of internationally agreed development goals such as the 2030 Agenda for Sustainable Development that seek to ensure healthy lives and promote economic development, by reducing the number of preventable deaths by a third by 2030 (United Nations, 2015). According to the World Health Organization (WHO), NCDs kill 40 million people each year, which is equivalent to 70% of all deaths globally. Cardiovascular diseases account for most NCD deaths, (17.7 million people annually), followed by cancers (8.8 million), respiratory diseases (3.9million), and diabetes (1.6 million). These 4 groups of diseases account for over 80% of all premature NCD deaths. Each year, 15 million people between the ages of 30 and 69 years worldwide die from NCD related complications; over 80% of these premature deaths occur in low- and middle-income countries (WHO, 2017). Non-communicable diseases are thus now recognized by the United Nations and WHO as a major public health crisis; and cancer care in low- and middle income countries (LMICs) is now acknowledged as a global health priority (WHO, 2011).

There is however, still insufficient data on NCDs, particularly in low- and middle-income countries. This is because the levels and capacities for reporting and surveillance are still very low in these countries. Over the past three decades, deaths from NCDs have increased at an astonishingly fast rate in LMICs and as a result, most of these countries are now suffering from a double burden of disease. This means that the already over-stretched public health services now have to also cope with the increasing trend of NCDs. A large proportion of people with high risk of NCDs in LMICs remain undiagnosed, and even those diagnosed have insufficient access to treatment at the primary health-care level (WHO, 2017).

Between 30-50% of cancers are preventable by healthy lifestyle choices such as avoidance of tobacco and public health measures like immunization against cancer causing infections such as

Human Papillomavirus (HPV) associated with cervical cancer; others, such as those that present with lumps or abnormal bleeding, can be detected early, treated and cured (WHO, 2017). Even with late stage cancer, the suffering of patients should be relieved with good palliative care. Late-stage presentation and inaccessibility of diagnosis and treatment resources are common. Low income countries are faced with challenges such as lack of adequate pathology services and treatment services (WHO, 2017).

The disparity in access to care and outcomes between countries is staggering. The predominant causes of the disparities are inadequate health coverage and low individual (or household) socioeconomic status (National Cancer Institute, 2008). Higher mortality rates are seen in LMICs and according to *Globocan* higher incidences of cancer and related mortalities are expected to be seen in these countries (IARC, 2012). In middle-income countries, cancer treatment centers exist, but most of them are located in urban areas (Cazap, Magrath, Kingham, & Elzawawy, 2016). Many people have little understanding of cancer, and in some cultural barriers keep others from seeking treatment. This, coupled with the cost of transportation and treatment and, frequently, the failure of the primary health care provider to recognize the possibility of cancer, results in an unknown fraction of patients with cancer dying before reaching a treatment facility. Because of these barriers, diagnosis is usually late such that the assumption that cancer is almost invariably fatal becomes a self-fulfilling prophecy. Three general barriers to cancer care have been identified as cost, education and access (Cazap et al., 2016).

Kenya's Ministry of Health in 2017 estimated the annual incidence of cancer in Kenya at nearly 37000 new cases, with an annual mortality of 28000 (MOH, 2017). The risk of getting cancer before 75 years is 14% and the risk of mortality from cancer approaches 12%. Cancer is estimated to be the third leading cause of mortality in Kenya and accounts for 7% of overall national mortality among the NCDs (WHO, 2014b).

Cancer is among the top five causes of mortality in Kenya. The leading cancers in Kenya are breast, cervical, prostate, Kaposi sarcoma and esophageal cancers (MOH, 2017). More than 70% of reported cases of cancer are diagnosed at advanced stages when little can be achieved in terms of curative treatment (MOH, 2012). The Kenya National Cancer Control Strategy aims at

reinforcing health promotion and cancer prevention, improve public awareness of cancer symptoms and risks, improve early detection of cancer and expand the treatment resources (MOH, 2017). Health promotion programs such as mass cancer awareness campaigns have been based on the idea that individuals are purposive and decisive thus providing them with knowledge on the illness will promote a change in their health seeking behavior. However, this has proven to be insufficient in itself to promote behavior change and thus there's need to explore the dynamics that influence the well-being of communities. A wide range of factors that may directly or indirectly influence health-seeking behavior have been identified. These include cultural, social, psychological and economic factors (Mackian, 2003).

In some countries such as in the United Kingdom, there is government policy in place to reduce diagnostic delay in all cancers with a focus on public education, screening and referral delay (doctor delay). In 2000, the UK government introduced the two-week-wait rule such that a general practitioner who suspects cancer should refer the patient within twenty-four hours while the secondary care provider should give an appointment for consultation within two weeks (Mansell Gemma, Shapley Mark, Jordan Joanne L, 2011; NHS, 2000). The referral guidelines in Kenya have neither explicitly described the desirable timelines during the referral of cancer patients nor addressed the issue of delay (MOH, 2014).

The time taken from the onset of symptoms to the diagnosis of cancer influences the stage and subsequent survival of the patient. Shortening the duration of patient delay would substantially improve survival and patient treatment outcomes. Longer time to diagnosis may be detrimental in several ways: a more advanced stage at diagnosis, poorer survival, greater disease-related and treatment-related morbidity and adverse psychological adjustment. Delays of 3–6 months are associated with lower survival. These effects cannot be accounted for by lead-time bias. Efforts should be made to keep delays by patients and providers to a minimum (Richards, 2009). It is therefore important to understand the patients' pathways to cancer diagnosis including the timing and the reasons behind help-seeking so as to inform the approaches to reduce delays (Fiona Walter, Webster, Scott, & Emery, 2012).

1.2 Problem Statement

Cancer is an important health condition, both in terms of the number of people affected and the impacts on those people and the people close to them. Many patients presenting for care at cancer treatment centers in Kenya present with advanced disease, including those with vaccine preventable cancers such as cervical cancer and those with malignancies that can also be detected early due to their usual presentation, such as breast cancer. This situation thus poses a big challenge for cancer care in Kenya because when these patients present with such advanced disease there is minimal chance for cure.

From a public health perspective, the economic impact of cancer at the population level is significant in terms of the loss of productivity during treatment and after treatment due to the adverse effects of cancer treatments, and also due to premature deaths associated with cancer. Thus understanding the pathways to care among cancer patients will guide the implementation of relevant and timely interventions to curb delays in seeking treatment. Measurement of patient experience is important because it provides an opportunity to improve care, enhance strategic decision making, meet patients' expectations, effectively manage and monitor health care performance, and document benchmarks for health care organizations. Measurement of patient experiences can also inform an organization on improvement of processes and clinical outcomes, utilization of resources, and enhancement of safety (LaVela & Gallan, 2014).

Several studies have been undertaken in various parts of the world to elucidate the possible causes of delays in presentation for cancer care but such research is minimal to non-existent in the Kenyan setting. This study thus sought to identify and describe the factors associated with delayed presentation of cancer patients for diagnosis and treatment.

1.3 Objectives

1.3.1 Main Objective

To examine the factors associated with delay in presentation for treatment among cancer patients at Kenyatta National Hospital.

1.3.2 Specific Objectives

The specific objectives of this study are:

    i.   To assess the average time to initial presentation for treatment after onset of symptoms by cancer patients;

    ii.   To examine the socioeconomic and demographic factors that contribute to delays in treatment among the cancer patients;

    iii.   To examine the role of patients' knowledge about cancer in delay for treatment;

    iv.   To document health system factors that contribute to late presentation of cancer patients for treatment.

1.4 Research Questions

This study therefore attempts to answer the following questions:

    i.   What is the average duration of patient delay among patients presenting for cancer treatment at Kenyatta National Hospital?

    ii.   What are the socioeconomic and demographic factors associated with delays in cancer treatment among patients presenting at the Kenyatta National Hospital?

    iii.   How are patients' knowledge and attitudes about cancer related with delays in presentation for cancer treatment in Kenya?

    iv.   What are the health system factors associated with delayed presentation for cancer treatment in Kenya?

1.5 Justification of the study

By understanding the patient's perspective regarding delays in seeking treatment, the findings of this study will serve as a guide in the making of cancer policies and guidelines by the Ministry of Health and thus formulate the relevant interventions to increase cancer awareness and responsiveness among Kenyan citizens and health care providers. The ministry will also be in a position to advance the formulation of relevant referral guidelines to necessitate timely referral of all patients diagnosed with cancer to facilities that are well equipped (in human resource and infrastructure) to manage cancer; and in capacity building to ensure that all regional referral facilities are well equipped to initiate cancer management, both diagnosis and treatment, in a timely manner. This will effectively reduce the numbers of patients waiting in line to commence

treatment at the two major referral facilities, that is, Kenyatta National Hospital and Moi Teaching and Referral Hospital.

The health facilities providing diagnostic and treatment services to cancer patients will understand better their role in reducing undue delay among cancer patients and consequently streamline their processes and systems to reduce inefficiencies.

Health care practitioners will be trained on early identification of possible symptoms of cancer (through the Ministry of Health) and appropriate referral practices thus minimize the doctor delay in cancer diagnosis and treatment.

Patients will be better equipped through cancer awareness programs to understand and identify probable symptoms of cancer and thus seek health care in a timely manner. This will improve their chances of survival and thus productivity within the economy. It will also reduce their healthcare spending and thus avoid the incidents of catastrophic spending in purchase of healthcare. The possibly improved outcomes will also lead to reduced psychological distress to the patients and their families.

The associated systemic changes will result in better cancer care outcomes in Kenya, less cancer related morbidity and mortality, and thus overall positively contribute to the economic development of the country.
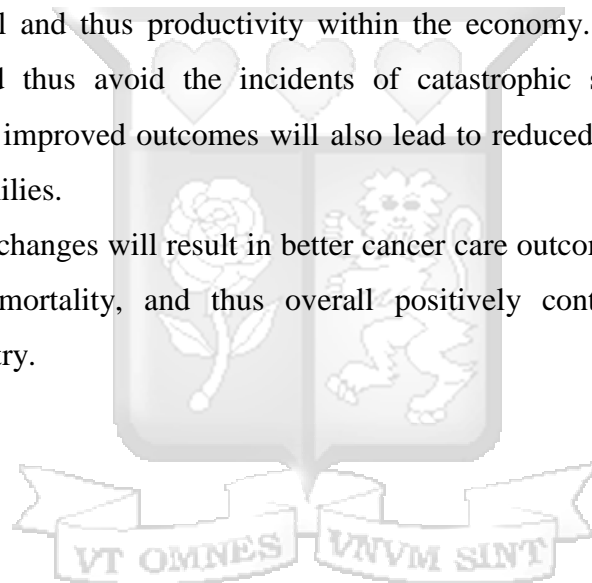
CHAPTER TWO
LITERATURE REVIEW

2.1 Introduction

Delay in presentation for cancer treatment has been extensively studied over the past years. The concept of delay was introduced in 1938 by Pack and Gallo (Pack & Gallo, 1938). Patient delay was defined as the interval between onset of symptoms and the initial presentation to the physician. They termed the delay as reasonable when the interval was less than three months and undue when the interval exceeds three months. Subsequent delay was described to arise from refusal to accept the physician's advice or delay in acting on the advice(Pack & Gallo, 1938). Delay in seeking help for treatment has also been demonstrated for other conditions aside from cancer such as in antenatal care (Manda-Taylor L, Sealy D-A, 2017).

A literature review of studies on cancer delay was conducted on data published in English journals up to date. Searches were made using various databases such as PubMed, Scielo electronic databases among others for a combination of terms such as: cancer delay, cancer experience and cancer help-seeking behavior, factors leading to delay in presentation for cancer treatment. References from relevant studies were also used to trace other studies.

This literature review explores the three dominant themes of the research questions. First studies done to assess the duration of delay, that is the time interval between onset of symptoms and initial presentation for treatment and the interval that follows till initiation of treatment, are reviewed. Patient factors associated with delay have been divided into the individual or behavioral factors and socioeconomic and demographic factors. Finally significant studies on health system (and physician) factors leading to delay in treatment have also been reviewed.

2.2 Theoretical Review

Several models of the diagnostic pathway have been used to describe the stages from the onset of symptoms to initiation of treatment. The diagnostics pathway has thus been divided into three component intervals termed as patient delay, doctor delay and system delay depending on the point at which the delay occurs (Rikke Pilegaard Hansen, Olesen, Sørensen, Sokolowski, & Søndergaard, 2008; Olesen, Hansen, & Vedsted, 2009; Fiona Walter et al., 2012). Patient delay may occur when the patient does not interpret the signs and symptoms appropriately and thus

fails to react in a timely manner. Doctor delay may occur when a healthcare provider, at the primary healthcare level, does not evaluate the patient adequately to consider the possibility of cancer and provides the wrong management for the patients' symptoms. System delay is about the clinical pathways that are initiated upon the initial consultation with the healthcare provider, the investigations, and referral until the diagnosis of cancer is confirmed and the appropriate treatment instituted (F Walter, Webster, Scott, & Emery, 2012).

Figure 1Categorization of delay
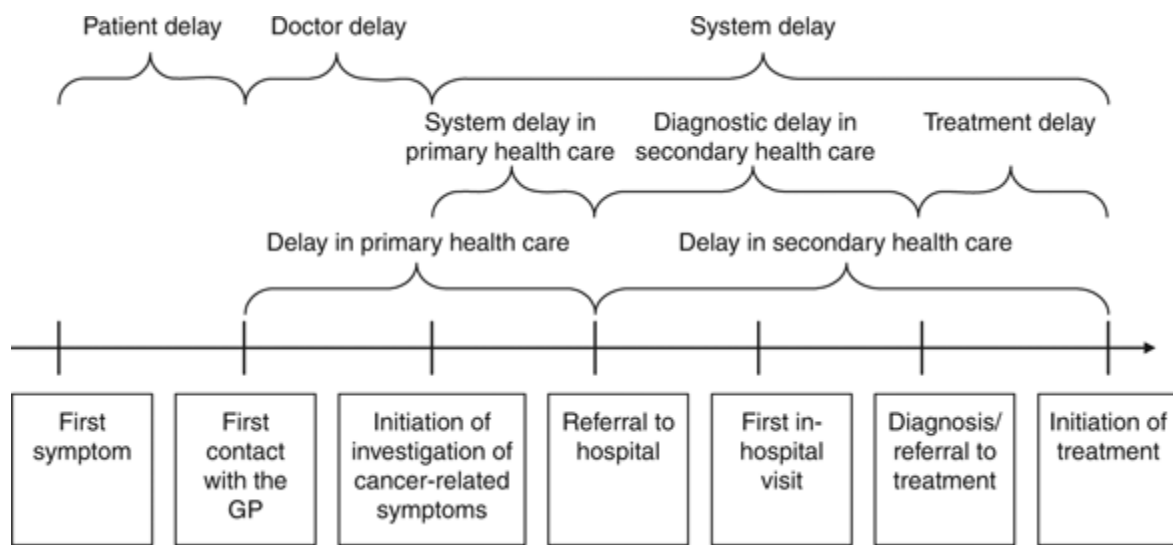
Source: (Rikke Pilegaard Hansen et al., 2008)

2.3 Empirical Review

2.3.1 Duration of delay

Malaysian study defined presentation delay as time taken from symptom discovery to first presentation of more than three months, diagnosis delay as time from presentation to diagnosis of more than a month and treatment delay as time from diagnosis to initial treatment of more than one month (Mujar et al., 2017). Determination of the duration of patient delay is challenging because it is dependent upon the patient's ability to recall which may not be accurate and the onset of symptoms may have been gradual (Brousselle et al., 2017; Weller et al., 2012). According to a Danish population-based cohort study, the median total delay (duration from initial onset of symptoms to diagnosis and treatment) was ninety-eight days. Most of this delay

was due to patient delay (median twenty-one days) and system delay (median fifty-five days) while doctor delay was insignificant. The total delay was shortest in breast and ovarian cancer and longest in prostate and bladder cancer (Rikke P. Hansen, Vedsted, Sokolowski, Søndergaard, & Olesen, 2011). More than 89% of breast cancer patients in Uganda's Mulago National Referral Hospital delayed more than three months (with an overall median of thirteen months) before the first consultation after noticing symptoms (Odongo, Makumbi, Kalungi, & Galukande, 2015). An earlier study done in Uganda had indicated an average delay of twenty nine months (median twelve months) among breast cancer patients and the delay was worse among rural patients (Galukande, 2014). A study done to assess the variation in promptness of presentation in patients with one of eighteen cancers described prompt presentation as being less than fourteen days and non-prompt presentation as fifteen or more days. The overall median patient interval was ten days (Keeble et al., 2014).

A retrospective observational study conducted in a primary care setting concluded that there is considerable delay in the management of colorectal cancer, especially in time to consultation and time to initiation of treatment. The median duration from onset of symptoms to initiation of treatment (total delay) was 138 days (Van Hout, de Wit, Rutten, & Peeters, 2011). A Colorectal Cancer Study conducted at Cross Cancer Institute in Edmonton, Alta, revealed that 51% of symptomatic patients delayed seeking medical advice for more than one month (Tomlinson, Wong, Au, & Schiller, 2012).

Among patients with non-small cell lung cancer patient delay was found to be 49.9+/-96.9 days, doctor delay was 87.7+/-99.6 days, and total delay was 131.3+/-135.2 days. The referral delay was 61.6+/-127.2 days and the diagnostic delay was found to be 20.4+/-44.5 days (Yurdakul et al., 2015).

Studies have also shown that the duration of delay depends on the tumor location. One study revealed the longest median duration to presentation with head and neck cancers (thirty days) and the shortest with bladder cancer (two days) patients with prostate and lung cancer were referred much later compared to other tumors with breast cancer patients experiencing the shortest delays in referral (Baughan, O'Neill, & Fletcher, 2009). In a separate study, prompt

presentation was more frequent in patients with bladder and renal cancer and least frequent in head and neck cancers (Keeble et al., 2014).

2.3.2 Patient (individual and behavioral) characteristics associated with delayed presentation

A qualitative study done to study delay among women reporting symptoms of breast cancer concluded that help-seeking behavior is influenced by a mixture of the patient's knowledge, perceptions, beliefs and attitudes (Burgess, Hunter, & Ramirez, 2001). The study suggested that the most important step in seeking help for women with breast cancer is in symptom identification. Women who experienced unexpected symptoms of breast cancer such as breast pain without a breast lump were more likely to delay in seeking help. Other women with seemingly 'ambiguous symptoms' chose not to bother their GP with 'unnecessary consultations'. Some women expressed their fear of the likely medical interventions as their reason for delaying to seek help while some delayed seeking help due to other competing priorities such as work or family (Burgess et al., 2001).

Patients may also tend to trivialize their symptoms or look for easier alternatives such as over the counter medication to manage symptoms thus delay in seeking appropriate diagnosis and treatment (Tomlinson et al., 2012). A cross-sectional study done to assess cancer awareness and barriers to medical help-seeking among Scottish adolescents showed that awareness of signs and symptoms of cancer is low and barriers to seeking medical help are high in this age group and are influenced by contextual (for example, ethnicity, gender, knowing someone with cancer), and emotional (for example, anxiety, fear, worry) factors (Hubbard et al., 2014).

A systematic literature review of studies conducted in Egypt, Nigeria, Ghana, Kenya and Libya identified the factors contributing to late presentation of breast cancer among most African women as negative symptom interpretation, fear, belief in alternative medicine, social relations and networks, lack of trust and confidence in orthodox medicine, and access to healthcare (Donkor et al., 2015). A South African study showed that patients' fear of treatment modalities and associated adverse effects contributed more to delays than socioeconomic or demographic factors (Rayne et al., 2017).

According to reports from two systematic reviews across cancer sites, non-recognition of symptom seriousness is the main patient-mediated factor resulting in increased time to presentation. Fear of cancer is a contributor to delayed presentation, while sanctioning of help seeking by others can be a powerful mediator of reduced time to presentation (Macleod, Mitchell, Burgess, Macdonald, & Ramirez, 2009). Better knowledge of the signs and symptoms of cancer may help people recognize possible cancer symptoms and therefore reduce appraisal delay, while more positive attitudes towards help-seeking may reduce behavioral delay (Simon, Waller, Robb, & Wardle, 2010). In a study conducted among patients with oral and oropharyngeal cancers the patients attributed lack of knowledge on oral cancer as the main reason for delay. Most patients assumed the symptoms were trivial and expected them to subside without much treatment (Rogers, Vedpathak, & Lowe, 2011). Recognition of the risk of cancer and persistence of the symptoms motivate help seeking behavior (Quaife et al., 2014; Whitaker, Macleod, Winstanley, Scott, & Wardle, 2015). Studies have also shown that when patients have better knowledge of the signs and symptoms of cancer, they might be able to recognize the cancer symptoms and seek care thus reducing the appraisal delay. Having positive attitudes towards help-seeking could also contribute to reducing behavioral delay (Simon et al., 2010). In addition to symptom misattribution, patients also cited other reasons such as the patients' social responsibilities as barriers to earlier presentation(Scott, Grunfeld, Main, & McGurk, 2006).

The use of Complementary and Alternative Medicine (CAM) among patients has also been shown to be associated with delays in presentation and diagnosis (Mujar et al., 2017). Studies have also shown the association of cultural beliefs and acculturation with delays in presentation (Tejeda, Gallardo, Ferrans, & Rauscher, 2017).

A thematic review of studies on delay among cancer patients, cases at the National Reporting and Learning System and consultation with relevant stakeholders in the United Kingdom was conducted by the NHS for the period between 2000 and 2008 identified the main risk factors in patient delay as symptom recognition and interpretation, psychological and behavioral factors and the age of the patient (Minghella E, Lakhani M, Hughes C, 2010).

2.3.3 Patients' socioeconomic and demographic differences associated with delay

Late presentations and higher mortality from cancer have been found among people of lower socioeconomic background and from ethnic minority populations (Waller et al., 2009). Ethnic minorities and people living in poverty frequently present with advanced cancer (Haynes, Smedley, & IoM(U.S.), 1999). Lack of symptom knowledge and awareness, fearful and fatalistic beliefs and emotional barriers were found to be more frequent in people within lower socioeconomic groups. These were found to contribute to prolonged symptom presentation among lower socioeconomic groups (McCutchan, Wood, Edwards, Richards, & Brain, 2015).

A retrospective study of delayed presentation among breast cancer patients done in Hong Kong concluded that delayed presentation was contributed to by socio economic/demographic factors such as low level of education and awareness of cancer, low family income and also a limited access to public health facilities since most citizens cannot afford private health care(Yau et al., 2010). There is strong evidence of an association between older age and patient delay for breast cancer, between lower socio-economic status and delay for upper gastrointestinal and urological cancers and between lower education level and delay for breast and colorectal cancers (Macleod et al., 2009). With less regular follow-up, patients with low socio-economic status have a two-fold risk of having late stage breast cancer regardless of cancer characteristics and detection mode (whether during screening or due to presence of clinical signs) (Orsini, Trétarre, Daurès, & Bessaoud, 2016).

A population-based breast cancer screening program was implemented in the Central Denmark Region in 2008–2009 with the objective to examine the association between socio-demographic characteristics and screening participation. Non-participation was associated with older age, immigrant status, low OECD-adjusted household income, high and low level education compared with middle level education, unemployment, being unmarried, distance to screening site >20 km, being a tenant and no access to a vehicle. Clients from socially deprived backgrounds were also more likely to be passive than active participants (Flytkjaer Jensen, Fischer Pedersen, Andersen, & Vedsted, 2012). More advanced and metastatic cancer is more likely in women who are higher deprivation groups and rural areas. Women who attend public hospitals and also those who miss out on screening events are more likely to have more advanced

cancers at diagnosis. This may be due to patient level or system level barriers that hinder access to healthcare (Seneviratne et al., 2016).

Postmenopausal women with shorter education, lower disposable income, no access to organized mammography screening and who were residents of rural areas were more likely to be diagnosed with higher risk breast cancers (Dalton et al., 2006). Delay among women with breast cancer is worst among patients with no social support (Odongo et al., 2015). Young patients, ethnic minorities and women also experience longer physician delays (Georgios Lyratzopoulos, Neal, Barbiere, Rubin, & Abel, 2012).

Patients with medical insurance were found to be less likely to present with advanced disease (stage III/IV) than those without for some cancers such as lung and prostate but not for breast or colorectal cancers where presentation times were similar (McCarthy et al., 2007).
 At Kenyatta National Hospital, women with advanced stages of cervical cancer were more likely to be single, HIV positive, older (50-75 years) and have lower levels or no education (Makena Frida, Carole Atieno, & Habtu, 2017). Similar findings have been shown among Danish patients with cervical cancer (Ibfelt et al., 2012).

Some studies have showed a relationship while in others there was no relationship between factors such as marital status, education and income with patient delay. According to one study women who were employed and those who smoked experienced longer patient delay than women who were retired and those who did not smoke, but there were no specific socio-economic predictors for patient delay in men (Minghella E, Lakhani M, Hughes C, 2010). According to Hansen et al. socioeconomic predictors of delay could be used to hypothesize social inequalities in the distribution of delay, but, in general, only a few socioeconomic variables predicted delay in cancer diagnosis. The authors suggested that future research should examine a broader array of patients' personal characteristics (Rikke Pilegaard Hansen et al., 2008).

2.3.4 Health system factors associated with delayed presentation

Pack and Gallo suggested that criticism on the part of the physician was based on the action taken after reviewing a patient with symptoms rather than solely on the time elapsing from presentation to initiation of treatment. They described five criticisms according to the type of error: wrong treatment, wrong advice, no treatment and no advice, acceptable treatment but delay in referring when no improvement results, and inability to diagnose within a month. They thus recommended that training of the medical practitioners in first contact with patients is very important to enable them to make early and correct diagnoses of cancer (Pack & Gallo, 1938).

Prolonged waiting times for review by medical specialists and for the diagnosis to be made also significantly contribute to the delay. Upon review of patients, physicians have also been guilty of conducting inadequate physical examinations on the patients thus a number may fail to diagnose cancer in a timely manner (Tomlinson et al., 2012). Inaccessibility of healthcare professionals greatly contributes to prolonging the delay (Scott et al., 2006).

Misdiagnosis occurring either through treating patients symptomatically or relating symptoms to an existing health problem other than cancer was found to be an important theme across cancer sites. For some cancers, this could also be linked to inadequate patient examination, use of inappropriate tests or failing to follow-up negative or inconclusive test results (Macleod et al., 2009).

The type of cancer was found to contribute to physician delay in a data analysis conducted in England based on the 2010 National Cancer Patient Experience Survey. This analysis revealed that patients with multiple myeloma, pancreatic cancer, stomach cancer and lung cancer were more likely to have had three or more pre-referral consultations while patients with breast cancer, melanoma, testicular cancer and endometrial cancer were more likely to have been referred after one or two consultations (Georgios Lyratzopoulos et al., 2012).

Sally Brown et al suggested that health system factors that may contribute to delays in diagnosis hence poorer outcomes may include centralization of services, free movement of patients

between primary providers, access to secondary care and the existence of patient list systems. They however did not establish a causal correlation between healthcare system characteristics and cancer outcomes (Brown et al., 2014).

A qualitative study conducted in Denmark concluded that that merely focusing on the patient in order to understand care-seeking decisions draws attention away from issues such as power and social control in the clinic, but also wider societal issues such as the economic and organizational aspects of health care (Andersen, Vedsted, Olesen, Bro, & Søndergaard, 2011). Missed opportunities for diagnosis of cancer may occur anywhere along the diagnostic pathway due to reasons such as rigid consultation norms, inadequate history and physical examination, language barriers, comorbidity, long waiting times, referral norms, patients' failure to take medical advice, complex diagnostic pathways and lack of follow up of abnormal or borderline normal results (G Lyratzopoulos, Vedsted, & Singh, 2015).

Healthcare provider delay has been shown to be related to initial misdiagnosis and insufficient examination by the practitioner. Some physicians may attribute symptoms to a non-cancer cause and fail to treat accordingly. Inconclusive or false negative test results have also been seen as factors causing delays. Patients who did not see their GP prior to diagnosis (those attending screening, presenting to A&E or secondary care) had shorter delays than those who consulted their GP. Co-morbidity may contribute to delay with GPs attributing the symptoms to the existing disease, though it has also been shown to prompt earlier referrals. Patient characteristics were also identified as having some influence on provider delay; men experienced longer doctor delays, and women with a larger household fortune experienced the shortest delay. Similarly, older people, those from higher social classes and higher socio-economic groups were referred more quickly, although the findings were inconclusive regarding gender (Minghella E, Lakhani M, Hughes C, 2010).

Healthcare system delay is under-researched but there is evidence to suggest that, even with improved diagnostic and treatment pathways in cancer, there are still problems with: waiting times for tests; waiting times for non-urgent referrals; administrative delays for follow up (leading to increased patient delays). Implementing referral guidelines and developing a faxable

urgent referral pro forma along with educational meetings reduced average waiting times (Minghella E, Lakhani M, Hughes C, 2010).
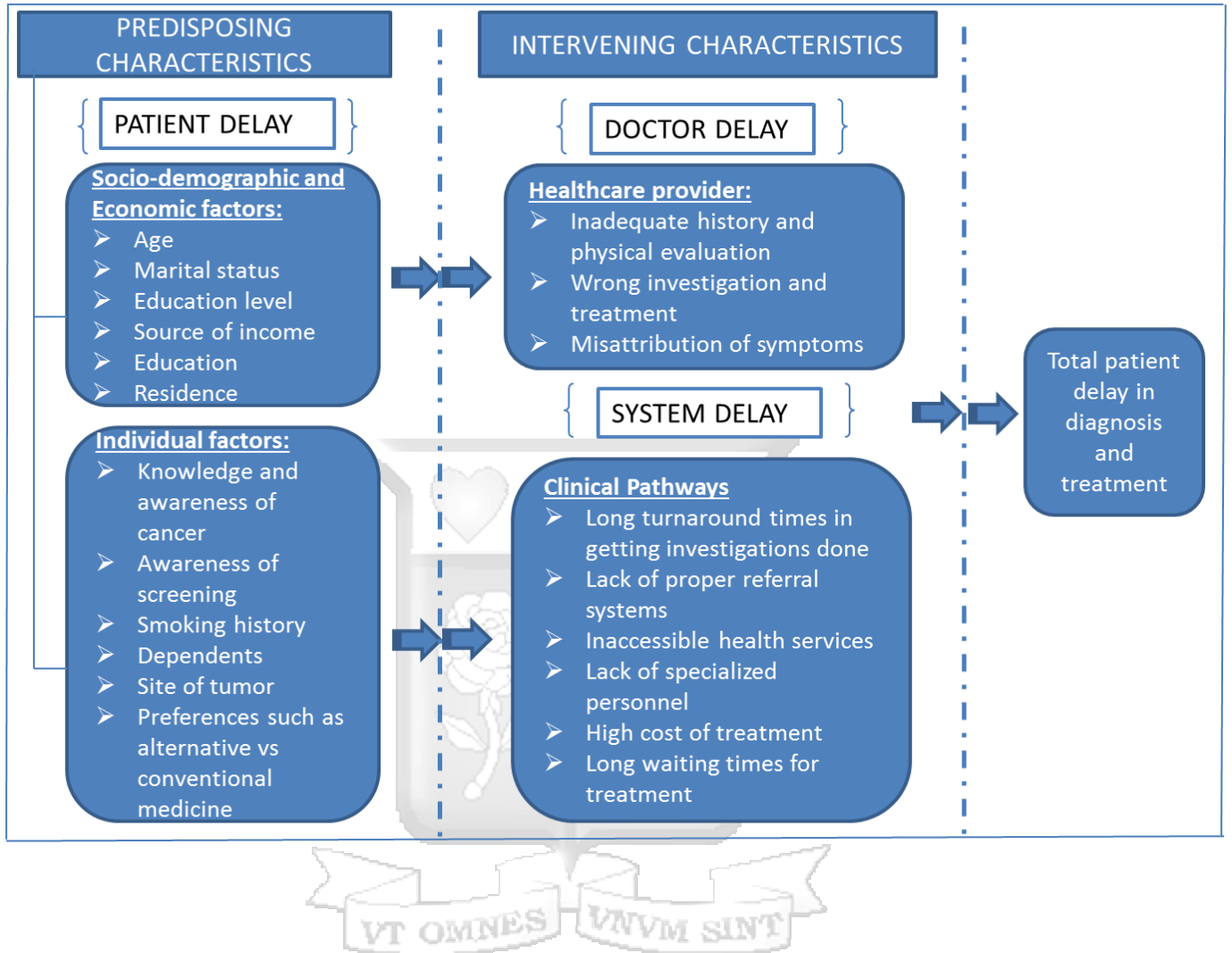
2.4 Conclusion

Most of the studies conducted have focused on patient delay and reveal that patient factors associated with delay play a huge role in the delayed presentation for cancer treatment. Patients' lack of awareness of cancer symptoms leads to lack of recognition and misattribution which adversely affect the duration prior to diagnosis and institution of treatment. Socially deprived (the poor, less educated, low socio-economic status) patients are more likely to experience delays in cancer diagnosis and treatment. However, the contribution of health provider and the health system to the delay cannot be overlooked. Unsuspecting healthcare workers may attribute patients' symptoms to other causes aside from malignancy and thus fail to adequately investigate, refer or initiate treatment. In countries with a shortage of cancer specialists and treatment facilities patients face delays due to prolonged waiting times. The material drawn in this review will provide direction in the formulation of the conceptual framework and the data collection tools.

2.5 Conceptual Framework

Many studies have focused on patient delay as the most significant factor in delayed presentation for cancer treatment. However, some studies have also shown that delay can also be attributed to some healthcare provider and system factors.

In this study the independent variables are patient factors classified into socio-demographic and individual factors. These interact with the intervening factors (health system-related factors) and lead to either early or delayed diagnosis of cancer. Older age, for example, has been associated with longer delay in seeking health due to various reasons such as lack of adequate social support. Older patients are more likely to have comorbidities hence probable cancer symptoms maybe inadequately evaluated and often dismissed as sequelae of the other existing illnesses leading to a delay in diagnosis.

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Figure 2 Conceptual Framework

PREDISPOSING CHARACTERISTICS

INTERVENING CHARACTERISTICS

PATIENT DELAY

Socio-demographic and Economic factors:
- Age
- Marital status
- Education level
- Source of income
- Education
- Residence

Individual factors:
- Knowledge and awareness of cancer
- Awareness of screening
- Smoking history
- Dependents
- Site of tumor
- Preferences such as alternative vs conventional medicine

DOCTOR DELAY

Healthcare provider:
- Inadequate history and physical evaluation
- Wrong investigation and treatment
- Misattribution of symptoms

SYSTEM DELAY

Clinical Pathways
- Long turnaround times in getting investigations done
- Lack of proper referral systems
- Inaccessible health services
- Lack of specialized personnel
- High cost of treatment
- Long waiting times for treatment

Total patient delay in diagnosis and treatment

VT OMNES VNVM SINT

CHAPTER THREE
RESEARCH METHODOLOGY

3.1 Introduction

This study sought to assess the factors associated with delays in cancer treatment and consequently contribute to the ongoing dialogue and efforts in cancer control in Kenya. This section describes the methodologies, the study area including the population and study tools. Ethical issues pertaining to the study are also mentioned here and how they were handled.

3.2 Study design

This study employed a descriptive cross-sectional design. Descriptive studies literally describe the phenomenon of interest and observed associations in order to estimate certain population parameters such as prevalence, for testing hypotheses, and for generating hypotheses about possible cause and effect associations between variables(Bowling, 2014). This design was chosen for this study because the study aimed at identifying and describing factors among the patients with advanced stages of cancer that could have contributed to their delay in diagnosis and treatment. Cross-sectional surveys are also easy to undertake and economical in terms of time and resources, and the standardized data collected are easily coded for analysis.

A structured questionnaire tool was administered to all consenting patients to generate data that was used to assess the demand-side factors influencing cancer treatment seeking behavior. A structured questionnaire enables the collection of unambiguous and easy-to-count answers for quantitative data (Bowling, 2014).

3.3 Sampling

3.3.1 Study setting and Population

This study was carried out at the Kenyatta National Hospital's Cancer Treatment center. Kenyatta National Hospital is Kenya's main public referral facility and is located in Nairobi's Upper Hill area. It has a bed capacity of 2000 inpatients with an average annual outpatient attendance of 600,000 and annual inpatient attendance of approximately 89,000. KNH was purposely selected as it is the only public facility with the capacity to offer comprehensive cancer treatment services that include diagnosis, surgery, chemotherapy, hormonal therapy and

immunotherapy, radiotherapy (2D, 3D and Brachytherapy, radioactive iodine treatment, and palliative care services. The other public cancer treatment facilities are Moi Teaching and Referral Hospital in Eldoret and Coast Provincial general hospital in Mombasa, which offer surgery, chemotherapy and palliative care services. Patients who can afford private health care can also access comprehensive cancer treatment at private facilities such as Nairobi Hospital, MP Shah, Aga Khan University Hospital and Texas Cancer Center, all located within Nairobi.

The KNH cancer treatment center thus attracts high numbers of cancer patients from rural and urban areas all over the country and the East African region. The cost of treatment is lower than in private facilities within the region thus KNH serves a socioeconomically diverse population mostly from the middle and the lower socioeconomic classes.

The cancer treatment center has had an almost constant number of five specialists and five medical officers for a long time which is grossly inadequate to serve all these patients. Many cancer patients in the country will almost invariably end up at KNH for treatment. This is because KNH may be the only affordable option for those unable to afford private healthcare and also for those who exhaust their finances or insurance cover at private facilities. In addition, KNH being centrally located in the country's capital city makes it easier to access for patient in different parts of the country.

The KNH Cancer Treatment Centre receives between 250-300 new patients from different parts of the country every month (Records Department, 2018). This translates to an average of 3,300 new cancer patients every year. In addition to close to 25,000 patients who are different stages of the treatment and follow up cycle also visit the clinic. Cancer is among the leading causes of hospitalization at Kenyatta National Hospital. According to the hospital's Cancer Registry, 53% of the patients admitted in 2015/2016 were due to cancer related morbidity. Mortality due to cancer accounted for around 15% proportionate to other diseases. More than 75% of the new patients present for treatment at advanced stages, that is, stage three and four disease.

The target population consisted new patients with advanced stages of cancer (stage three and four) presenting for treatment at the cancer treatment center during the month of April 2018. This study focused on the patients who were presenting to start their treatment, either chemotherapy, radiation therapy or both, after the diagnosis and other investigations had been done. This group of patients was chosen because they had undergone the major steps of experiencing symptoms,

diagnosis and now starting their treatment and thus they could respond to all sections within the questionnaire.

3.3.2 Sampling and Sample Size Determination

This study used the non-probability purposive sampling method in selection of participants. The technique was favorable for this study because of the limited resources, both time and financial, that would have been required for a probability sampling technique. The researcher set out to identify all patients with stage three and four cancer as they attended the cancer treatment center during that period. Each of these patients was taken through the information sheet concerning the purpose of the research and was assured of the confidentiality of the information provided. Those who agreed to participate in the study then provided their written consent by signing the provided consent forms. The study was conducted over a period of two weeks from 11th to 22nd April, 2018. A total of 69 participants participated in this study.

3.4 Eligibility Criteria

Eligibility criteria included male and female adult patients with histologically proven stage III or IV cancer, and ability to communicate in English or Swahili.

Patients who had previously begun treatment, those below the age of eighteen years and those who were too sick to communicate were excluded from the study.

3.5 Data Collection, methods and procedures

Data collection was by use of standardized questionnaires. The questionnaire was developed following the review of other similar studies done elsewhere, including the Cancer Awareness Measure from the UK, and also based on the specific objectives of the study. The questionnaires consisted mainly of closed-ended questions on bio data such as gender, age, level of education, and occupation; awareness of cancer and also had a section on health system factors. Some sections included Likert scale type of questions. Patients' medical records were also reviewed to ascertain the stage of the disease and also when the cancer diagnosis was made which was correlated with the time of onset of symptoms as reported by the patient to confirm its correctness.

Most patients were assisted in filling the questionnaires by the investigator and the probing was done in English or Swahili as appropriate. Application of the questionnaires through face-to-face interviews was desirable due to the challenges that may arise with self-administered questionnaires among mixed populations of educated patients and others with little formal education. Data collection was carried out solely by the primary investigator. Unique patient identifiers were used to identify the patients so as to maintain confidentiality.

3.6 Data Management and analysis

Independent variables of interest were: Demographic details such age, marital status and residence; socio-economic details such as education and occupation; individual factors such as knowledge and awareness level, smoking and preferences such as for alternative medicine; and health system factors such as availability of diagnostic tests, promptness of referral, proximity to diagnostic center, accessibility, duration of diagnostic test, and cost of treatment. The dependent variable was the late diagnosis and treatment.

Quantitative data collected was entered into a Microsoft Excel spread sheet for clearance and analyzed using the MINITAB 14 statistical package. Descriptive analysis using measures of central tendency such as the median and mode, frequencies and range were then calculated and summarized in graphs and charts.

3.7 Measures of validity and reliability

Pre-testing of the questionnaire was done to ensure that it was easy to understand and able to elicit the desired responses from the participants. As a result, the section of the questionnaire containing the health system factors was edited and reformatted using the Likert-scale type questions.

3.8 Ethical Considerations

The proposal was submitted to the Strathmore University Institutional Ethics Review Committee and subsequently, ethical approval was obtained (SU-IRB 0190/18). An information sheet containing the purpose of the study, confidentiality and the right not to participate in the study, and a subsequent consent form, was prepared and administered to each participant, either in English or in Swahili to ensure informed consent. No reference to real identifiers such as

patients' names or any reference to individual participants was made so as to ensure confidentiality. There were no incentives offered to the participants.

CHAPTER FOUR

PRESENTATION OF RESEARCH FINDINGS

4.0 Introduction

This chapter describes the results obtained from the study. The main objective of this study was to examine the factors associated with late presentation of cancer patients for diagnosis and treatment at Kenyatta National Hospital. This study targeted adult cancer patients presenting with advanced stages of cancer, that is, stage three and four cancers.
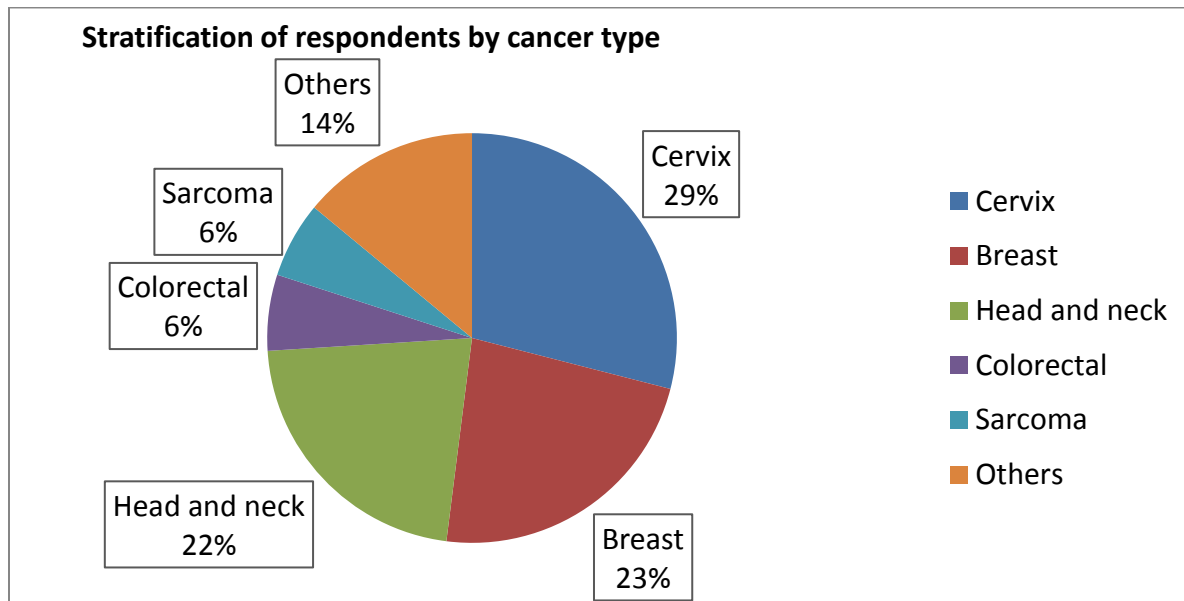
The results are presented in four main sections aligned to this study's specific objectives: The first section describes the duration of delay prior to consulting a healthcare provider. The second section describes the socio-demographic and economic factors associated with delay among the patients sampled. The third section highlights knowledge and awareness of cancer and its prevention among the participants and the fourth section is about health system factors (doctor and system factors) that were significant for delay among these patients.

All those eligible were confirmed to have either stage three or four of cancer. A total of 69 patients responded to the questionnaires administered. 7 of the questionnaires were excluded from the analysis due to missing responses, thus a total of 62 questionnaires were analyzed.

The type and stage of cancer was ascertained by reviewing the patients' medical records. The distribution of the cancer types among the respondents is shown in figure 3 below. The top two cancers were cervical (29%) and breast cancer (23%), followed by cancer of the back of the nose/upper throat.
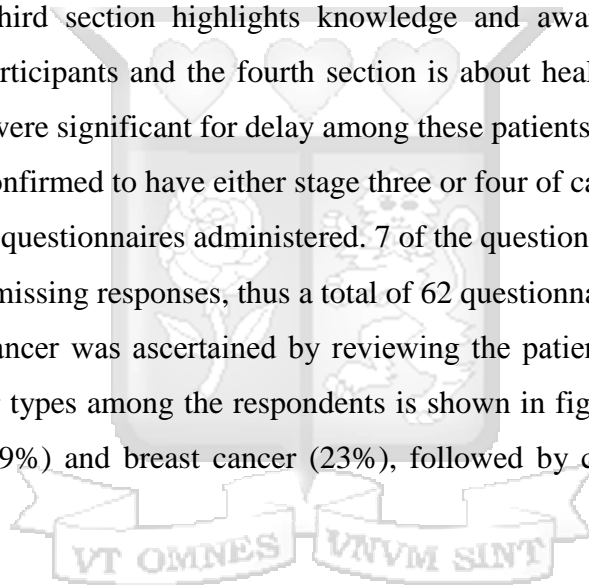
Figure 3 Stratification of respondents by cancer type

Stratification of respondents by cancer type

- Cervix 29%
- Breast 23%
- Head and neck 22%
- Colorectal 6%
- Sarcoma 6%
- Others 14%

Legend:
- Cervix
- Breast
- Head and neck
- Colorectal
- Sarcoma
- Others

4.1 Duration of symptoms prior to consulting a healthcare provider (Patient delay)

The study assessed the duration that the participants had experienced their symptoms prior to consulting a healthcare provider (Figure 4 below).

From Figure 4, about 78% of the respondents had had their symptoms for more than six months, 13% had had their symptoms for 3-6 months and 10% had had their symptoms for less than three months. 40 respondents (65%) admitted to have used some medication to ease their symptoms prior to their diagnosis of cancer. Of these, 29% used over-the-counter (OTC) medicines, 29% prescription medicines, and 6% used herbal and alternative medicine.

Figure 4 Duration of delay

Duration of patient delay

- 0-3 months
- 3-6 months
- 6-12 months
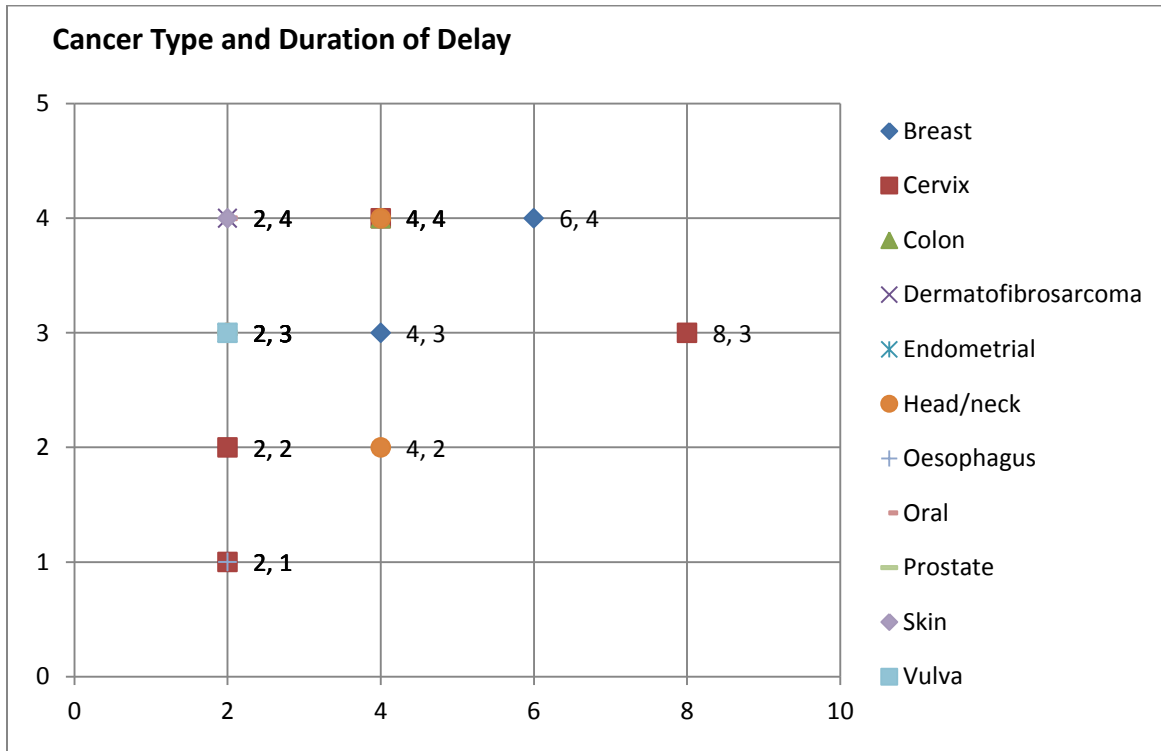- More than 12 months

0-3 months 10%

3-6 months 13%

6-12 months 38%

More than 12 months 39%
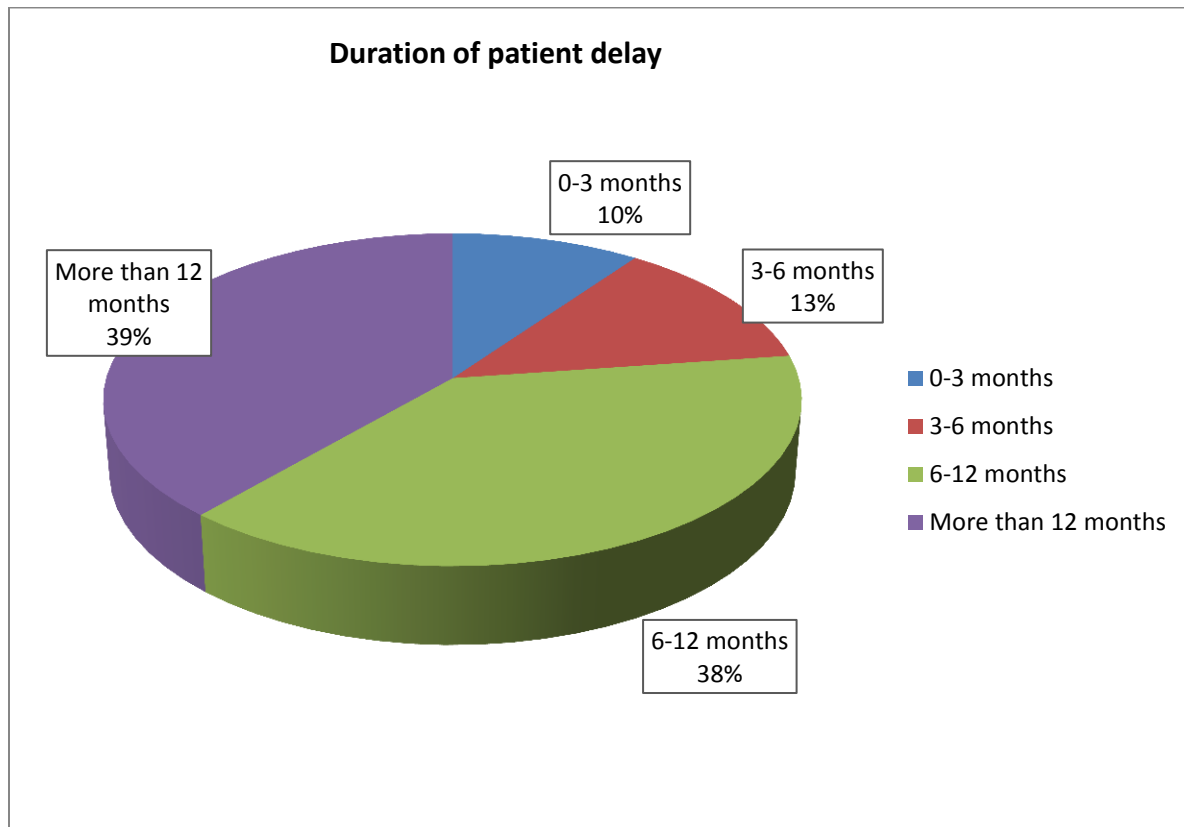
The delay (as in figure 5 below) was longest for breast cancer where ten patients delayed for more than six months (four of them had delayed to consult a medical practitioner for more than a year). This was followed by cervical cancer where eight patients delayed for more than six months. Six patients with head and neck cancer delayed for more than six months before seeking medical advice while for the other cancers in the sample the delay ranged from 3-12 months. Breast, cervical and head and neck cancers had the highest prevalence and thus correspondingly contributed to the longest duration of delay.

Figure 5 Duration of delay by cancer type

Cancer Type and Duration of Delay

Legend:
- ◆ Breast
- ■ Cervix
- ▲ Colon
- ✕ Dermatofibrosarcoma
- ✳ Endometrial
- ● Head/neck
- ＋ Oesophagus
- － Oral
- ▬ Prostate
- ◆ Skin
- ■ Vulva

Data points: 2, 4 | 4, 4 | 6, 4 | 2, 3 | 4, 3 | 8, 3 | 2, 2 | 4, 2 | 2, 1

4.2 Socio-demographic and economic characteristics of patients

The socio-demographic characteristics of interest were age, marital status, residence, education and occupation. The mean age was 49 years, with a median of 46 years old (Figure 6 below).

**Figure 6 Percentage of patients in each age group**
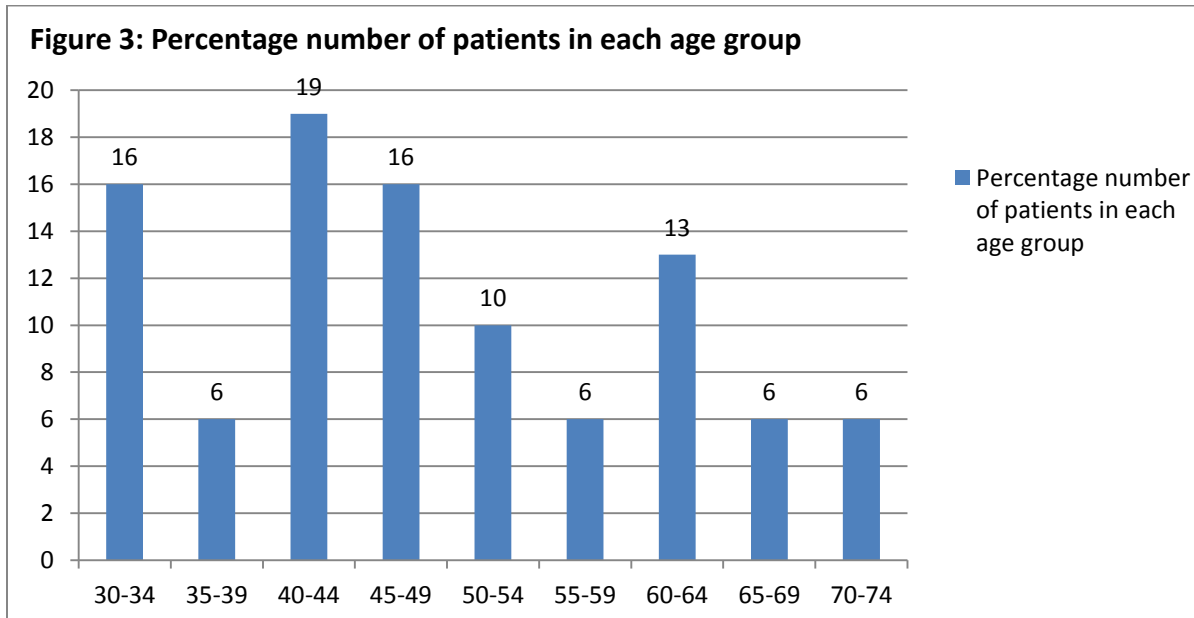
From Figure 6, the youngest patient in the study was 30 years while the oldest was 72 years. The data was further grouped into 5-year age groups and further analyzed. Eighty-seven percent (58 patients) of the patients were still in their productive years, that is, below the sixty-five years retirement age. The highest number of participants, 22 (35%) was in the 40-49 age group, indicating potential high economic losses from the most productive age-groups.

Female participants constituted 68% of the total number of participants, while men were 32%. 71% of the respondents were married, 13% were single (never married), 13% were separated (or divorced) and 3% were widowed. About 58% of them had dependents.

Majority of the respondents (71%) had only up to primary level education; 16% had attained secondary education while only 10% of the respondents had acquired tertiary education. About 3% of the respondents had had no formal education. The education level is shown in figure 7 below.

Figure 7: Education level of the participants
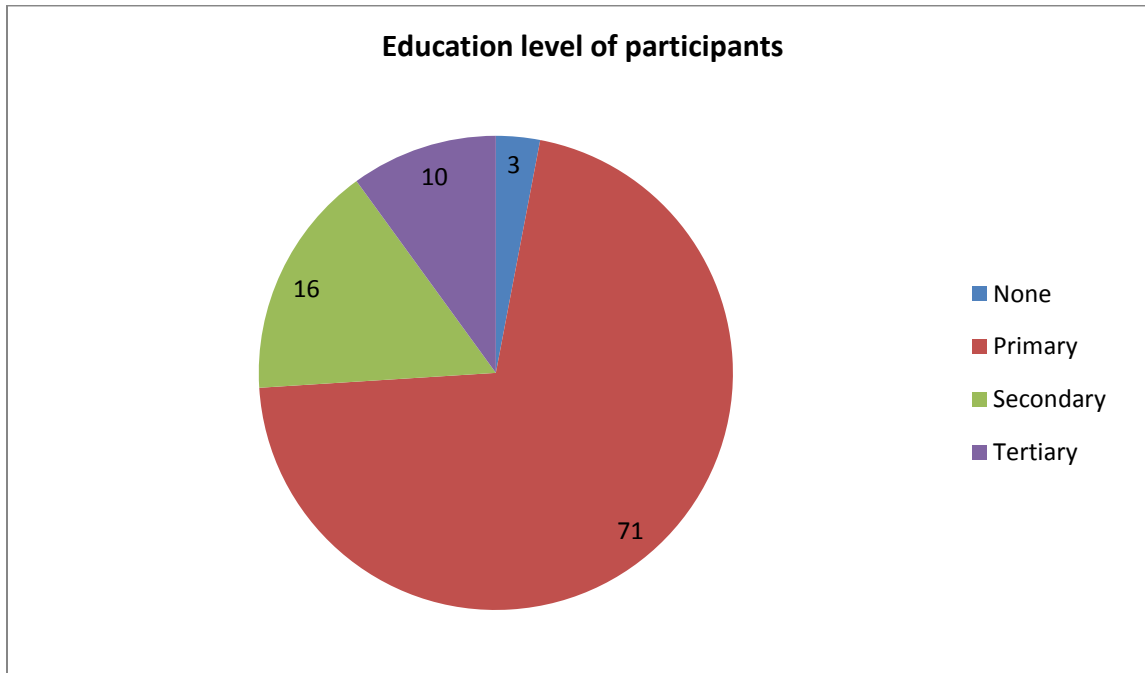
Female respondents reported higher education status than the male respondents; 58% of the female respondents had attained at least primary level education as compared to 29% of the male respondents.

The study also assessed the residence of the respondents. Out of the forty-seven counties in Kenya, the participants in the study only represented 17 counties. Nairobi, Murang'a, Nakuru and Nyeri counties had the highest number of patients with a combined percentage of 49%, and Nairobi County where the hospital is based having 19% of the participants. This could be explained by the proximity and ease of access of these locations to the Kenyatta National Hospital.

Of all the patients, 74% were from rural areas while only 26% were from urban areas. Overall, 84% of the respondents were from the informal sector, 13% were from the formal sector and 3% had no source of income.

Figure 8 Type of residence and source of income
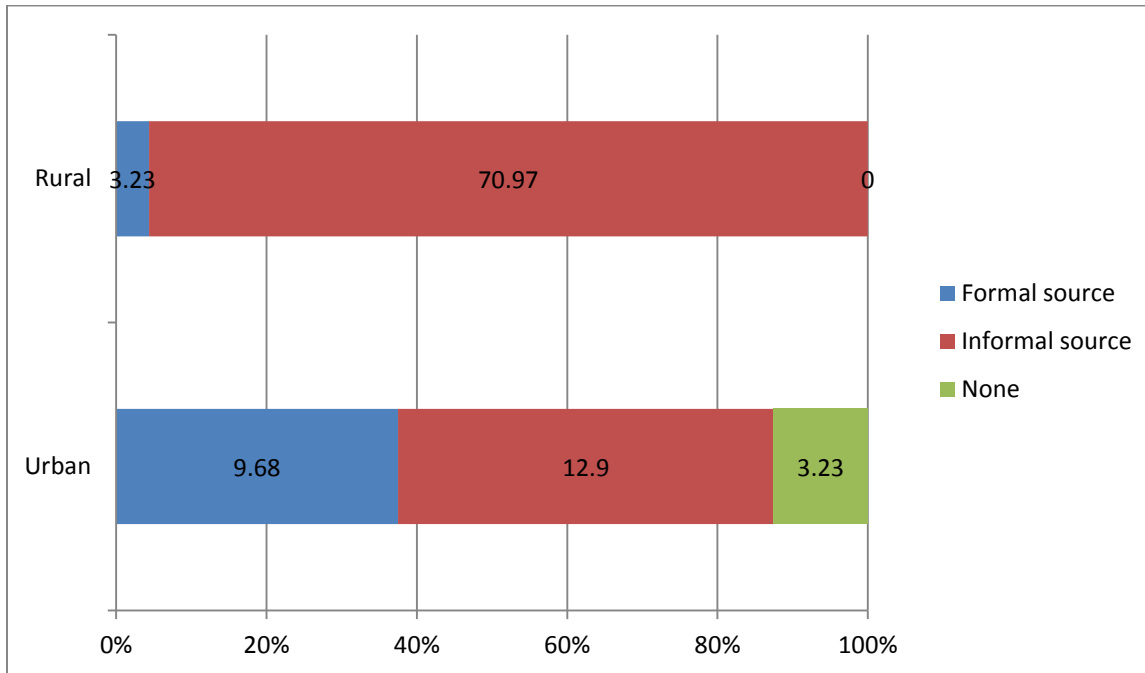
From figure 8 above, 71% of those from rural and 13% of those participants from urban residences were members of the informal sector. The overall picture indicates the likelihood that rural and low-income informal sector cancer patients are more likely to seek treatment from public facilities than other population groups.

Only 14 (23%) of the respondents admitted to a prior history of cigarette smoking. 54 (87%) of the respondents had no other pre-existing illnesses beside their diagnosis of cancer and eight of them admitted to have had other pre-existing conditions.

4.3 Knowledge of cancer and prevention

65% of the respondents denied any knowledge of cancer prior to their diagnosis and correspondingly, only 23% of the respondents had known someone else with cancer before their diagnosis.

40 respondents (65%) admitted to have used some medication to ease their symptoms prior to their diagnosis of cancer. Of these, 29% used over-the-counter (OTC) medicines, 29% prescription medicines, and 6% used herbal and alternative medicine.

71% of the respondents had not heard of any measures that could be taken to prevent cancer and similarly, only 12 of the respondents, that is, 19% had been screened for cancer before their diagnosis.

When queried on the lack of screening (figure 9 below), 50% reported that they were not aware about screening services, 28% said that they thought there is no need for screening and 22% said there were no screening services available near their place of residence.

Figure 9 Awareness of cancer screening services
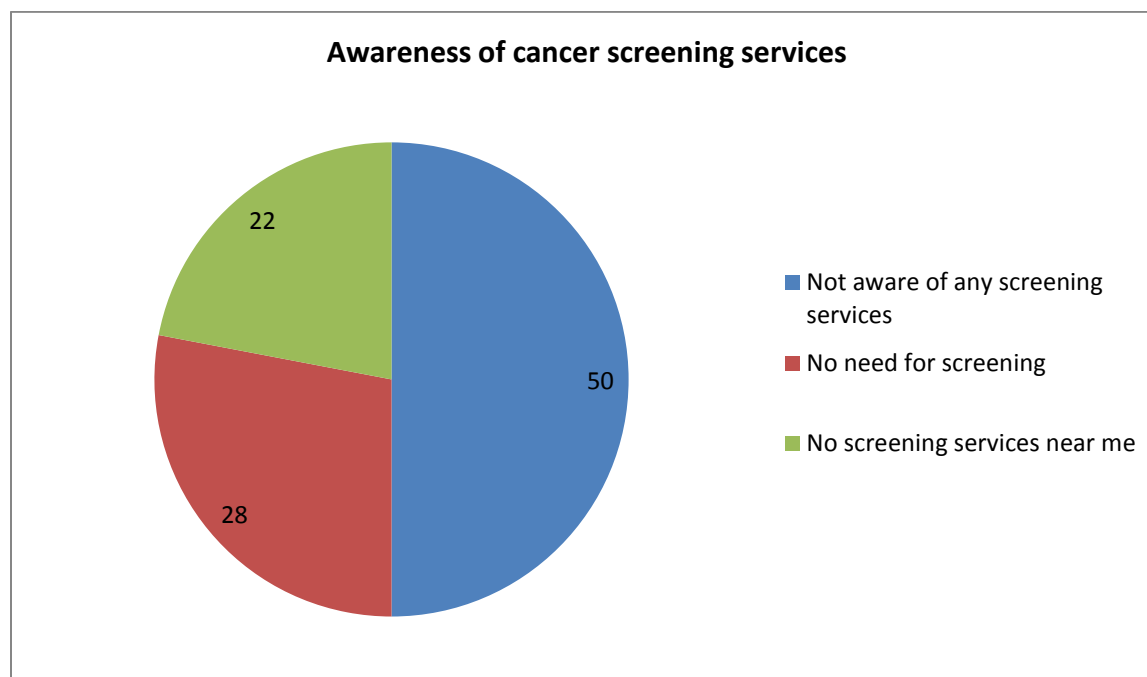
A selected number of possible measures to reduce the risk of cancer were adapted from the Cancer Awareness Measure CAM (Uk, 2008). These were presented to the participants and by use of the Likert scale, the participants were asked to rate the extent to which they agreed with the statements.

Most of the respondents (58) strongly agreed that not smoking and reduced alcohol consumption could reduce the risk of cancer. 40 of the respondents agreed that having a balanced diet could help prevent cancer and 15 agreed on the need for regular cancer screening. Most (52) were not sure about how having knowledge of one's family history was significant in the diagnosis of cancer.

4.5 Health system factors contributing to delayed care

In figure 10 below, the majority of the respondents, 36 (58%), presented to private healthcare providers after discovering their symptoms. 19% presented to primary public and 19% secondary public facilities. Only 3% of the respondents visited tertiary public facilities for evaluation of symptoms prior to their diagnosis of cancer.

Figure 10 Type of health facility that participants presented to for initial evaluation of symptoms

Figure 5 Type of health facility that participants presented to for initial evaluation of symptoms

- Primary level public facility
- Secondary level public facility
- Private facility (primary and secondary)
- Tertiary public facility
- Tertiary private facility
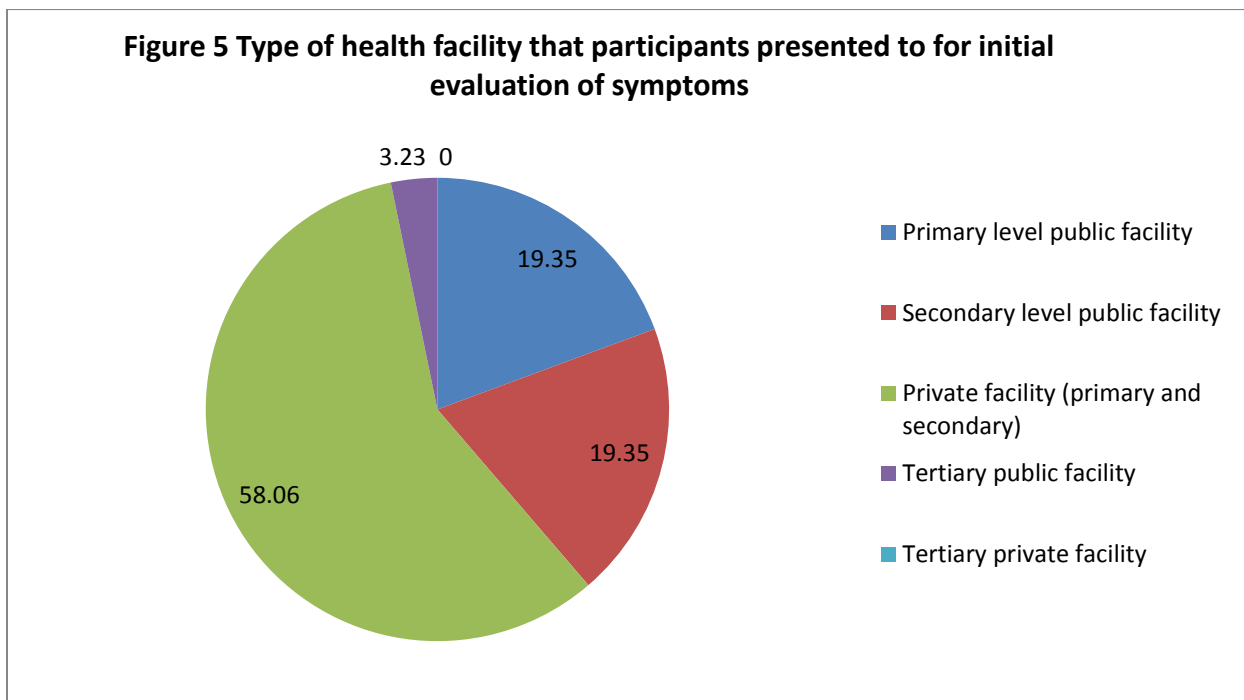
As seen below in figure 11, 28 of the respondents (45%) had their diagnosis of cancer made at private facilities; 39% of them were seen at smaller (primary and secondary level) private facilities while 6% had their diagnosis at tertiary private facilities. The rest (34 respondents) had their diagnosis made at public health facilities; 35% at secondary level public facilities and 19% at public tertiary facilities.

Figure 11 Health care facility where diagnosis was made

Health care facility where diagnosis was made

- Primary public level facility
- Secondary public facility
- Private facility (primary and secondary)
- Tertiary public facility
- Tertiary private facility

Values shown: 0, 6.45, 19.35, 35.48, 38.71
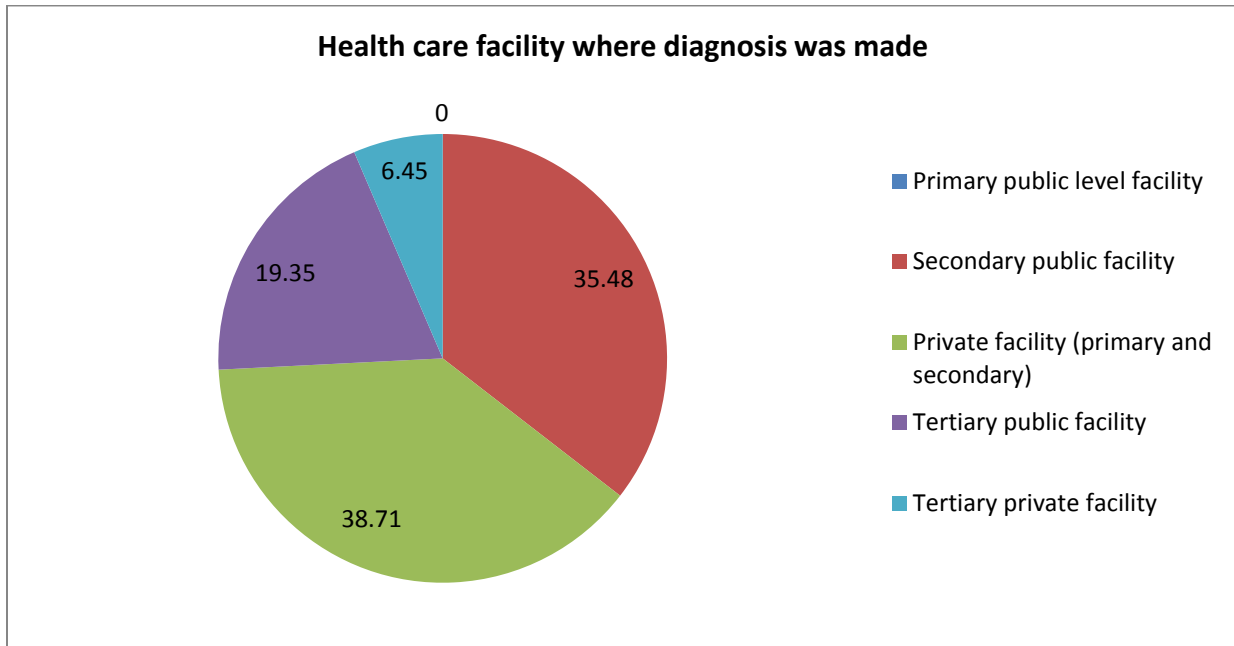
38 of the respondents (61%) had to wait for more than six months after visiting the health facility before knowing that they had cancer. 23% of them waited for a period of 3-6 months and only 16% of them learnt of their cancer diagnosis within three months of presenting to the health facility.

8 of the respondents (13%) received timely initiation of treatment after getting their diagnosis of cancer, that is, within two to four weeks after diagnosis. 26% started their treatment in the first three months after their diagnosis while the majority, 61% had to wait for more than three months before starting their cancer treatment as seen in figure 12 below.

Figure 12 Waiting period before initiation of treatment at KNH
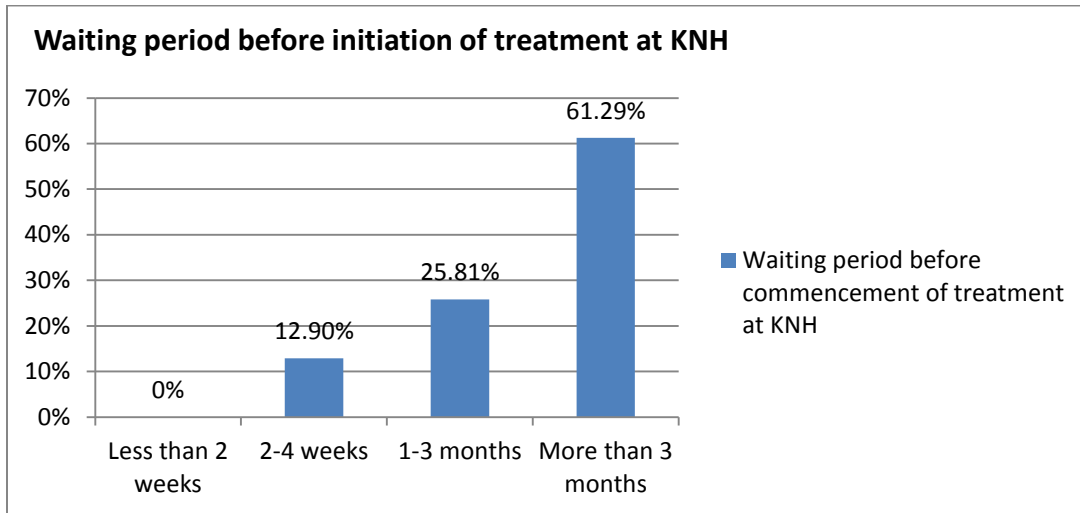
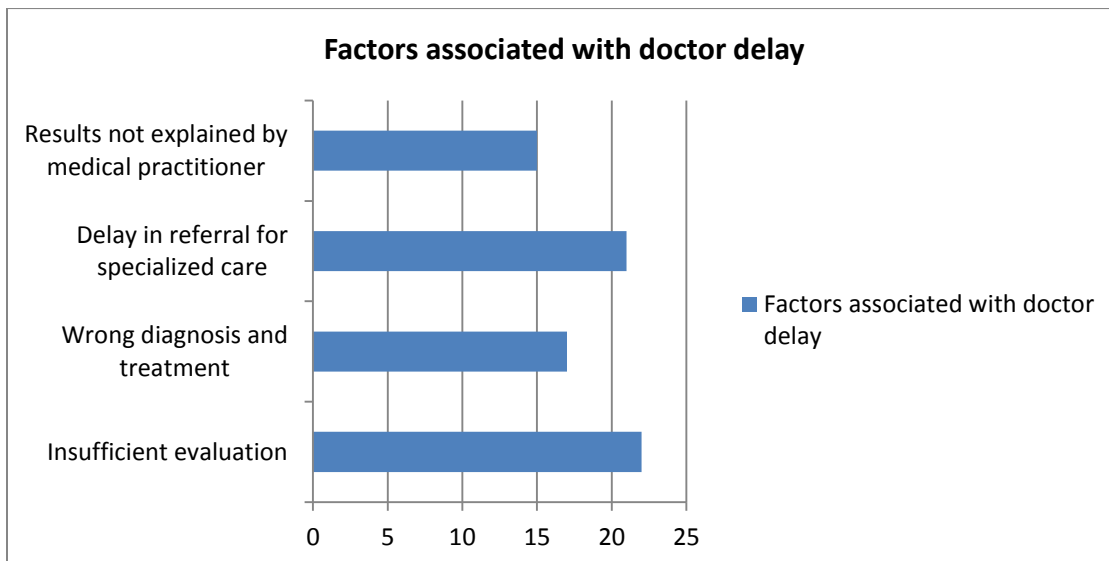Health system factors related to delay in treatment were assessed using a 5-point Likert scale ranging from 0-5 (strongly disagree, disagree, not sure, agree, strongly agree) .The patients were asked to rate the extent to which they agreed with the provided statement. These highlighted factors that were associated with either doctor or system delay. Several respondents (as shown in figure 13 below) strongly agreed that insufficient evaluation, wrong diagnosis and treatment, delayed referral for specialized care and the medical practitioner not explain the results adequately as significant factors in their delay.

Figure 13 Factors associated with doctor delay

Long waiting times was ranked as the highest reason for delay among the health system factors. 38 of the respondents strongly agreed that it was the factor that most contributed to their delay in diagnosis and treatment of cancer. Other factors that also featured significantly include inaccessibility of care in terms of treatment not being available at nearby facilities or there being no facility in the proximity of the patients and 12 respondents said the cost of treatment was unaffordable to them. This has been summarized in figure 14 below.

Figure 14 Health system related factors in delay
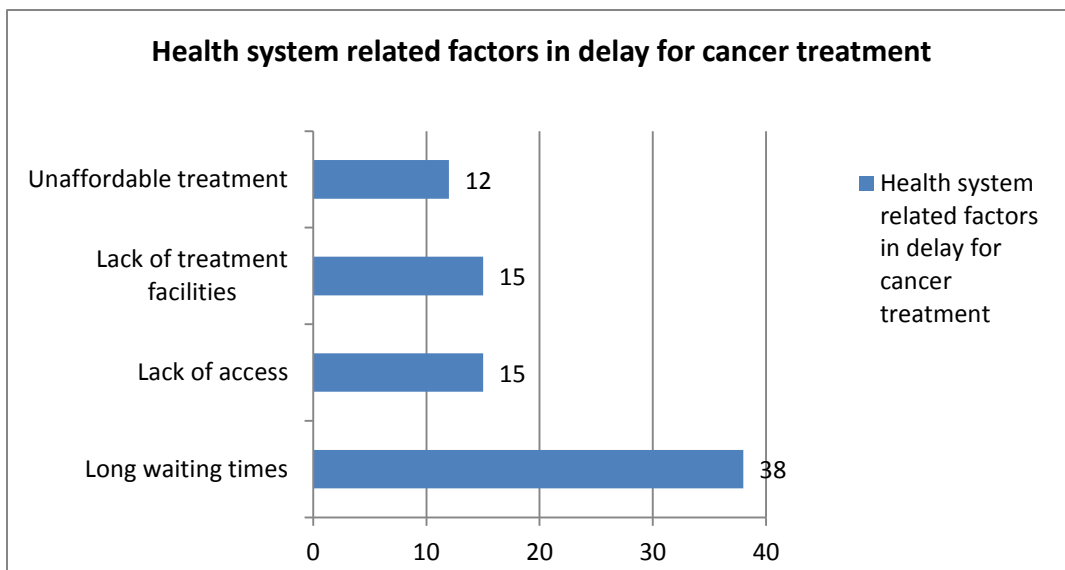
Health system related factors in delay for cancer treatment

CHAPTER FIVE
DISCUSSION OF RESULTS

This study sought to identify the variables associated with delay in treatment of cancer from the onset of symptoms based on the responses to the pretested questionnaire. Expectedly, most of the respondents in this study were still within the productive age of below sixty-five years. This significantly corresponds to the national and international findings on the rising burden of cancer among younger populations which adversely affects the productivity especially in developing countries like Kenya.

This study revealed a high level of lack of awareness of cancer, the risk factors and information on screening among the respondents. Studies have shown that lack of knowledge of the disease and measures for prevention are the key barriers to uptake of preventive services like screening (Islam, Billah, Hossain, & Oldroyd, 2017). More than seventy percent of the respondents were residents in rural settings. A vast majority of the Kenyan population is in the informal sector and most of the respondents in this study belonged to the informal sector. Level of education, urban living and employment outside the home have been shown to be indices of the opportunity for knowledge acquisition (Islam et al., 2017). This majority of Kenyans in the informal sector may thus suffer lack of knowledge on cancer and the prevention measures available for them. Some organizations also collaborate with healthcare providers to provide screening services to their employees which may be unavailable to those in the informal sector. The availability of employer-sponsored health insurance schemes also allows members of the formal sector to access services such as screening and cancer awareness at the facilities within their coverage. People with formal employment also have more education and less cultural barriers to health care utilization. Urban populations are more likely than rural populations to be aware of cancer, the risk factors, screening, diagnostic and treatment facilities available to them simply due to the inequitable distribution of health facilities in Kenya (Kimathi, 2017). More healthcare providers prefer urban to rural locations thus significant proportions of rural populations remain largely underserved (Kumar Mohajan, 2014).

Sixty-eight percent of the respondents with advanced stage of disease sampled in this study were female. Women seek more health care than men in response to both physical and mental health concerns (Thompson et al., 2016). Some studies have shown that delayed presentation for treatment is more likely among patients with little to no social support, while others showed no association between marital status and the time to presentation (Pedersen, Olesen, Hansen, Zachariae, & Vedsted, 2011). In this study, however, most of the respondents were actually married as opposed to being single or widowed. Some studies, however, have shown that women are more likely than men to present with advanced disease due to lack of empowerment and the existence of highly patriarchal societies however others concluded that there is no significant variation between men and women in the use of primary care facilities prior to diagnosis (Wang, Freemantle, Nazareth, & Hunt, 2014).

Most of the participants in this study reported no pre-existing illnesses. Studies done in the United States showed higher prevalence of comorbidities among cancer patients (Sarfati, Koczwara, & Jackson, 2016). This difference may be due to the fact that cancer patients in the US present at a much older age than those in Kenya and in particular, in this study, most of the patients were below sixty five years. Several studies have shown a higher likelihood for delay among patients with other pre-existing illnesses compared to those without because in some instances their symptoms may be ignored and attributed to the existing disease processes by the patient or the doctor as opposed to a new disease process (Louise, Hill, Collier, & Gemine, 2017)(Luo et al., 2015).

Smokers are less likely to present early for treatment and are also more likely to have other smoking-related comorbidities such as cardiovascular and respiratory illnesses thus compounding their risk for late presentation (Louise et al., 2017). In this study the proportion of smokers was very low compared to the non-smokers. This may be due to the fact that this part of the world, women are less likely than men to be smokers and women formed the bulk of the respondents in this study.

The most significant contributor to delay in presentation for treatment has been shown to be the duration between the onset of symptoms and the initial presentation for treatment at a health

facility (Fiona Walter et al., 2012). Most of the patients in this study waited for more than six months before presenting for treatment. Previous research has attributed this delay to issues such as wrong symptom appraisal and interpretation, competing priorities as is evident among patients with dependents and financial constraints and lack of social support, among others (Minghella Edana, Lakhani Mayur, Hughes Cathy, 2010).

Some patients are also more likely to experience delay due to the unusual presentation of their disease while others such as those with breast lumps identify their symptoms early and thus avoid unnecessary delay for treatment. This study involved only those with advanced stages of disease thus did not compare disease specific delayed presentation. The study however identified cervical and breast cancer to be among the top cancers which corresponds with the national and international statistics in developing countries (WHO, 2014a).

The main cancer treatment centers are located in Nairobi, that is, both public and private tertiary level facilities. Patients are referred from other counties all over the country to Nairobi when in need of cancer treatment services. Kenyatta National Hospital is the only public facility with the capability of offering both chemotherapy and radiotherapy, which are the two main forms of treatment for cancer patients. Patients who cannot afford to purchase healthcare from other similar cadre private hospitals such as Aga Khan University Hospital, MP Shah and Nairobi Hospital thus end up for treatment at KNH. Once the patients are reviewed by clinicians at KNH, they are referred to do imaging and laboratory investigations to corroborate the diagnosis and also for treatment planning. Not all patients are able to do these investigations in a timely manner as advised by the clinicians, mostly due to financial constraints (Ngugi et al., 2017). Thus the delay in getting the investigations done may also significantly contribute to the treatment delay. At the same time, patients found to have abnormalities in the laboratory or imaging results are often referred to other sections or providers to first address these abnormalities before the cancer treatment is initiated.

It is notable that 58% of the participants in this study initially presented to private facilities for evaluation of their symptoms and 45% had their diagnosis made in private facilities. This may be evidence of a broken down public healthcare system within the country. There have been many

instances where public healthcare facilities lack basic facilities and supplies such as laboratory reagents and functional imaging machines and this can discourage the Kenyan citizens from seeking health care at the lower levels of hospitals such as county and sub-county hospitals.

Scheduling to commence treatment is mostly done on a first-come first-served basis and occasionally based on the urgency of the symptoms; for example, patients with active bleeding or very severe pain are often prioritized over more stable patients. Due to the limited capacity for treatment at the facility, there is often a waiting list of around three to four weeks before the patients can finally commence their treatment. Most patients are currently paying for their cancer treatment through the National Hospital Insurance Fund (NHIF). Ordinarily most of the Kenyan patients are not aware, (Makau-Barasa et al., 2018) and do not subscribe to the National Health Insurance scheme (Chuma & Okungu, 2011; Nyorera & Okibo, 2015) until they are faced with illness such as a diagnosis of cancer. Upon diagnosis and the realization of the high costs of treatment they are advised at the hospitals to register with NHIF to help them meet their healthcare costs. For patients in the informal sector, the NHIF subscription takes around sixty days after registration before it is activated for use. A number of patients therefore also delay their initiation of treatment as they await the activation of their NHIF subscription. All these factors in addition to the health system factors may compound the treatment delay to longer than would be recommended for cancer patients.

This study sought to describe the characteristics of patients presenting with advanced stages of cancer and was based on the findings of other studies that have been done in other parts of the world (Brown et al., 2014; Donkor et al., 2015; Rikke Pilegaard Hansen et al., 2008; Minghella E, Lakhani M, Hughes C, 2010; Olesen et al., 2009; Sarfati et al., 2016; Tiwari et al., 2015). The present study did not involve international comparisons, but the results indicated some themes that have also been associated with patient delay in other countries, such as lack of knowledge. It was a cross-sectional (descriptive) survey and thus direct causality cannot be inferred; knowledge about cancer may influence symptom interpretation and people who have known others with cancer may be more likely to be aware of the possible symptoms. Non-probability sampling also poses a challenge with generalizations. Being a retrospective study opens it to the risk of possible recall bias. Patient delay studies have been shown to be prone to the risk of

reduced reliability and validity (Andersen, Vedsted, Olesen, Bro, & Søndergaard, 2009). The use of structured questionnaires may be restrictive, in that, not all answers may be sufficiently accommodated. Some respondents may be 'forced' to choose inappropriate pre-coded answers that may not fully represent their views (Bowling, 2014). This population is somewhat representative of the Kenyan population of cancer patients because most of them invariably end up at KNH for their treatment; both those who cannot afford private healthcare and those who exhaust their private insurance cover at the private facilities. The fact that the responses concerned actual experiences and help-seeking behavior from the respondents enhances the strengths of this study.

CHAPTER SIX

CONCLUSION AND RECOMMENDATION

Cancer is gradually becoming a major public health issue in Kenya. This study corroborates the evidence that cancer is affecting the productive age groups which will adversely affect the overall economic productivity in the country. Delay in cancer diagnosis and treatment is an important factor for the overall outcome of the disease process (Caplan, 2014; Neal et al., 2015). Economic costs related to advanced stages of cancer include the higher costs of chemotherapy, radiation therapy and other relevant treatments, the loss of productivity due to morbidity and eventual mortality of those that fail to respond to the treatment (Africa & Initiative, 2014). Having been ranked among the top five causes of morbidity and mortality in Kenya thus indicates the weighty impact of the matter. The Ministry of Health in Kenya has a functional division of Non-Communicable Diseases (NCDs) and has been successful in releasing two cancer control strategy documents in 2011 and most recently in 2017. Efforts in cancer prevention and control by the Ministry of health have however been uncoordinated and mostly concentrated within Nairobi County. Early detection is one of the primary goals of cancer control as outlined in the National Cancer Control Strategy (MOH, 2017). Vaccination of young girls to reduce the incidence of cervical cancer and Hepatitis B vaccination for high risk workers such as those in health care; reduction of cigarette and alcohol use and maintaining a physically active lifestyle are among the primary prevention strategies advocated for in the NCCS. Proper planning and implementation of cancer control programs within the country is therefore of paramount importance.

This descriptive survey of factors associated with late diagnosis and treatment of cancer patients has highlighted important characteristics among patients who present with advanced stages of disease. The knowledge and awareness levels on cancer, the possible risk factors and the available measures for early diagnosis remain significantly low among the Kenyan population. This highlights the need to intensify the awareness campaigns in all counties within the country. At the same time, an increase in awareness will herald an increased need to diagnose and treat the identified cases. The findings in this study corroborate the conclusions of studies done elsewhere that improving the levels of awareness of the early symptoms of cancer may increase people's ability to positively identify them and thus promote help-seeking (Busolo & Woodgate,

2015). However, it is also clear that creating awareness alone is insufficient to address delays and thus dealing appropriately with barriers to seeking medical care (cost, access and quality) will be required. Cancer control strategies within countries must prioritize primary and secondary prevention, alongside cancer management and palliative care and integrate these measures into existing health care plans (Bray, Jemal, Torre, Forman, & Vineis, 2015).

There will thus be need to correspondingly build capacity for cancer treatment within the counties to reduce the high pressure laid on the two major referral facilities, that is Kenyatta National Hospital and Moi Teaching and Referral Hospital. This study has revealed a prolonged treatment delay which may be a consequence of several factors as highlighted in the discussion. Significantly also is the fact that radiation therapy for those who cannot afford to purchase healthcare privately is only available at KNH. The Ministry of Health needs to identify other regional facilities with adequate physical capacity and that would form an easier access point for the patients within those regions and set up the required radiation therapy services. Installation of radiation therapy equipment at MTRH also needs to be fast-tracked since part of the needed infrastructure is already in place.

The study has also highlighted the need to ensure that the primary health care providers are well equipped to identify possible symptoms of cancer and be able to act on them or refer promptly to avoid undue delay to the cancer patients. The MoH should plan for and coordinate refresher courses for healthcare providers such as clinical officers and medical officers at primary and secondary level facilities to boost their clinical acumen and confidence in identification and initiation of relevant management for cancer patients.

Further qualitative studies in evaluating the diagnostic and treatment delay are recommended to provide an in-depth analysis of the patients' experience and pathways to care. Research may also need to be conducted to quantify the actual delay related to access to care, in particular, the delays due to National Health Insurance scheme activation and preauthorization processes.

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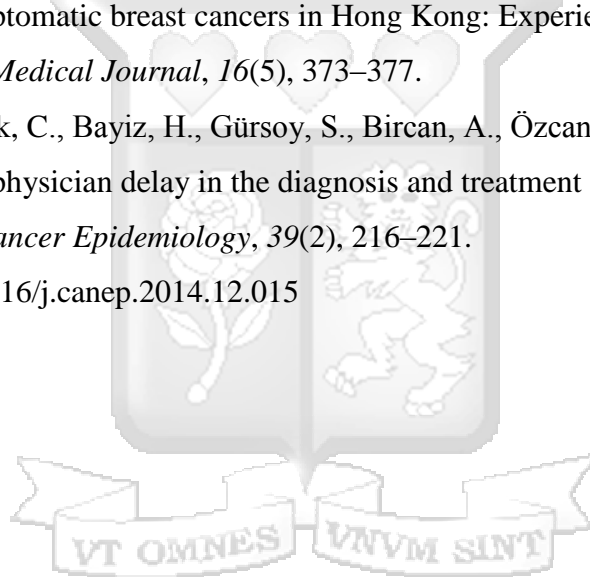
QUESTIONNAIRE

PART ONE: SOCIOECONOMIC AND DEMOGRAPHIC CHARACTERISTICS

A) PATIENT CHARACTERISTICS

1	Age	
2	Level of education 　　a) None 　　b) Primary 　　c) Secondary 　　d) Tertiary	☐ ☐ ☐ ☐
3	County of origin	
4	Gender 　　a) Male 　　b) Female	☐ ☐
5	Any other pre-existing health condition? 　　a) Yes 　　b) No	☐ ☐
6	Source of income (occupation) 　　a) Formal 　　b) Informal 　　c) None	☐ ☐ ☐
7	Marital status 　　a) Single 　　b) Married 　　c) Separated/divorced 　　d) Widow/Widower	☐ ☐ ☐ ☐
8	Residence: 　　a) Rural. 　　b) Urban	☐ ☐
10	Smoker 　　a) Yes 　　b) No	☐ ☐
11	Average weight at diagnosis: 　　a) Overweight. 　　b) Normal weight	☐ ☐
12	Dependents 　　a) Yes 　　b) No	☐ ☐

PART TWO: PATIENT, PHYSICIAN AND HEALTH SYSTEM FACTORS

A) PATIENT KNOWLEDGE AND ATTITUDES

1. Did you know about cancer before your diagnosis?

    a) Yes

    b) No
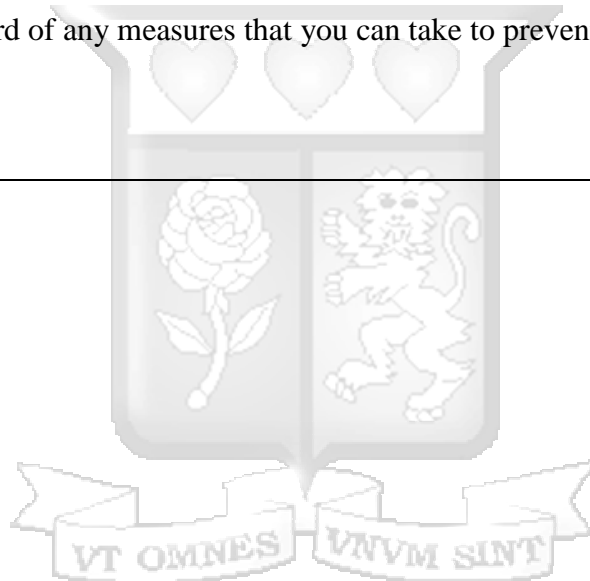
2. Do you know anyone with cancer?

    a) Yes

    b) No

3. Have you heard of any measures that you can take to prevent cancer?

    a) Yes

    b) No

If yes, how much do you agree that each of these measures can reduce the likelihood of getting cancer?

	Strongly Disagree	Disagree	Not sure	Agree	Strongly Agree
Not smoking					
Reduced alcohol consumption					
Doing physical exercises					
Committing to one sexual partner					
Having a balanced diet					
Regular cancer screening					
Knowledge of family history					

4. Have you ever been screened for cancer before this diagnosis?
   a) Yes
   b) No

If NO, to what extent do you agree with the statements below?

	Strongly Disagree	Disagree	Not sure	Agree	Strongly Agree
There is no need for screening					
Screening services not available near me					
Cost of screening not affordable					
I have not heard of screening before					

5. How long (in days, months or years) before diagnosis had you experienced the symptoms?
   a) Less than 3 months
   b) 3 – 6 months
   c) 6 months – 1 Year
   d) More than 1 year

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6. Did you take any medications during onset of symptoms?

   a) Yes

   b) No

   (If YES above) Source of medications:

   a. Over the Counter.

   b. Herbal remedies

   c. Prescription medicine

7. What is the cancer type (given by site of primary tumor, e.g. breast cancer)-------------
   ----

8. What is the cancer stage? --

PHYSICIAN AND HEALTH SYSTEM FACTORS

1. Which was the first health facility you presented to after discovering the symptoms?

   a. Primary level public facility- dispensary, health center, sub-county hospital)

   b. Secondary level public facility- county referral hospital)

   c. Private facility

   d. Tertiary public facility

   e. Tertiary private facility

2. In which health facility was your diagnosis of cancer made?

   a) Primary level public facility- dispensary, health center, sub-county hospital)

   b) Secondary level public facility- county referral hospital)

   c) Private facility

   d) Tertiary public facility

   e) Tertiary private facility

3. How long did it take for you to know you have cancer?
    a. Less than 3 months
    b. 3 – 6 months
    c. More than 6 months
    d. Don't remember

4. After receiving your diagnosis, how long did it take before you finally began receiving treatment?
    a. Less than 2 weeks
    b. 2 – 4 weeks
    c. 4 weeks – 3 months
    d. More than 3 moths

5. Which of the following health system-related factors contributed most to your delay in diagnosis and treatment?

	Strongly Disagree	Disagree	Not sure	Agree	Strongly Agree
The health facility was far from where I live					
Treatment was not available at the hospital near me					
I was insufficiently evaluated by the medical practitioner					
I received the wrong diagnosis and treatment before I finally knew it was cancer					
Delay in referral to a more specialized hospital					
Long waiting times for specialized care					
My results were misplaced/got lost					
The medical practitioner did not explain the results to me to help me understand the urgency					
The cost of treatment was not affordable					

PARTICIPANT INFORMATION AND CONSENT SHEET: ENGLISH VERSION

Factors associated with delay in presentation of cancer patients for treatment: A patient's perspective

Investigator: Ann Kabura

Institutional affiliation: Strathmore Business School

Dear participant,

You are being invited to take part in a research study. Before participating in the study, please take time to read the following information carefully.

What is the purpose of the study?

The purpose of this study is to understand what factors lead to delayed presentation for treatment among cancer patients in Kenya. The results will be used to develop better and more effective hospital and countrywide interventions and services towards early diagnosis of cancer.

Who is eligible to participate?

All adult patients with cancer coming to start treatment will be eligible to participate in this study.

Do I have to take part?

Taking part is voluntary. If you do decide to take part you will be given this information sheet to keep and be asked to sign as evidence of your consent. You will then be guided through some questions to get information on factors that may have contributed to the time you took before starting your treatment. There are no risks in taking part in this study

Confidentiality

All the information that is collected will be anonymous and kept strictly confidential. Your personal data will be held in accordance with the principles of confidentiality in research.

Benefits

The findings of this study will help us to build our understanding of patients' pathways to cancer treatment so that we can develop ways to improve cancer services and the overall patient outcomes in our country. In the future, researchers will also be able access and read the findings of this study to build on future research.

In case of any further questions:

You can contact me, Ann Kabura, by email kaburaann@yahoo.com or by phone 0723717870

You can also contact my supervisor Dr. Vincent O., by email vokungu@strathmore.edu

If you want to ask someone independent anything about this research please contact:

The Secretary–Strathmore University Institutional Ethics Review Board, P. O. BOX 59857, 00200, Nairobi, email ethicsreview@strathmore.edu Tel number: +254 703 034 375

Consent

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 researcher _____

Date of signed consent _____
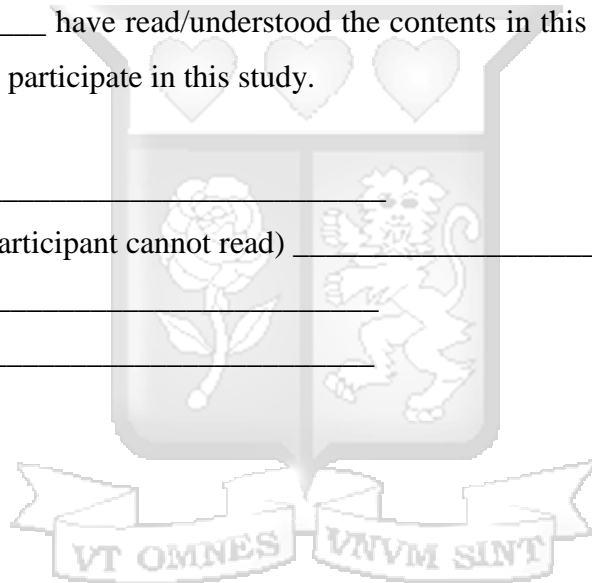
INFORMATION AND CONSENT SHEET: SWAHILI VERSION

Ridhaa ya Kushiriki katika utafiti huu

Habari, umealikwa kuhusika katika mradi huu wa utafiti wenye lengo la kukusanya maoni toka kwa wagonjwa wa saratani kuhusu sababu zinazosababisha wagonjwa wa saratani kuchelewa kupata matibabu. Unaombwa kushiriki katika utafiti huu kwa sababu una uelewa na ambao unaweza kuwa muhimu katika tafiti hii.

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. Unaweza kukataa kujibu swali lolote na unaweza kusimamisha usaili wakati wowote.

Taarifa utakayotupatia itasaidia kuongeza uelewa wetu kuhusu kuhusu sababu zinazosababisha wagonjwa wa saratani kuchelewa kupata matibabu na kufika wakati saratani iko kwenye hatua ambayo ni vigumu kutibika. Pia taarifa hizi zitasaidia katika kutayarisha mipango, mikakati na sera kwa wagonjwa wa saratani nchini yetu.

Sahihi

Mimi _____ nimesoma na 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 _____