TIME TO DIAGNOSIS AND CLINICAL DECISION FOR PATIENTS AT THE ONCOLOGY UNIT AT THE JARAMOGI OGINGA ODINGA TEACHING AND REFERRAL HOSPITAL (JOOTRH), KISUMU, KENYA

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THIS THESIS IS SUBMITTED IN PARTIAL FULFILMENT OF THE REQUIREMENT FOR THE AWARD OF THE MASTER OF SCIENCE DEGREE IN EPIDEMIOLOGY AND BIOSTATISTICS OF THE JARAMOGI OGINGA ODINGA UNIVERSITY OF SCIENCE AND TECHNOLOGY

DECLARATION AND APPROVAL

I, Jully Awino Odero, declare that this is my original work, and it has not been submitted to any other university or institution for the award of a degree or any other award.

Signed : 

……. **Date……**

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APPROVAL

This thesis was prepared under our supervision and has been submitted to the Research and Higher Degrees Committee of Jaramogi Oginga Odinga University of Science and Technology for examination with our approval as the candidate's supervisor.

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DEDICATION

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LIST OF ABBREVIATIONS AND ACRONYMS

CAD:	Cancer Diagnosis
CD:	Clinical Decision
JOOTRH:	Jaramogi Oginga Odinga Teaching and Referral Hospital
TAT:	Turnaround time
JOOUST	Jaramogi Oginga Odinga University of Science and Technology
JOOTRH	Jaramogi Oginga Odinga Teaching and Referral Hospital
WHO	World Health organization
GLOBOLCAN	Global Cancer Observatory
NIH	National Institute of Health
KEMRI	Kenya Medical Research Institute
HIV	Human Immunodeficiency Virus
TB	Tubercule Bacilli
ICD	International Classification of Diseases
HR	Hazard Ratio

DEFINITION OF OPERATIONAL TERMS

Turnaround Time (TAT): Time taken to an event for instance TAT1 is equal to Turnaround time form onset of illness to first hospital visitation. TAT2 is time from first hospital visit to cancer diagnosis. TAT3 is the time from cancer diagnosis to clinical decision.

Cancer Time to Diagnosis: Cancer to diagnosis is the period it taken between first encounter with the health facility to the time diagnosis based on the different tests like blood tests, x-rays, CT scans, MRI scans or ultrasounds. Some may require endoscope and or biopsies conducted.

Cancer Time to Clinical: This is the time it takes for a cancer patient to receive a clinical determination on whether there is initiation of chemotherapy, radiology, surgery combination and or palliative care.

Cancer clinical Pathway: Cancer clinical pathway includes duration from screening, consultation, referrals, diagnosis and treatment.

ABSTRACT

Delays in the onset of cancer to hospital visitation, diagnosis, and treatment of cancer can have adverse consequences on cancer management outcomes. Monitoring turnaround for various processes in the cancer pathway can provide important gaps that exist in the cancer treatment continuum, otherwise, patients would continually suffer due to personal delays, and hospital system delays leading to increased morbidity and mortality. This study aimed to explore the reasons for the patient's delay in seeking early medical care for various cancers at the Jaramogi Oginga Odinga Teaching and Referral Hospital (JOOTRH). Specifically, this study determined the time taken for Cancer diagnosis (CAD) and clinical decision (CD) among patients and barriers to clinical decision (CD) and referral networks that exist. Data was obtained through a questionnaire and desk review of patient records, analysis done using various statistical packages R and SAS, and graphs and tables using Excel. The WHO Cancer classification based on anatomical classification was used. Of the 320 cancer participants enrolled, the majority >30% of the cancer cases were from Kisumu and Siaya counties. Breast, cervix, esophagus, and prostate cancers were most prevalent respectively. More than 60% of patients were in stages II and III at the time of diagnosis. The median overall TAT from onset to clinical decision was 21 months. In a Cox proportional Hazard regression model, employed patients were less likely to visit the hospital after the onset of the disease compared to the unemployed patients (HR: 0.51; 95% CI: 0.39-0.65; $P < 0.005$) while TB Patients were more likely to visit the hospital after onset of disease compared to their counterparts who did not have TB (HR: 3.68; 95% CI: 1.16-11.7; $P = 0.03$) and this outcome remained significant even on time between diagnosis and clinical decision. Females were less likely to be diagnosed with cancer (HR: 0.74; 95% CI: 0.56-0.98; $P = 0.03$) compared to male and equally married patients were less likely to have a shorter TAT for cancer diagnosis (HR: 0.71; 95% CI: 0.51-0.98; $P = 0.04$) compared to those who were single and similarly those who had initial cancer screening compared to those without (HR: 0.71; 95% CI: 0.53-0.97; $P = 0.03$). Further, alluding the role of social behavior on the impact of uptake of cancer services as amidst the many cancer screening programs in place. The turn around tine determined in this study demonstrated that regardless of cancer type or staging of the cancer , the delay was longer in all the two groups on time between onset of illness and time to first hospital visit. In conclusion, being a woman, being in a relationship through marriage, and having initial screening for cancer contributed to a delay in cancer turnaround time, while on the other hand, TB patients experienced short turnaround times across the cancer management pathways. There is a need for public health education and follow-up on the need for early cancer screening. The role of gender, employment status, and marital status on the social influence on the uptake of cancer needs to be investigated.

CHAPTER ONE: INTRODUCTION

1.1 Background to the study

Cancer is among the leading causes of morbidity and mortality worldwide with an exponential increase in both mortality and incidence overtime (Plummer et al., 2016). The increase in mortality and morbidity has been associated with delays in the clinical pathway. Clinical pathway is an operating procedural process for healthcare that would ensure multidisciplinary standardized health care functions. Documented barriers to cancer management range from poor health seeking behaviour to facility related factors such as poor follow up, insufficient expertise in cancer pathology leading to delays in service delivery and poor implementation of health policy on cancer management (Oketch et al. 2019b; Oketch et al. 2019a; Kisiangani et al. 2018) . Other barriers have been shown to contribute to delay in diagnosis and late initiation of cancer therapy (Carrera, Kantarjian, and Blinder 2018; (Adeloye et al. 2018; Finocchario-Kessler et al. 2016). Cancer referral networks are key in the entire chain of clinical pathways in ensuring all services needed are received within the health facility or a second opinion sought on particular cancer management elsewhere. Where referral networks are not well defined or chain of clinical pathway is not complete, patients are bound to be lost to follow up resulting to possible regression (Khakbazan et al. 2014; Click or tap here to enter text. While Western countries have developed policies to mitigate on delay in cancer patients' management (Girolamo et al. 2018; Niëns et al. 2014), developing countries in Sub-Saharan Africa (SSA) are yet to do so. This study investigated turnaround times, barriers to diagnosis and clinical decisions and also existing referral networks along the continuum of cancer management pathways at the JOORTH as one of the biggest regional cancer centres.

Cancer being a progressive disease if diagnosed early can be treated and patients recover fully. Delays in cancer diagnosis may occur throughout the diagnostic pathways and time taken to make clinical decision for patient, primary care, and secondary care have not been defined. Identifying patients with cancer pose a lot of challenge even though it remains an important task in the medical practice (Salika et al., 2018). Short turnaround time for cancer management is important in ensuring duration taken for presumptive diagnosis and clinical decisions is shortened to allow maximum benefit for patients. Delay in cancer presentation and diagnosis is well documented as

major determinants to cancer management and cancer survival (Tapela et al., 2018; Kisiangani et al., 2018) In Kenya, turnaround time for cancer diagnosis and clinical decision is not clearly defined in the various hospital charters, making it difficult to measure performance of cancer management at health facility level. Therefore, this study sought to determine the existing turnaround time for cancer diagnosis and cancer treatment at the JOOTRH.

In both developed and developing countries, barriers to cancer diagnosis and treatment have been demonstrated to contribute to poor cancer outcomes (Mwaka et al., 2013; Wabinga, and Mayanja-Kizza 2013 ;Moriceau et al. 2016; Kitano et al., 2019; Kitano et al., 2019). These barriers range from shortage of health facilities to shortage of qualified clinical staff that can detect early signs and symptoms of cancer at lower cadres of the health system. Cancer management is part of the primary health care services and should be given prominence just like other infectious diseases. However, the extent to which patient-related barriers like health seeking behaviour and facility-related barriers affect patient decision to access care, cancer diagnosis and treatment for cancer patients is unknown. While these barriers to achieving acceptable access to diagnosis and treatment remain varied and contextualised in various settings, there remain limited understanding on the documented barriers. In this study, barriers to diagnosis and clinical decisions through directly engaging the cancer patients were sought.

Effective referral systems with traceability of patient's prognosis while on treatment is crucial to the success of cancer interventions. While countries in the western world ensure efficiency in care and treatment for their cancer patients through an integrated health system (Neal et al., 2014; Click or tap here to enter text. the opposite has been reported in the sub-Saharan African region and Kenya being one of them (Allgar & Neal, 2005; Gopal et al., 2012; Bentrem et al., 2013; Kisiangani et al., 2018b). Cancer referrals from Kenya to other countries has increased exponentially and most of such referrals are done in the quest to seek a second opinion (Kurian et al., 2017). These decisions are made when there is apparent disease which has progressed to worse stages (May Pini et al., 2012)are fragmented and not easily accessible or data untraceable, the magnitude of the cancer problem is not clearly known. The fragmented referral system for cancer patients increases the overall cost of management and unnecessary wastage of resources. Where there is access to treatments, the cost of treatment remains unaffordable to many

households Click or tap here to enter text.Carrera, Kantarjian, and Blinder 2018; Kanarek et al., 2014; Geynisman et al., 2014). Therefore, strengthening cancer referral systems and follow-ups would ensure efficiency and effectiveness in the management of cancer patients. This study determined the existing referral networks across the various counties (inter-referrals and extra-referrals) for cancer patients as they received services from the JOOTRH.

1.2 Statement of the problem

Half of the patients diagnosed with cancer in Kenya die before they reach their fifth year due to delay in cancer diagnosis, or clinical decision leading to delayed initiation of treatment or lack of treatment associated with costs (Gershon et al., 2019). According to the Ministry of Health reports, by the end of 2020, reported cancer prevalence was 82,620 cases, incidences 42,116 cases, and deaths 27,092 cases against a population of 53,771,300 (MoH, 2023). Delay in diagnosis and initiation of cancer treatments are the major contributing factors to most of the cancer related deaths (Hoang Lan et al., 2013;. Studies conducted on the various cancer conditions have linked poor outcomes of cancer on knowledge gap (Tsai et al., 2018;Tsai et al., 2018;Tsai et al., 2018) , lack of skills for early detection (Shen et al., 2016) and delay in medical pathway or health seeking behaviour among patients (Salika et al., 2018)**.** To date, in Kenya, there has not been any study designed to look at turnaround time in terms of delay in accessing diagnostic and treatment for cancer and factors that hinder timely cancer diagnosis and treatment and equally identify promising channels of treatments that exist through referral networks both in country. This study was designed to provide baseline information on the time taken to receive diagnostics and clinical decisions, while determining the actual barriers associated with these and time taken through the clinical pathway for cancer patients. Additionally, the study identified the various referral networks that exist within the JOOTRH clinical pathways.

1.3 Justification of the Study

The study performed a descriptive analysis of the sampled study population at the Jaramogi Oginga Odinga Teaching and Referral Hospital (JOOTRH) oncology centre with primary focus on delay in Turnaround time (TAT) for cancer diagnosis, barriers to cancer diagnosis and clinical decision among patients seeking services at the centre. Since the facility was not a one stop shop

for all cancer services, this study identified the various referral networks that exist in terms of intra-referral (within the country) of patients and their influence in the TAT for service provision at the oncology centre, JOOTRH in Kisumu.

1.4 Research Questions

i. What is the turnaround time for cancer diagnosis and clinical decision at the JOOTRH**?**
ii. What are the barriers to achieving acceptable TAT for cancer diagnosis and clinical decision at the JOOTRH?
iii. What are the referral networks for cancer patients who seek services at the JOOTRH?

1.5 Main objective

To determine factors associated with delay in cancer diagnosis and clinical decision at the JOORTH hospital.

1.6 Specific objectives of the study

i. To determine the turnaround time for cancer diagnosis among patients at the JOOTRH.
ii. To determine the barriers to cancer diagnosis and clinical decision at the JOOTRH
iii. To determine the referral networks for cancer patients seeking services at the JOOTRH

1.7 Significance of the Study

Diagnosis and clinical management of cancer in Kenya has a lot of challenges that includes delay in diagnosis, delay in clinical decisions and weak and unstructured patient referral systems for further management. Despite the creation of the regional cancer centres to spearhead developments of policy on cancer treatment and management in Kenya by 2014, seven years later there are still challenges with delay in cancer diagnosis and clinical decisions coupled with lack of expertise in early medical detection of cancer cases. This study has provided data and information that will enable the county health department in planning, prioritizing and institutionalizing interventions for strengthening the delivery of cancer prevention, diagnostic and treatment services in Kisumu County. The findings and the recommendations of this study are useful as a reference point for the managers and administrators of health systems and units in Kenya as a whole. In addition, the study findings form a basis for further research and contribute to literature

not only for the management of cancer patients, but in the management of health institutions in general.

1.8 Scope of the Study

This study was conducted among patients seeking services at the oncology centre at JOORTH in Kisumu, which serves as a referral hospital for the western region of Kenya.

1.9 Limitations of the Study

The study considered patient related TAT, which is mainly based on recall period, which could be longer than indicated, however this was verified from the patient records at the cancer registry but also patient recall period. Verification of the extreme TAT process took longer than expected to ensure data collected was accurate. TAT calculations were clearly defined in three categories/phases to look at patient associated delay in TAT, and hospital associated delay processes.

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

Cancer is a term used in describing a group of malignant tumors with a common characteristic of uncontrolled growth of abnormal cells that have acquired the capacity to spread and metastasize to distant site through the circulation (NIH, 2014) Cancers are caused by combined genetic and non-genetic changes induced by environmental factors that trigger inappropriate activation or inactivation of specific genes leading to neoplastic transformations, or abnormal cell growth (Feng et al. 2018;Williams et al. 2014). There is little information on key cellular events that occur in early stages of cancer development as well as environmental factors and internal indications that trigger these changes in the cellular make up. Recent advances in molecular epidemiology allowed researchers the opportunity to do in-depth basic research as well as possible causes of cancers, their distributions, and the various population at risk of acquiring the various cancers. In the developed countries it's now possible to identify particularly high-risk individuals and potentially design an efficient strategy for cancer prevention yet this still pose a significant challenge in the developing countries, especially the sub- Saharan Africa.

2.2 Classification of the Common Cancer Types

The term cancer is a condition in which abnormal cells divide without control and can invade nearby tissues. Cancer cells can also spread to other parts of the body through the blood and lymphatic systems a term called metastasis. There are several types of cancer; carcinoma is a cancer that begins in the skin or in tissues that line or cover internal organs. Sarcoma is a cancer that begins in bone, cartilage, fat, muscle, blood vessels, or other connective or supportive tissue. Leukaemia is a cancer that starts in blood-forming tissue, such as the bone marrow, and causes large numbers of abnormal blood cells to be produced and enter the blood. Lymphoma and multiple myeloma are cancers that begin in the cells of the immune system. Central nervous system cancers are cancers that begin in the tissues of the brain and spinal cord also called malignancy (NIC Dictionary of cancer terms of 2010).

According to the World Health Organisation international classification of diseases tenth edition (WHO-ICD-10), cancer have been classified under major categories based on their occurrences and tissues affected. As follows; lip, oral cavity (ICD-10 C00-08), nasopharynx (C11), other

pharynx (C09-10, C12-14), oesophagus (C15), stomach anus C18-21), liver (C22), gallbladder (C23-24), pancreas (C16), colon and rectum (including (C25), larynx (C32), lung (including trachea, C33-34), melanoma of skin (C43), Kaposi sarcoma (C46), female breast (C50), cervix uteri (C53), corpus uteri (C54), ovary (C56), prostate (C61), testis (C62), kidney (including renal pelvis and ureter, C64-66), bladder (C67), brain and central nervous system (C70-72), thyroid (C73), Hodgkin lymphoma (C81), non-Hodgkin lymphoma (C82-85, C96), multiple myeloma (C88 1 C90), leukaemia (C91-95) and all cancers combined, excluding non-melanoma skin cancer (C00-97, except C44).

2.3 Epidemiology of Cancer

Cancer is the second leading cause of mortality globally with an estimated 9.6 million deaths by 2018 (Bray et al., 2018; 2018). Existing statistics indicate that 32.5 million persons are living with cancer and 14.1 are new cancer cases. It is estimated that by 2030 the number of new cancer cases will increase to 21.7 million persons. Globally approximately 1 in 6 deaths that occur are associated with cancer and approximately 65% of such deaths occurred in the low- and middle-income countries across the world. Worldwide, the most common cancer is lung cancer that accounts for 13% of all cancer detected, followed by breast cancer at 12%, colorectal cancer 10%, prostate 8%, stomach 7%, liver 5%, cervix 4%, oesophagus 3%, bladder 3% and the remaining cancer accounted for 35% of all the cases reported worldwide. The most common cancer in men was lung cancer and breast cancer in women (Plummer et al., 2016; 2016; Bray et al. 2018).

In Kenya, cancer ranks third among diseases with the highest mortality rate after HIV and cardiovascular disease with an estimated 5% annual incidence. Breast cancer is the leading cause of cancer followed by colorectal 10%, oesophagus 9%, prostate 8%, cervix 6%, stomach 4%, lung 4% ovary 4% and the remaining 24 cancer types accounted for 38% of the total cancer detected with prostate cancer being more prevalent in men followed by oesophagus (Health, 2017).

2.4 Risk Factors for Cancers

Risk factors for cancer fall into five key areas namely environmental pollutants, tobacco use, unhealthy diet, and physical inactivity (Danaei et al. 2005; Gopal et al. 2012). There is well documented scientific evidence to show that tobacco use, alcohol use, unhealthy diet, and physical inactivity are major cancer risk factors worldwide (Epping-Jordan, 2005) 2005) and also remains the risk factors for the other non-communicable diseases (Lewandowska et al. 2019). Chronic infections are also risk factors for cancer (Sayed et al., 2016; and have major relevance in low- and middle-income countries across the continent. Approximately 15% of cancers diagnosed in 2012 were attributed to carcinogenic infections (Plummer et al., 2016), including Helicobacter pylori (Plummer et al., 2016), Human papillomavirus (HPV) (De Vuyst et al. 2013; Finocchario-Kessler et al. 2016) , Hepatitis B virus (Plummer et al., 2016) , Hepatitis C virus (Mumtaz et al., 2014, and Epstein-Barr virus (Gopal et al. 2012; Buckle et al. 2016; . Hepatitis B and C virus and some types of HPV were also known to increase the risk for liver and cervical cancer, respectively (Plummer et al., 2016). Infection with HIV substantially increases the risk of cancers such as cervical cancer and Kaposi Sarcoma due to suppressed immunity (Parkin et al. 2008; Sasco et al. 2010).

2. 5 Turnaround Time for Cancer Diagnosis and Clinical Decision

Delays in cancer diagnosis may occur throughout the diagnostic pathways. Time taken to make clinical decision and referral network pathways for patient primary care, and secondary care is never clearly defined in many resources limited settings. Early Identification of patients with cancer pose a lot of challenges even though it remains an important task in the medical practice. Studies conducted on the various cancer conditions have linked poor outcomes of cancer on knowledge gap (Tsai et al., 2018) , lack of skills for early detection (Shen et al., 2016) and delay in medical pathway or health seeking behaviour among patients (Salika et al., 2018). However, time intervals to cancer diagnosis and clinical decision and barriers and their effects have not been explored especially in the sub-Saharan African countries (Torre et al. 2015; Health 2017; Pace and Shulman 2016). Patient associated delays may occur when a patient fails to recognize and act on suspicious early cancer symptoms. This has been occasioned by poor public awareness for early symptoms of cancer which is considered to be the predominant reason for delayed presentation,

particularly if symptoms are atypical in nature (Tsai et al., 2018). Most of the cancer patients seek clinical care with symptoms but only a fraction of them present known alarm symptoms of cancer. Several studies conducted in both developed and developing countries have reported increase in morbidity and mortality of cancer patients due to delay in diagnosis and clinical decision that would ensure initiation of treatment (McKenzie et al. 2018; Lewandowski et al. 2017; Akuoko et al. 2017; Baishya et al. 2015).

Delay in the cancer diagnosis may worsen the prognosis and diagnosis thus requiring more intensive and extensive treatment which may have more adverse effects, high-cost implications and sometimes death (Black and Richmond 2019; Ginsburg et al., 2017) . A lot of patient factors are contributed due to symptoms that present like for other common diseases thus treatment is accorded for such until no response is observed (Lewandowski et al., 2017). The symptoms that are commonly appearing and are associated with the delay in early cancer diagnosis includes unexplained bleeding, difficulty in swallowing, change in bowel or bladder habits, sores that do not heal, unexplained pain, cough or hoarseness, unexplained lump or swelling, change in the appearance of a mole, and not limited to unexplained weight loss. It is therefore very important to limit delay of cancer diagnosis and ensure high quality at every step in the diagnostic and clinical decision pathways because unnecessary delay in cancer diagnosis increases progression of cancer. Use of inappropriate tests and procedures and failure to make follow up on in conclusive tests results. Symptomatic treatment, erroneous assessment of symptoms origin and organization of the health care system could play a role in the overall delay in time taken to achieve better cancer diagnostic services and prompt clinical decisions and further investigations and referral options.

2.6 Barriers to achieving acceptable TAT for cancer diagnosis and clinical decision.

Several barriers or changes that affect access to cancer diagnosis and treatment are well documented (Sayed et al., 2019;Lewandowski et al. 2017). For instance, despite the fact that cervical cancer is preventable through effective screenings and treatment when diagnosed early, incidences and mortality associated with it still ranks high in both low- and middle-income countries (Oketch et al., 2019a). High incidence deaths associated with cervical cancer have been documented. As such, it remains the most common cancer among women and the leading cause of death in many African countries. In Kenya, new cases and mortality rates are expected to rise by

75% by 2025 in the absence of effective scale up of interventions for screening programs and early treatments (MFA RU, 2010;Oketch et al. 2019a). This increase is caused to by patient related factors like poor health seeking behavior which leads to late presentation at the hospital when there are apparent cancer symptoms or when condition have progressed to later stages. Some African traditionalist beliefs that associate some swellings or cancer symptoms for curses that would in return seek traditionalist for treatment or cleansing. Patients presenting at the hospital with late-stage cancer also reduce their chances of survival even in the presence of the best cancer care program. Such stigma may prevent cancer patients and such incidence of deaths may affect other persons with similar conditions not to seek medical attention due to fear of deaths or stigma associated.

While high quality, increased access and acceptable screening programs are necessary in the prevention of cervical cancer, well trained medical staff, effective referral system and laboratory facilities, lack of transport and tracking system in most cases makes screening strategies unfeasible in most low-income countries (Vanderpuye et al., 2017 Kohler et al. 2017; Kohler et al. 2017; Mwaka, Wabinga, and Mayanja-Kizza 2013). However, the extent to which these barriers affect access to patient decision to access care, cancer diagnosis and treatment for cancer patients is unknown. While barriers to achieving acceptable access to diagnosis and treatment remains varied and contextualise in various settings, there is need for an in-depth understanding of these barriers and their root causes in order to mitigate on them. In the developed countries an acceptable TAT has been established throughout the treatment pathway for cancer patients contrary to many countries in the sub-Saharan Africa where Kenya belongs.

2.7 Referral networks for cancer patients

While cancer prevalence remains a valid tool for monitoring cancer epidemic patterns in countries where >1% of populations have cancer of any various form, this data more often than not is limited to specific institutions or programs. Effective referral systems with traceability of patient's prognosis while on treatment is crucial to the success in the cancer intervention as demonstrated in Countries like United Kingdom. While many countries in the western world ensures efficiency in care and treatment for cancer patients through integrated health system that ensures referrals occur within two weeks and traceability done, the opposite is reported in sub-Saharan Africa. In many

countries within the sub-Saharan region, cancer referral services are fragmented and not easily accessible due to long waiting list, cost of diagnostic services, and complexity of initiation on therapy or surgical procedures or data traceable hence the magnitude of the cancer problem is not clearly known. Where there is access to treatments, the cost of treatment remains unaffordable to many households. Identifying early-stage cancer and providing the necessary clinical intervention at the right time is the key to improving cancer survival. Screening for early-stage cancer confers high survival benefit, presumably by permitting timely detection of early stage of cancer disease. For instance, in lung cancer, stage progression is associated with decreased surgical cure rates and poorer overall survival. Delays in the diagnosis and treatment of cancer of any form leads to clinical progression and thus not uncommon. In most cases this delay is associated with incomplete or fragmented referral system that ensures patients are referred to specialists in the next level of clinical care. Referral of cancer patients for specialist care should guarantee better clinical management and outcome, however there are factors that influence the referral chain that would not guarantee the complete chain of custody of the referred patients. Additionally, some patients are referred to distance health facilities that would require patients to put up in hotels or need specialized transport arrangement and all at a cost. To look for resources before seeking such services from the referred facility. These delays in the referral system contribute to the outcome not referred for specialized medical care due to challenges in the manage, and the timely care of lung nodules suspicious for cancer is presumed critical for individual patients and population health.

2.8 Theoretical Framework

The most suitable theory for this study would be the systems theory originated by Hegel, the German philosopher who stated that the whole is greater than the sum of its parts. Overall, the systems theory has two versions: the closed and the open systems. The closed systems (also known as the rational or natural system) view an organization, including a health facility, as a closed entity separate and independent of environmental influences. The open systems theory postulates that an organisation is open and dependent on the environment, especially as concerns connections with internal and external components. This study adopted this theory because it is

most suitable for cancer management in health care settings with administration component, because in a health facility, there are many independent activities.

Systems theory postulates that health facilities are like other open systems which of necessity engage in various modes of exchange with the environment. The theory emphasises the consideration of the relationships between the health facilities and its environment as well as what goes on within the health facilities. This theory is basically concerned with the problems of relationships, of structures and of interdependence, rather than with the constant attributes of objects. In the systems theory approach, a health facility is a set of interacting units with relationships among them. The properties (or behaviour) of a health facility as a whole emerge out of the interaction of the components composing the health facilities. Therefore, if the inputs of human resources (laboratory staff time, the oncologist, pathologist, cancer nurses etc. and other non-laboratory staffs' resources), material resources (health facilities as institutions and health facilities supplies) and symbolic resources (Diagnostic methodology or standard operating procedures etc.) are well adhered to (management actions), it will result to internally efficient health system. This is defined in a schematic diagram in Figure 2.1 show below. As adapted in this study, the systems theory postulated that several factors, managerial in nature, influence cancer services in health facilities: that health-facility related factors, culture, community, environment, and personal related factors all work independently and co-ordinately to influence the time for cancer diagnosis and clinical decision in health facilities. Hence the way they are regulated by the management dictate the number of patients who seek cancer services and the quality of services that they offer or received by recipients.

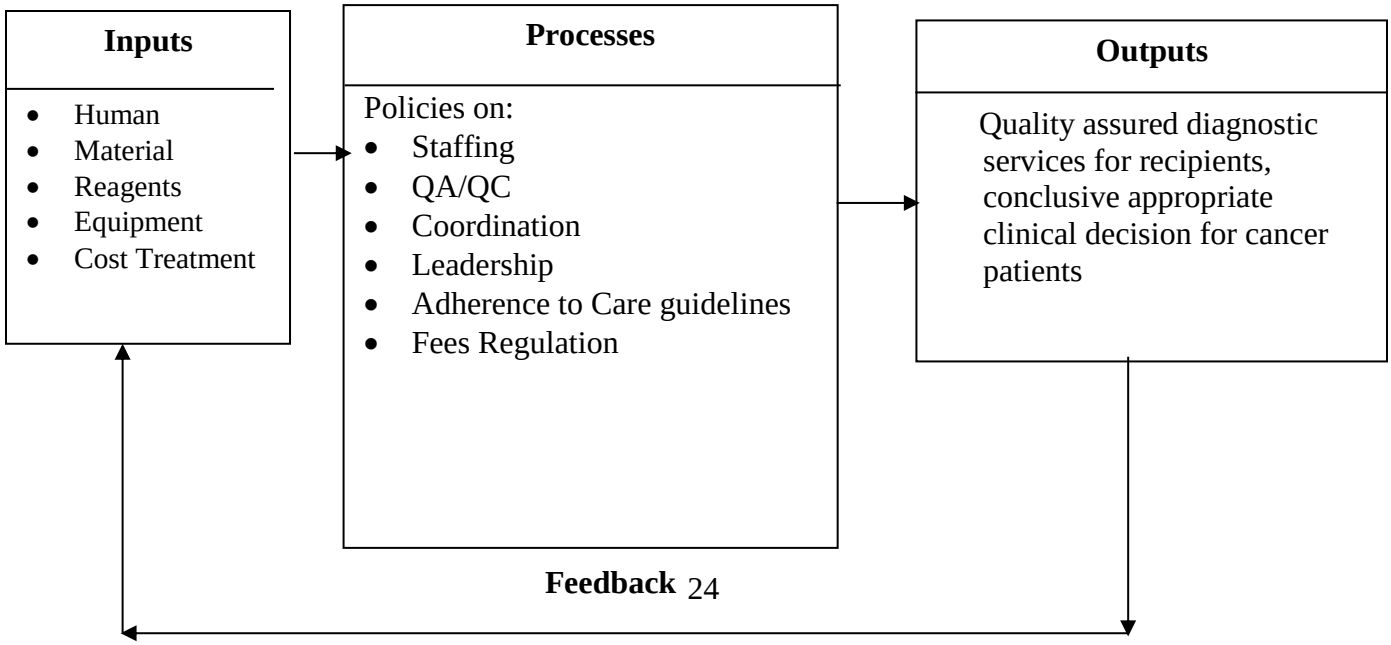


Figure 2.1: Components of the Health System viewed from this perspective, the inputs that health facilities obtain from the environment and the process that is takes the inputs through one important determinants of internal efficiency. **Source:** Adapted from Owolabi (1987).

2.9 The Conceptual Framework of the Study

The conceptual framework adopted in this study is rooted in the open systems theory of health administration. According to this theory, a health facility is an open system that engages in various modes of exchange with the environment. It emphasises the consideration of the relationships between the health facilities and its environment as well as what goes on within the health facilities (Hall et al., 1988)**.** The theory is basically concerned with the issues of relationships, of structures and of interdependence, rather than with the constant attributes of objects. In this framework, several questions are posed to have a bearing on the time taken to receive conclusive cancer diagnostic services and appropriate clinical decision and its implication on the outcome of cancer services. These core areas are presented in the schematic diagram below for ease of understanding the interrelationship between the independent variable and the dependent variable.

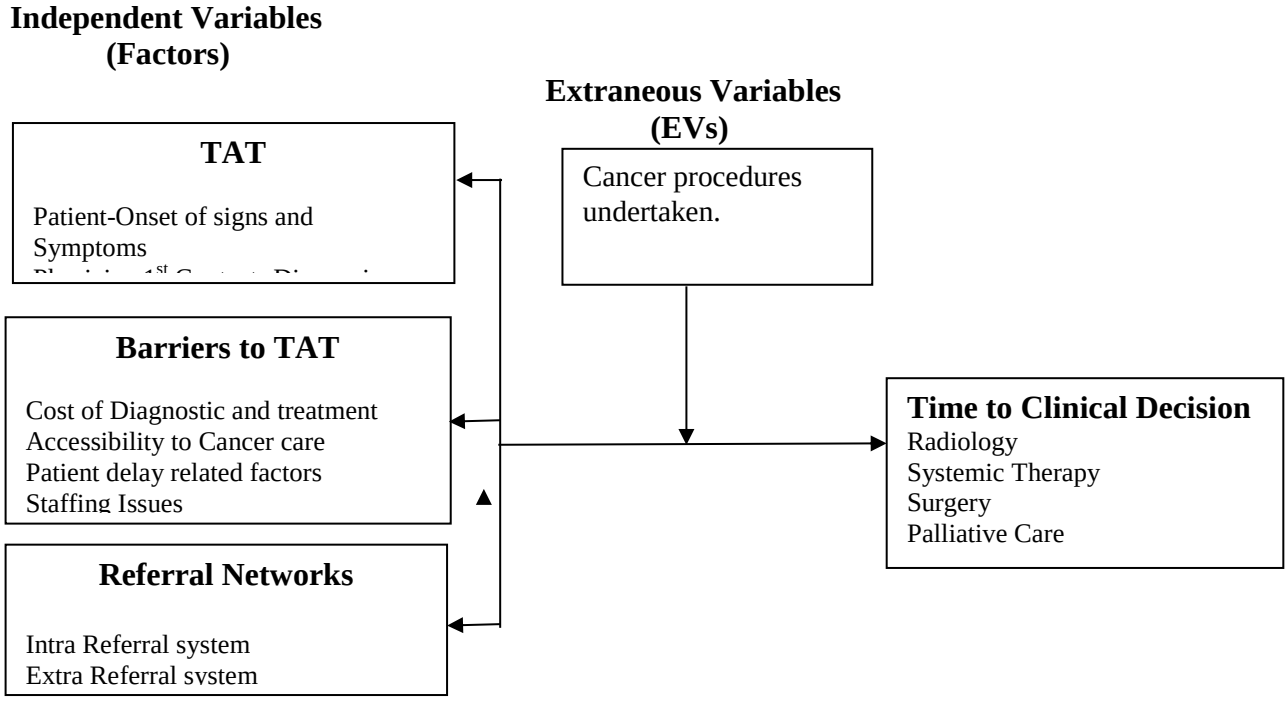


Figure 2.2: Conceptual framework for the factors influencing the Turnaround time in Cancer diagnosis and clinical decision. **Source:** Adopted from Oso, W. Y. & Onen, D. (2008)

CHAPTER THREE: METHODOLOGY

3.1 Introduction

This chapter describes the research procedure and techniques which were used in the study. It describes the research design, population, sample size, and sampling procedures employed as well as the basis for planning, selecting, and developing the instruments that were used in the study. It also describes the procedure for the applications of the instruments, and the data management and analysis techniques used.

3.2 Study Site

This study was conducted at the Jaramogi Oginga Odinga Teaching and Referral Hospital (JOOTRH) in Kisumu city. This study site is a level six health facility in the country and was selected because is a referral hospital for cancer services in the wider Nyanza and western regions.

3.3 Research Design

This is a cross-sectional surveillance study that employed desk review through abstraction of data retrospectively from the cancer registries from between April-May 2022. A prospective component allowed identification of the prospective participants who were contacted for interviews. A cross sections survey design was preferred because it enables the researcher to collect a lot of data within a very short time. It also enabled the researcher to provide quantitative description of the population from just a part of it. The cross-sectional design was adopted here instead of longitudinal survey because it enabled the researcher to collect data at one point in time and to analyse for fuller explanation on the identification of time in cancer diagnosis and clinical decisions made, the prevalence of the cancer in the region, demographic information on the patients and other important data that allowed the researcher to answer on the research questions posted. The study gathered as much facts as possible which enabled researcher to clarify and describe in overall the nature of time taken to diagnose cancer patients and the time taken for a

clinical decision to be made on the cancer patient management, the barriers that are associated with the delay and the existing referral networks that operate for cancer patient's management.

3.4 Study Population

A study (or parent) target population here referred to the population to which this study drew its target population. In this particular study, the study population consisted of patients seeking services at the cancer centre at the JOOTRH hospital and providers of such services.

3.5 Sample Size and Sample Selection

This section describes the sample size and sample selection that were used in the study.

3.5.1 Sample Size

The Fisher's (with Finite Population Correction Factor Fishers') sample size formula *(Mugenda, 2003)* was used to obtain the sample size.

$$n = \frac{\left(Z_{\alpha} + Z_{2\beta}\right)^2 \times p(1-p)}{m^2}$$

Where:

n = required sample size

Z_{α} = 1.96 stand critical value at which we make a statistical decision at 5% alpha level of significance and $power\ of\ (1-\beta)$ where $Z_{2\beta} = 1.64$

p = estimated prevalence of cancer of 5% (GLOBALCAN)

m = margin of error at 5%

This implies:

$$n = \frac{(1.96 + 1.64)^2 \times 0.05(1-0.05)}{0.05^2} = 246.24$$

Where a projected 30% attrition for any eventually (n= for) i.e., missing data.

$$n = (0.30 \times 246) + 320$$

An attrition of 30% was used to caution on the fore able challenge with incomplete consenting processes or during administration of the questionnaire as many of the patients were being consented while on chemotherapy and to minimize potential bias and maintain statistical power. $Z_{2\beta}$ is the Z-score for the desired power level. Alfa is the desired level of significance at 95% Confidence Interval.

3.5.2 Sampling Techniques

The study used purposive sampling technique to select respondents who have been diagnosed and seeking cancer services at the JOOTRH hospital cancer centre. Purposive sampling method was employed in the selection of potential participants to be enrolled in the study,who were diagnosed with cancer. The technique enabled the researcher to obtain data from a defined period from the cancer registry and also only from the potential respondents that had the kind of information needed, and to cut down on time and other resources that could have been wasted in interviewing people who did not have the required criteria of enrolment. Convenience sampling technique was used in the data abstraction process to pick relevant information from the registries that included dates patients seen, diagnosis requested, and clinical decision made, type of cancer, demography, and the referral data for those who sought services in a different facility or out of the country. This technique was used to save time and to cut down on the cost of the study, secondly, from the sample population used is a representation of a general population since JOOTRH is a referral hospital for more than 6 counties in Western Kenya with approximate population of 8 million (30%) of national population.

3.6 Validity and Reliability of Data Collection Tools

This section deals with quality control. Controlling quality involves adjusting the values of validity and reliability coefficients of the study instruments until each instrument attained acceptable value. This could be in terms of performance of standard control panels, daily performance of machine etc.

3.6.1 Validity of Instruments

The researcher used structured questionnaires and data abstraction forms attached at the end of (Appendix I and II) to obtain data during the study. Thus, the validity of research instruments is a measure of the extent to which the instruments measure what they were intended to measure. A research instrument is valid if it actually measures what it is supposed to measure and when the data collected through it accurately represents the respondents' opinion. The validity of the instruments was determined by experts. The instruments were given to two experts in the research field: my supervisors and an experienced data specialist colleague in KEMRI program where they evaluated and judged the relevance of each item in the instrument to the study objectives and the overall purpose of the study. The validity of the instruments was determined by experts using Cronbach Alpha method where a calculated validity index of >0.8 was determined and was considered acceptable. From the assessments, the validities of the instruments were determined by calculating the Content validity index from the total number of items rated as relevant by both experts.

3.6.2 Reliability of Instruments

In this study, the reliability of the study instruments was determined through the test-re-test method, data abstraction tool was tested for reliability of data collected in a test- re- test method until it was ascertained that the intended data was what was collected before it was implemented for use. Quality assurance issues of the data collected was also done to ensure reliability.

3.7 Data Collection and Processing

Quality control /quality assurance was done on data collected that have been abstracted. Individual data collected was entered into an excel sheet and accuracy and completeness determined. Data analysis was done using R statistical package (P, version 16, College Station, Texas, USA). Data entered in excel was uploaded into the SAS (SAS CORP, version 16, College Station, Texas, USA) software and quality, accuracy and completeness determined. All tools for data collection were stored well and used in verification or clarification.

3.8 Methods of Data Management and Analysis

3.8.1 Data management

Data Storage:

1. Data management: To protect respondents' confidentiality, each respondent was assigned a unique identifier. This unique identifier was used for data collected during the study so that the data can be linked. All persons who had access to data forms were asked to sign confidentiality agreements. Identifying information was not entered in the electronic dataset. All data collection instruments were stored in closed, locked file cabinets with restricted access to except for the authorized persons. The electronic data was stored in a password-protected computer database with restricted access. The number of people who had access to information was limited to study staff and the researcher and her supervisors.
2. Database Devices: Results obtained from data abstraction forms and questionnaires were directly entered into the database. Data was stored and managed using Microsoft Access and Excel (Windows 2010).

3.8.2 Data Analysis

Data was managed and analyzed using SAS (SAS, Institute version 16, College Station, Texas, USA) and R package. Descriptive statistics of mean and median was calculated. The median delay was calculated in days. The patient delay was estimated as median. For comparing the variables, non-parametric Mann-Whitney U test and Kruskall-Wallis test was done to determine whether there were significant differences between lengths of delay. Participant demographics were summarised using percentages, ordinal and nominal variables. Chi square test was used to check for the association between categorical variables (age, staging of cancer TB, screenings, etc.). Fisher Exact test was used to test for the association between expected categorical variables with values <5. Multiple linear regression was used to model for TAT with other covariates of barriers to cancer diagnosis (continuous variable and other covariates). A Cox regression analysis model was conducted on the variables of interest to determine their association with the TAT the to event.

Data was analysed using R version 4.3.0. Turnaround time was obtained by calculating period taken between the time patient diagnostic request was made and the time diagnosis and clinical decision was determined. A survival analysis model was done to model for time taken to achieve clinical decision. Survival plot was used to describe the time to patient getting clinical decision or determination in their pathway in health seeking. To determine time to diagnosis and clinical decision for patients receiving cancer services at the oncology unit at JOOTRH, Turn Around Time (TAT) was first calculated by subtracting dates between the following time points and results recorded as months; Onset of the disease and first hospital visit (TAT1), First hospital visit and cancer diagnosis (TAT2) and Cancer diagnosis and clinical decision (TAT3). Next, Cox proportional hazards were used to model time taken to achieve clinical decision given the hypothesized predictors. Significant predictors of TAT were further analyzed with a multivariate Cox proportional-hazards model. Additionally, Cox proportional-hazards model was used to compute survival curves describing time to cancer diagnosis and clinical decision while the distribution of cancer cases at JOOTRH were analyzed using the maps package in R software version 4.2.0. Level of significance was determined at $P \leq 0.05$ was considered as statistically significant. Statistical analysis frequency of cancer, distribution by age gender, location, cancer stage, cancer treatment, occupation, and predisposing factors were obtained by questionnaire method. Raw data were entered into Microsoft Excel and password protected to ensure access by authorized persons only. Other analysis involved the calculation of descriptive statistics; frequencies, standard deviations, and means and medians. Outputs of statistical analysis were presented in the form of tables, graphs, and charts. Chi-square analysis was used to examine the association between the risk factors and type of cancer in the study area.

3.9 Ethical Considerations

The approval to conduct the study was given by the Jaramogi Oginga Odinga University of Science and Technology Ethical Review Committee and the School of Graduate Studies. National Commission for Science and Technology (NACOSTI), The Jaramogi Oginga Odinga Teaching and Referral Hospital Ethical Review Committee provided approval for the study to be conducted at the JOOTRH. The Leadership of the Hospital equally provided his approval for the study to be conducted at the Hospital premises. Consent was sought from the study participants and data entry

was done using unique identifiers/codes to delink patient identities from the study records. The research records were kept in a locked file and all electronic information was coded and secured using a password.

CHAPTER FOUR: RESULTS

4.1 Baseline Characteristics

Between Jan 2022 to Sept 2022, a total of 322 participants seeking services from the oncology centre at the Jaramogi Oginga Odinga Teaching and Referral Hospital were taken through the study consenting process of and screened. Out of the 322 screened, 320 met study eligibility criteria and were consented and enrolled into the study. The baseline characteristics of the study population is presented in **Table 4.1a.** Kisumu and Siaya Counties bored the burden of the cancer patients seeking services at the JOOTRH and this accounted. On clinical characteristics, the average TAT was determined to be 21.2 months. Majority of the participants enrolled were women which accounted for 64% of the total population compared to men who were 36%. Majority of the population were married 81% (259/320) and the difference in men and women who were married was significant (Chi-square Test: $P<0.001$). There was also significant difference in household income (chi-square test: $p=0.01$) with approximately, 79% (253/320) of the participants having average monthly income of 10,000Ksh or less. Majority of the participants had low level education below primary and highest education as Primary School level, and the accounted for 70% (223/320) Chi-square Test : $p=0.008$.

Table 4.1a: Baseline Demographic Characteristics of the study Participants in a cohort of cancer patients receiving clinical care at the Jaramogi Oginga Odinga Teaching and Referral Hospital in Kisumu.

Characteristic	**Overall**, N = 320[1]	**Female**, N = 205[1]	**Male**, N = 115[1]	**p-value**[2]
Overall Turn Around Time (months):	21 (6, 48)	21 (6, 48)	21 (8, 48)	0.92
Home County				0.89
Kisumu	144 (45%)	96 (47%)	48 (42%)	
Siaya	77 (24%)	48 (23%)	29 (25%)	
Homabay	45 (14%)	29 (14%)	16 (14%)	
Vihiga	31 (9.7%)	18 (8.8%)	13 (11%)	
Other	23 (7.2%)	14 (6.8%)	9 (7.8%)	
Occupation				0.65
Farmer	136 (73%)	91 (74%)	45 (%)	
Employed	99 (31%)	62 (30%)	37 (32%)	

Unemployed	85 (27%)	52 (25%)	33 (29%)	
Marital Status				<0.001
Married	259 (81%)	155 (76%)	104 (90%)	
Single	28 (8.8%)	18 (8.8%)	10 (8.7%)	
Widowed	33 (10%)	32 (16%)	1 (0.9%)	
Level of Education				0.008
No education	79 (25%)	49 (24%)	30 (26%)	
Primary	144 (45%)	100 (49%)	44 (38%)	
Secondary	69 (22%)	46 (22%)	23 (20%)	
Tertiary	28 (8.8%)	10 (4.9%)	18 (16%)	
Religion				>0.99
Christianity	313 (98%)	200 (98%)	113 (98%)	
Muslim	7 (2.2%)	5 (2.4%)	2 (1.7%)	
Household Income				0.011
>10,000	67 (21%)	34 (17%)	33 (29%)	
10,000	253 (79%)	171 (83%)	82 (71%)	
Funding Medical Costs				0.67
NHIF	288 (90%)	184 (90%)	104 (90%)	
SELF	14 (4.4%)	8 (3.9%)	6 (5.2%)	
HARAMBEE	18 (5.6%)	13 (6.3%)	5 (4.3%)	

4.1.1 Clinical Characteristics of the Study Participants

On the clinical characteristics of this study population, 69% (220/320) of the study participants had previously gone for cancer screening compared to 31% (100/320) who had never gone for initial cancer screening. Women (n=161) accounted for the majority of cancer patients who went for the initial screening compared to men (n=59). Majority of participants enrolled were at cancer Stage II and Stage III and accounted for 82% (262/230). Those who had no comorbidity with HIV and diabetes accounted for 99% and 89% respectively. The most prevalent cancers in the study population were, Cervix Uteri (C53)-Ca Vulva (C51) accounted for 22% (72/320), oesophagus/Nasopharynx (C15/C11) accounted for 17% (53/32 Breast Cancer (C50) accounted for 16% (51/320) , prostate (C61) accounted for 13% (41/320) cancers respectively.

Table 4.1b: Clinical Characteristics of the study participants in a cohort of cancer patients receiving clinical care at the Jaramogi Oginga Odinga Teaching and Referral Hospital in Kisumu, Kenya

Clinical Characteristic	**Overall**, N = 320[1]	**Female**, N = 205[1]	**Male**, N = 115[1]	**p-value**[2]
Initial Screening				<0.001
Initially Screened	220 (69%)	161 (79%)	59 (51%)	
Not Screened	100 (31%)	44 (21%)	56 (49%)	
Treatment N=317*)				0.92
Chemotherapy	196 (62%)	127 (63%)	69 (61%)	
Radiotherapy	16 (5.0%)	9 (4.4%)	7 (6.1%)	
Chemo/Surgery	32 (10%)	20 (9.9%)	12 (11%)	
Surgery	73 (23%)	47 (23%)	26 (23%)	
Stage				0.15
Stage I	18 (5.6%)	12 (5.9%)	6 (5.2%)	
Stage II	145 (45%)	83 (40%)	62 (54%)	
Stage III	117 (37%)	81 (40%)	36 (31%)	
Stage IV	24 (7.5%)	19 (9.3%)	5 (4.3%)	
Unknown	16 (5.0%)	10 (4.9%)	6 (5.2%)	
Use of Tobacco				0.13
Use tobacco	4 (1.3%)	1 (0.5%)	3 (2.6%)	
Non-tobacco-smoker	316 (99%)	204 (100%)	112 (97%)	
HIV				0.12
Positive	59 (18%)	43 (21%)	16 (14%)	
Negative	261 (82%)	162 (79%)	99 (86%)	
Diabetic				0.14
Diabetic	8 (2.5%)	3 (1.5%)	5 (4.3%)	
Not diabetic	312 (98%)	202 (99%)	110 (96%)	
Type of Cancer				
Breast Cancer (C50)	51 (16%)	50 (24%)	1 (0.9%)	
Cervix Uteri (C53) - Ca Vulva (C51)	72 (22%)	72 (35%)	0 (0%)	
Colon & rectum (C25) - Anal carcinoma (C18-21)	20 (6.2%)	13 (6.3%)	7 (6.1%)	
Eosophagus (C15) - Nasopharynx (C11)	53 (17%)	21 (10%)	32 (28%)	
Liver (C22) - Leukemia (C91-95)	16 (5.0%)	12 (5.9%)	4 (3.5%)	
Non-Hodgkin lymphoma (C82-85,C96) - Hodgkin lymphoma (C81)	13 (4.1%)	7 (3.4%)	6 (5.2%)	
Pacrease (C16) - Gallbladder (C23-24)	8 (2.5%)	4 (2.0%)	4 (3.5%)	
Prostate (C61)	41 (13%)	0 (0%)	41 (36%)	
Other cancers	46 (14%)	26 (13%)	20 (17%)	

[1]Median (95th - percentile)

[2]Wilcoxon rank sum test; Pearson's Chi-squared test; Fisher's exact test

[3]Missing data (*) unless indicated- 3 missing data

4.1.2 Distribution of the Cancer Types Prevalence in the Study Population vs. Cancer Referral Sites

Cancer cases at the JOOTRH were mostly from Kisumu and Siaya County which accounted for more than 70% of the cases. Figure 4.1 demonstrates, the most prevalent cancers in this study population were cancer of the cervix/Ca vulva, followed by oesophageal cancer, breast cancer, prostate cancer, and cancer, of cancer the colon. Kisumu county and Siaya bore the burden of cancer in his study population other groups of cancers. Cancer of the cervix was more prevalent ion Siaya followed by Migori, Kisumu and Vihiga counties respectively. Leukaemia was more prevalent in Kakamega and Migori counties. Oesophageal cancer was most prevalent in Vihiga, Kakamega and Kisumu. Cancer of the prostate was most prevalent in Kisii, Siaya, Kisumu and Vihiga Counties. It is not clearly known the cancer distribution patterns in Kisii, Busia and Kericho demonstrated as the numbers of patients referred from these counties were very few and were lump up as others differential pattern prevalence different from the rest of the counties as seen in Figure 4.1.

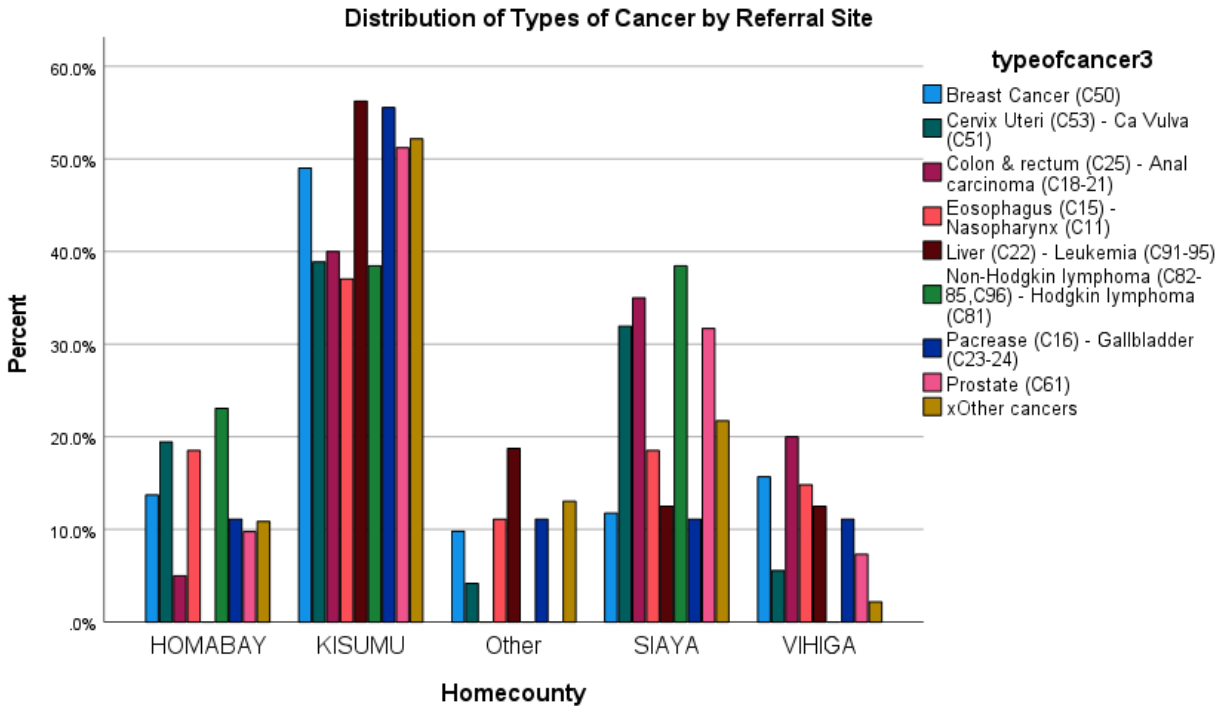


Figure 4.1: Overall Distribution of Cancer Cases by location of the habitat Referral Sites for the Patients Seeking Health Services from and type of cancers in a cohort of cancer patients seeking services at the Oncology Unit Jaramogi Oginga Odinga Teaching and Referral Hospital in Kisumu, Kenya,

4.1.3 Cancer Turnaround Time Outcomes vs Cancer Staging

The average Cancer turnaround time (TAT) was 21.2 months, with TAT between the onset of cancer to the time a study participant visited the healthcare facility for health services was 15.3 months, and the time taken between first visitation to the hospital to the time of diagnosis was 0.83 months and time between when the diagnosis was done to the time when a presumptive clinical decision was made was 2.63 months. It is notable that even though overall, the difference in TAT stratified by type of cancer was not significantly different (*p=0.056*), The delay in Onset and first hospital visitation was more than any TAT category especially for patients with Stages III, Stages IV, and those with unknown staging documented the longest TAT even though I wasn't statistically significant across the various cancer staging (*p=0.073*). Similar trend was documented on TAT between Diagnosis Treatment/Clinical Decision There was no significant association between the various TAT, and the cancer staging as demonstrated in Table 4.2.

Cancer Stage

Turn Around Time	**Overall**, N = 320[1]	**Stage I**, N = 18[1]	**Stage II**, N = 145[1]	**Stage III**, N = 117[1]	**Stage IV**, N = 24[1]	**Unknown**, N = 16[1]	**p-value**[2]
Onset- Visiting Healthcare (months):	15.3 (1.5, 40.1)	10.3 (0.7, 25.7)	13.3 (2.2, 37.1)	16.1 (1.9, 40.1)	16.5 (33.3, 103.9)	16.2 (1.3, 62.0)	0.073
Visiting Healthcare- Diagnosis (months):	0.83 (0.1, 8.4)	0.9 (0.1, 14.7)	0.83 (0.2, 6.9)	0.86 (0.1, 8.6)	0.8 (0.2, 11.1)	0.6 (0.06, 12.3)	0.89
Diagnosis-Treatment/clinical decision (months):	2.63 (0.4, 12.7)	2.26 (0.5, 12.0)	2.67 (0.4, 13.1)	2.3 (0.5, 11.2)	4.7 (0.53, 18.0)	2.6 (0.4, 5.0)	0.20
Total Turn Around Time (months):	21.2 (0.6, 48.0)	19.7 (4.7, 35.0)	20.2 (5.3, 48.1)	21.8 (10.1, 45.7)	26.4 (12.1, 106.1)	20 (6.2, 66.1)	0.067

[1]Median (95th - percentile)

[2]Kruskal-Walli's rank sum test; Pearson's Chi-squared test; Fisher's exact test

Table 4.2: Turnaround Time for Cancer stratified by cancer staging for patients Seeking Services at the Jaramogi Oginga Odinga Teaching and Referral Hospital, in Kisumu

Cancer Turnaround Time Outcomes vs Type of Cancer

The median Cancer turnaround time (TAT) was 21. months, stratified by type of cancer, this was However, overall, there was no statistical significance (Chi-square test: *P=0.056)* in the difference in TAT when stratified by the type of Cancer. On the Time between Onset of illness and First hospital visit, with Breast Cancer (C50)cancer, Liver (C22) - Leukaemia (C91-95) , Prostate (C61) and Colon & rectum (C25) - Anal carcinoma (C18-21), accounted for cancers with extended delay of 17 months. However, this difference in the TAT in this time point was not statistically significant (Chi-square Test: *p=0.32*). TAT between the hospital visit and diagnosis was 0.83 months and was not statistically significant (p=0.90) with no major variations observed in the various cancers. Analysis on TAT between Diagnosis to Treatment/ clinical decision, a median TAT of 2.6 months was record and the difference in TAT in the various cancer types was statistically significant (*p=0.24*) as demonstrated in Table 4.3.

Table 4.3: Analysis of Turnaround time stratified by type of cancer in a cohort of cancer patients attending cancer care at the Jaramogi Oginga Odinga Teaching and Referral Hospital Laboratory.

Turnaround Times Measurements vs Type of Cancer Patients

TAT	Overall, N = 320[1]	Breast Cancer (C50), N = 51[1]	Cervical (C53) - Ca Vulva (C51), N = 72[1]	Colon & rectum (C25) - Anal carcinoma (C18-21), N = 20[1]	Esophagus (C15) - Nasopharynx (C11), N = 53[1]	Liver (C22) - Leukemia (C91-95), N = 16[1]	Non-Hodgkin lymphoma (C82-85, C96) - Hodgkin lymphoma (C81), N = 13[1]	Pancreases (C16) - Gallbladder (C23-24), N = 8[1]	Prostate (C61), N = 41[1]	Other cancers, N = 46[1]	p-value[2]
Turn Around Time (months):	21 (6, 48)	23 (11, 56)	22 (9, 46)	21 (9, 40)	20 (5, 37)	19 (13, 41)	13 (7, 22)	16 (14, 93)	22 (10, 48)	22 (4, 55)	0.056
Onset-Healthcare (months):	15 (2, 40)	17 (5, 47)	16 (2, 38)	16 (8, 36)	14 (1, 35)	17 (10, 29)	9 (2, 18)	10 (2, 91)	17 (4, 35)	14 (1, 54)	0.32
Healthcare-Diagnosis (months):	0.83 (0.13, 8.35)	0.80 (0.12, 7.20)	0.98 (0.19, 11.64)	0.63 (0.16, 6.77)	0.60 (0.17, 5.93)	0.90 (0.27, 10.76)	1.10 (0.25, 4.99)	1.50 (0.12, 10.32)	0.93 (0.20, 5.67)	0.80 (0.04, 12.61)	0.90
Diagnosis-Treatment (months):	2.6 (0.4, 12.7)	2.8 (0.4, 9.2)	2.8 (0.5, 11.5)	2.7 (0.5, 8.6)	2.4 (0.6, 9.0)	1.5 (0.4, 7.0)	2.0 (0.5, 8.7)	2.2 (0.6, 9.7)	3.2 (0.5, 30.8)	3.0 (0.6, 11.4)	0.24

[1]Median (95th - percentile)

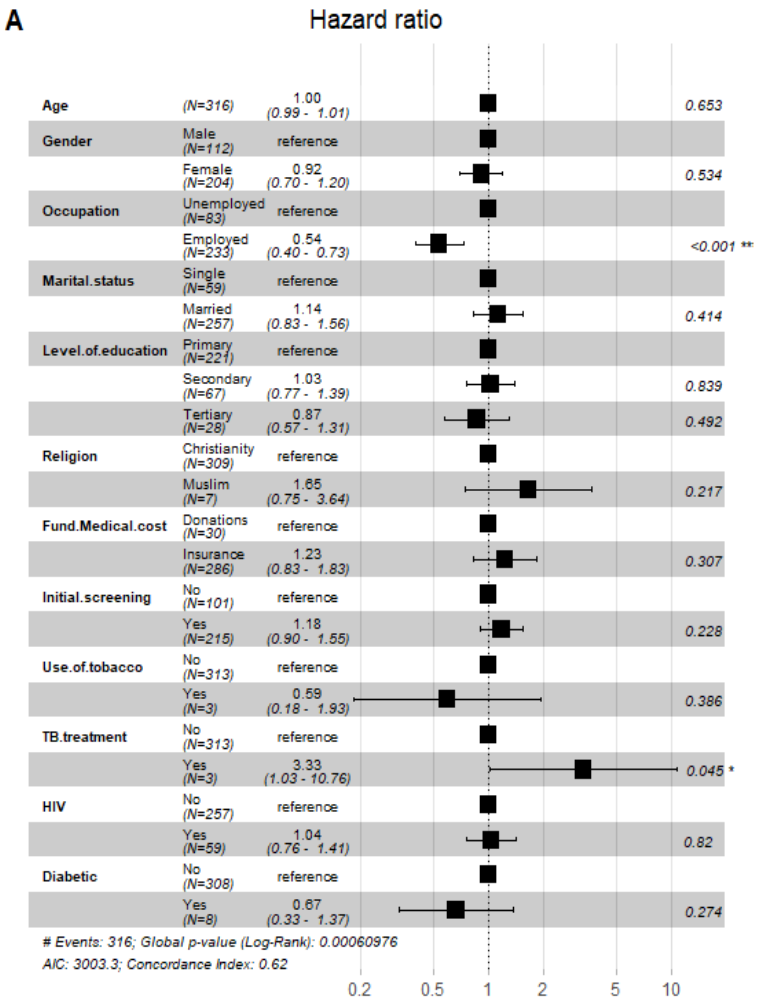
[2]Kruskal-Wallis rank sum test

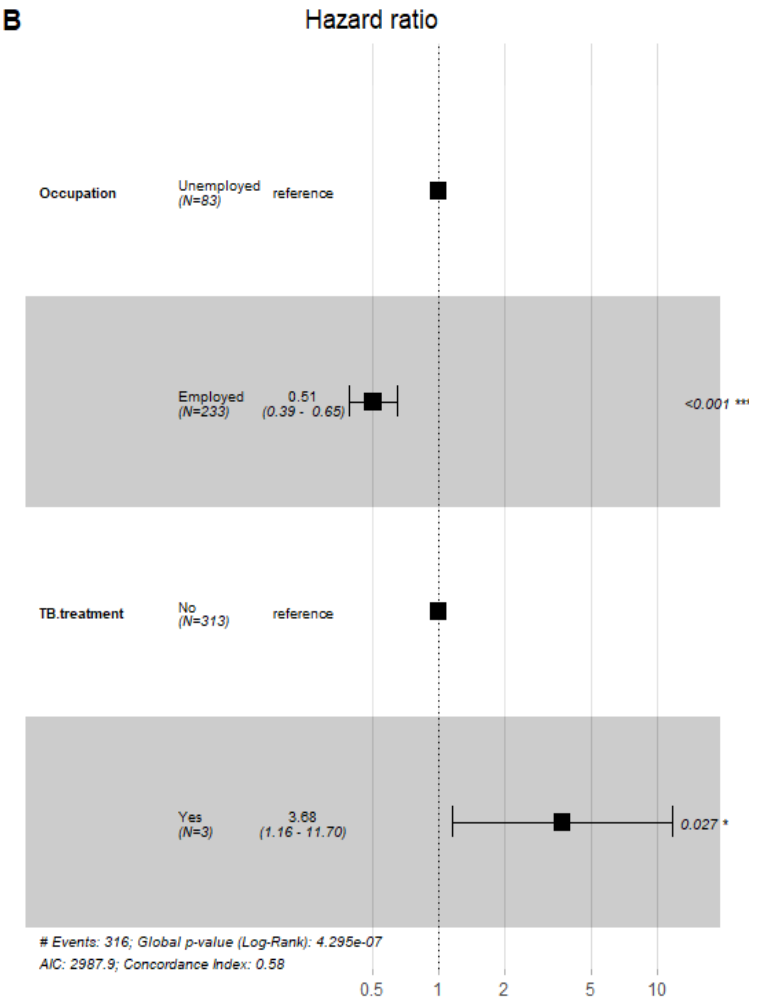
4.2 Barriers to cancer diagnosis and clinical decision

4.2.1 Barries Associated with Time to onset of illness and Time to First Hospital Visit

This univariate and multivariable cox proportions regression model was restricted to 316 patients who had complete data on TAT1. In a univariate analysis, cancer patients who were employed were less likely to visit the hospital for cancer services compared to those who were unemployed, given the delay in TAT1 between onset of illness to first hospital visitation HR: 0.54 (95% CI: 0.40-0.73; *p<0.001*). Similar outcome in an adjusted model was observed in a multivariable analysis with HR:0.51 (0.39-0.68; *p<0.001*) and remained significant. Those who were on TB treatment were three times more likely to visit the hospital compared to those who did not have TB disease on time of onset of illness and time of first visitation to the hospital for cancer services had HR: 3.33 (95% CI 1.03-10.76; *p=0.045*) were three times more likely to visit the hospital compared to those who did not have TB disease at onset of illness and first visitation to the hospital for cancer services. Similar outcomes in an adjusted model in the multivariable analysis remained statistically significant HR: 3.68 (95% CI 1.16 -11.70; *p=0.027*) when compared to those who had no TB.

Figure 4.2 below shows Forest plot of hazard ratios for association of Turnaround time (TAT 1) on Time taken from onset of illness to time of first healthcare facility visit and the barriers associated with the delay in cancer. BLACK boxes represent the hazard ratio for each variable and the whiskers represents 95% confidence interval (CI).


A
Hazard ratio
Age (N=316) 1.00 (0.99 - 1.01) 0.653
Gender
Male (N=112) reference
Female (N=204) 0.92 (0.70 - 1.20) 0.534
Occupation
Unemployed (N=83) reference
Employed (N=233) 0.54 (0.40 - 0.73) <0.001 **
Marital.status
Single (N=59) reference
Married (N=257) 1.14 (0.83 - 1.56) 0.414
Level.of.education
Primary (N=221) reference
Secondary (N=67) 1.03 (0.77 - 1.39) 0.839
Tertiary (N=28) 0.87 (0.57 - 1.31) 0.492
Religion
Christianity (N=309) reference
Muslim (N=7) 1.65 (0.75 - 3.64) 0.217
Fund.Medical.cost
Donations (N=30) reference
Insurance (N=286) 1.23 (0.83 - 1.83) 0.307
Initial.screening
No (N=101) reference
Yes (N=215) 1.18 (0.90 - 1.55) 0.228
Use.of.tobacco
No (N=313) reference
Yes (N=3) 0.59 (0.18 - 1.93) 0.386
TB.treatment
No (N=313) reference
Yes (N=3) 3.33 (1.03 - 10.76) 0.045 *
HIV
No (N=257) reference
Yes (N=59) 1.04 (0.76 - 1.41) 0.82
Diabetic
No (N=308) reference
Yes (N=8) 0.67 (0.33 - 1.37) 0.274
Events: 316; Global p-value (Log-Rank): 0.00060976
AIC: 3003.3; Concordance Index: 0.62
0.2
0.5
1
2
5
10


B
Hazard ratio
Occupation
Unemployed (N=83) reference
Employed (N=233) 0.51 (0.39 - 0.65) <0.001 ***
TB.treatment
No (N=313) reference
Yes (N=3) 3.68 (1.16 - 11.70) 0.027 *
Events: 316; Global p-value (Log-Rank): 4.295e-07
AIC: 2987.9; Concordance Index: 0.58
0.5
1
2
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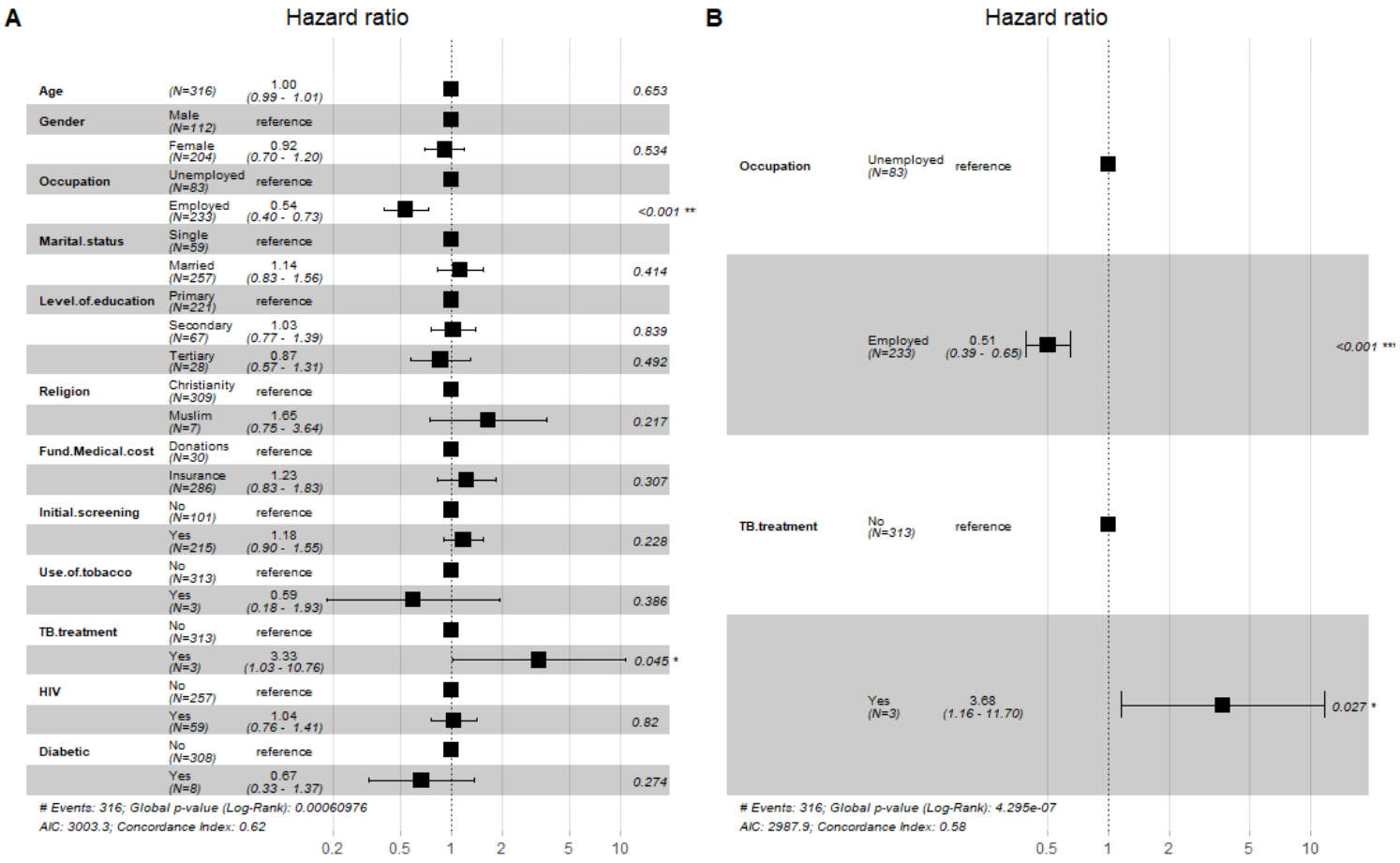
10



Univariate Cox regression (A) with multivariate adjusted (B).

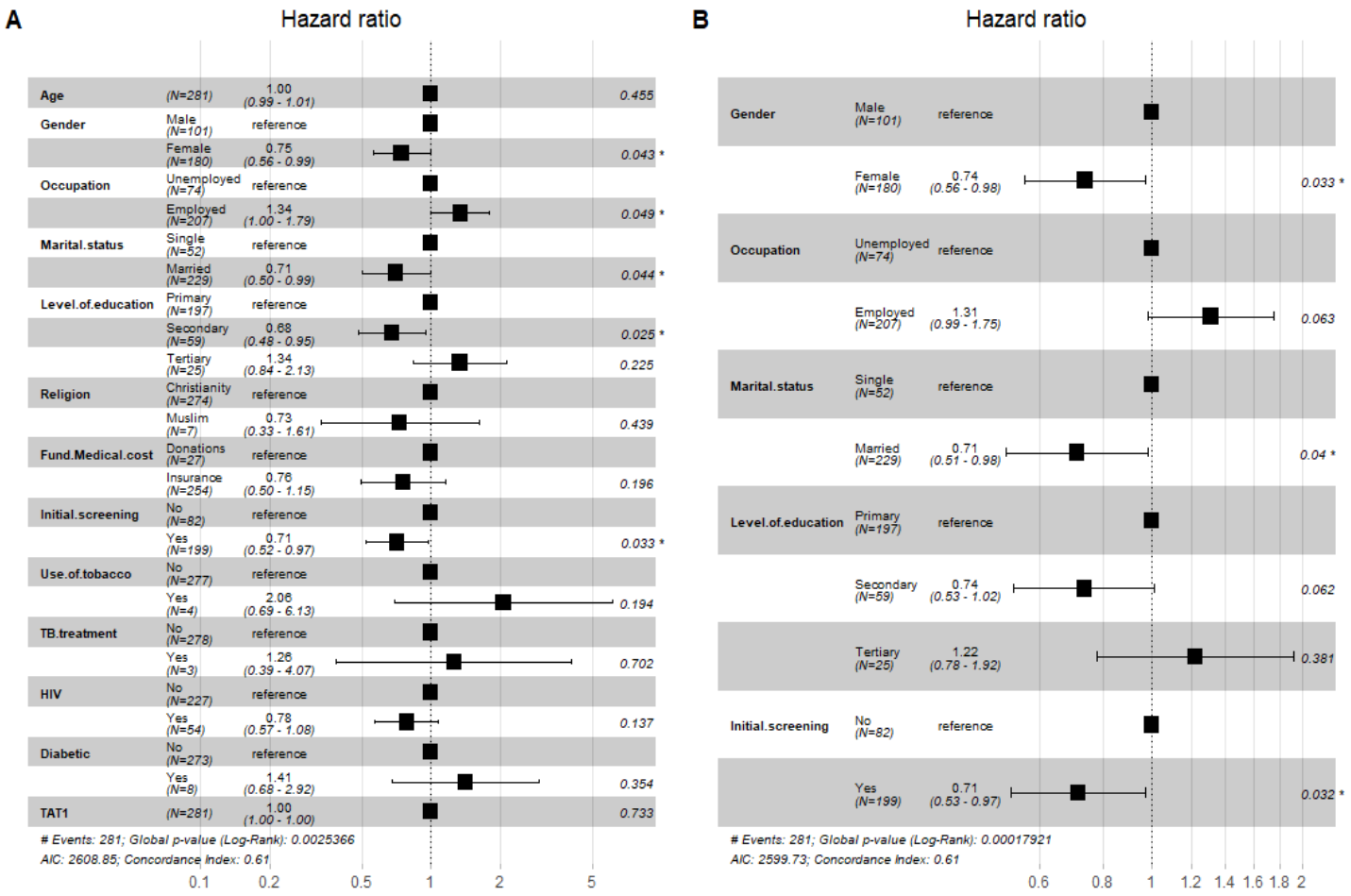
Figure 4.2: A forest plot on Univariate and Multivariate Cox proportional Hazard Regression Analysis for Determinants of Turnaround time for cancer care between onset of illness to first health facility visitation (TAT1) in a cohort of Cancer patients seeking care at the Jaramogi Oginga Odinga Teaching and Referral Hospital.

4.2.2 Barries Associated with Time to First Hospital Visit to Time to Diagnosis

This univariate and multivariable cox proportions regression model was restricted to 261 patients who had complete data on all variables and time between first hospital visit – clinical diagnosis denoted (TAT 2). In a univariate analysis, female cancer patients were less likely to be diagnosed early and experienced a to delay between hospital visit and time to cancer diagnosis HR:0.75 (95% CI 0.56-099; *p=0.043*) and in an adjusted model (HR: 0.74 (0.56-0.98); *p=0.033*) when adjusted, and this remain significant in a in both univariate and multivariable analysis. Those who were employed, were more equally less likely to be diagnosed early than those who had no

employment, and this was statistically significant in univariate model and shown weak association in the adjusted model given the delay in time in time between first hospital visitation – time of clinical diagnosis with a HR: 1.34 (95% CI 1.00-1.79;*p=0.049*) which was significant and HR:1.31 (95% CI 0.99-1.75;*p=0.063*) respectively. In univariate and multivariable analysis respectively. Cancer patients who were married compared to those who were not, equally were less likely to diagnosed given the delay in time between first hospital visitation to time of clinical diagnosis with HR: 0.79 (955 CI 0.50-0.99;*p=0.049*) and HR=0.71 (95% CI 0.51-0.98; *p=0.04*) which remained significant both in univariate and multivariable Cox hazard regression model. Cancer patients with tertiary education when compared to those with primary level of education were less likely to be diagnosed early between first visitation to hospital and time to clinical diagnosis with hazards of HR:0.68(95% CI 0.50-0.99;p=0.044) and HR:0.74 (95% CI 0.53-1.02*; p=0.062*) with levels of significance seen in univariate and not in multivariable models respectively. Cancer patients who had gone for the prior cancer screening were equally less likely to be diagnosed early on TAT 2 , which was between first hospital visitation to time to clinical diagnosis with HR: 0.71 (95% CI 0.53-0.97; *p=0.032* and HR=0.71 (95% CI 0.52-0.97*; p=0.033*) and remained significant in both univariate and multivariable analysis. It's not clearly known why patients who had previously gone for initial cancer screening experienced delayed in getting diagnosis done, as described in *Figure 4.3.*

Forest plot of hazard ratios for association of Turnaround time (TAT 2) on Time from first healthcare facility visit – to diagnosis and the barriers associated with the TAT2 in cancer. BLACK boxes represent the hazard ratio for each variable and the whiskers represent 95% CIs.



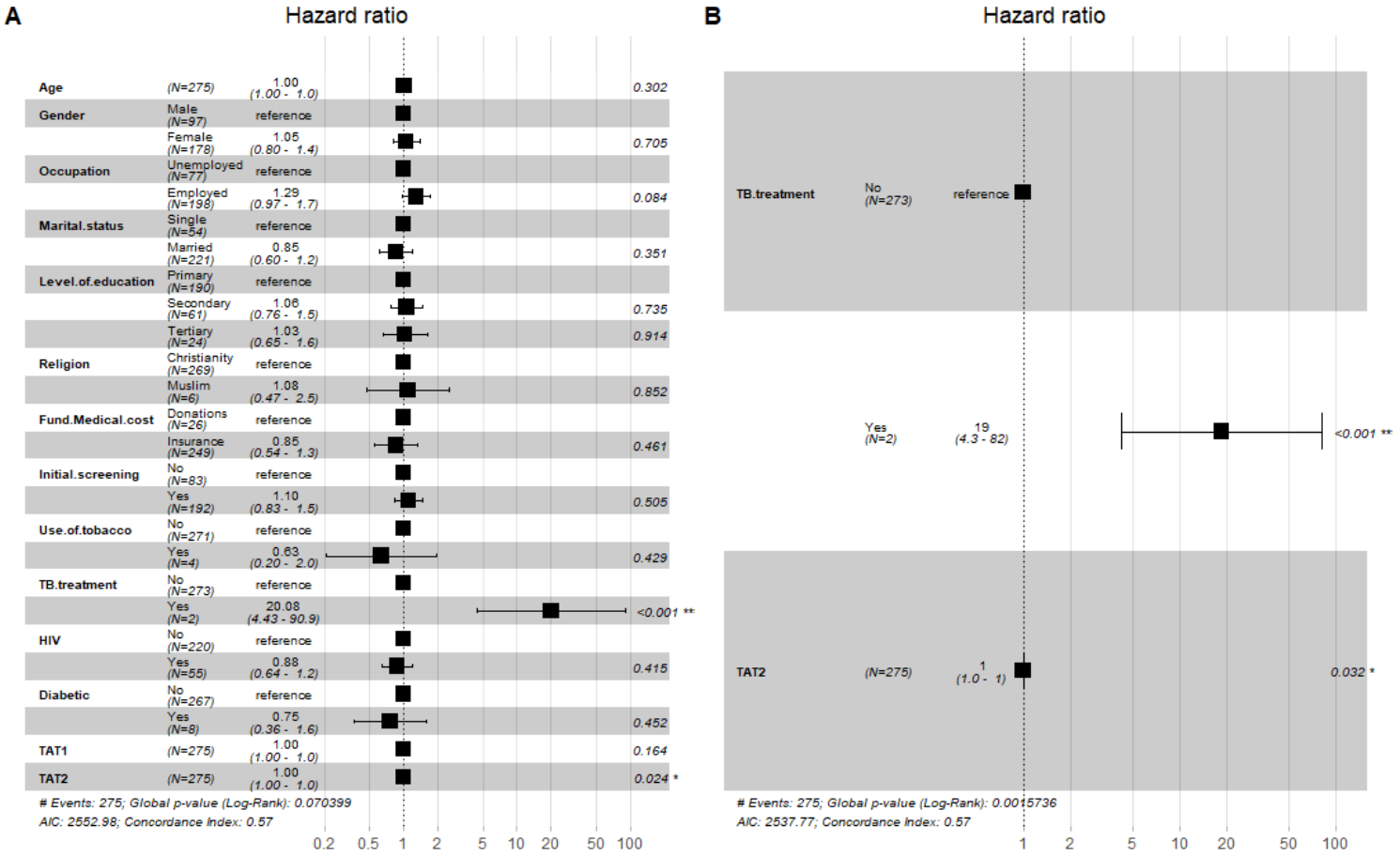
Univariate Cox regression (A) with multivariate adjusted (B).

Figure 4.3: A Forest Plot on Univariate and Multivariate Cox proportional Hazard Regression Analysis for Determinants of Turnaround time for cancer care between first health facility to time receiving presumptive diagnosis for cancer (TAT2) in a cohort of Cancer patients seeking care at the Jaramogi Oginga Odinga Teaching and Referral Hospital, in Kisumu.

4.2.3 Barriers Associated with Time to Diagnosis to Time to Clinical Decision

This univariate and multivariable Cox proportions regression model was restricted to 275 patients who had complete data on time between diagnosis – clinical decision denoted (TAT 3) and other covariates. In a univariate analysis, patients who had having TB disease were more than 17 times likely to have their clinical decision made compared to those who were not, both in unadjusted and adjusted model (presented HR: 20.08 (95% CI 4.43-90.9;$p<0.001$) and HR: 19 (95% CI 4.3-82) in univariate and multivariable respectively. indicating more than 19 times more likely to be

diagnosed compared to those who had no TB, with significance levels of $p<0.001$ in univariate analysis., indicating that patients on TB treatments were most likely to be diagnosed for cancer and have early clinical decision made for their treatment when compared to those who had no TB. The hazards for TAT2 were statistically significant similar both in univariate and multivariable analysis with an HR: 1(95% CI 1.00-1.00;*p=0.024*) and 1 (95% CI1.0-1.0; *p=0.032*) respectively. This implied that even though the hazard to achieve clinical decision early was same, it was remained statistically significant in b. Having a delay in TAT2 provided a hazard of 1.0 in determining delay in TAT3 in which is time between diagnosis and time to receiving clinical decision as seen in Figure 4.4 which shows Forest plot of hazard ratios for association of Turnaround time (TAT 3) on Time from diagnosis to time of clinical decision and the variables associated with the TAT3 in cancer. BLACK boxes represent the hazard ratio for each variable and the whiskers represent 95% confidence interval (CI).



Univariate Cox regression (A) with Multivariate adjusted (B).

Figure 4.4: Forest plot on Univariate and Multivariate Cox proportional Hazard Regression Analysis for Determinants of Turnaround time for cancer care between time to receiving presumptive diagnosis for cancer (TAT2) to time of clinical decision (TAT3) in a cohort of Cancer patients seeking care at the Jaramogi Oginga Odinga Teaching and Referral Hospital, in Kisumu

4.3 Cancer Distribution and Referral Networks

The cancer referral networks were within the five major counties with Kisumu bearing the burden for cancer cases. Referrals occurred from facilities withing the Western region with more patients coming from Kisumu County which accounted for 45% (145/320) of the total patients followed by Siaya County 24% (77/320), Homabay 14% (45/320) and Vihiga Counties 10% (31/320) and other counties accounted for 7% (24/320) respectively as demonstrated in the Figure 4.5. This figure on the right (below) provides information on the referral network staggered by the types of cancers as distributed in the referring sites. Figure 4.5 provides the various cancer distributions across the various referring counties. Prostate cancer was the most prevalent in Kisii while cervical cancer was most dominant in Busia Counties. Kisumu, Siaya, Homay and Vihiga laboratories had cancer referred almost all the cancer types as described in the study population.

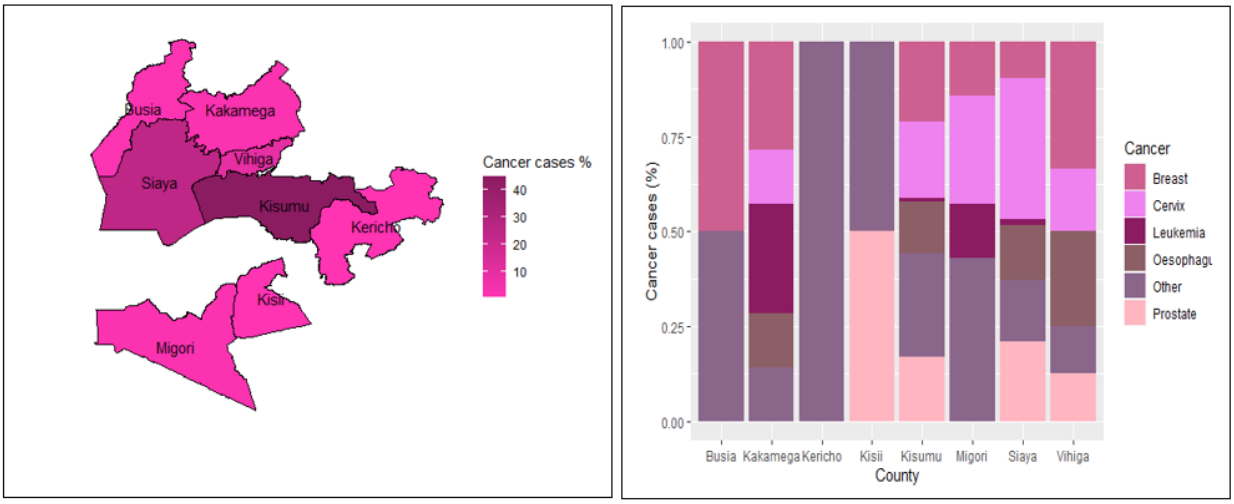


Figure 4.5 The cancer burden based on the Cancer referring and the distribution by type of cancer Patients to the JOOTRH in Kisumu Kenya. distribution across the various referring counties.

4.5: Distribution of the Cancer Staging by the Patients Referral Site.

Approximate 40% of all the patients who were referred from Homabay were in Stage IV cancer, followed by 22 % from Vihiga counties. Of the participants who were enrolled in the study, cancer referral cases with stage III were mostly from Kisumu and Siaya Counties 40% and 29% respectively. Kisumu County accounted for 78% of the patients who came for cancer services at Stage 1. Followed by Siaya at 18% and Homabay counties at 4%. However, it is worrying that a good proportion of participants 5% (16/320) were not staged or records captured in the clinical records for reference.

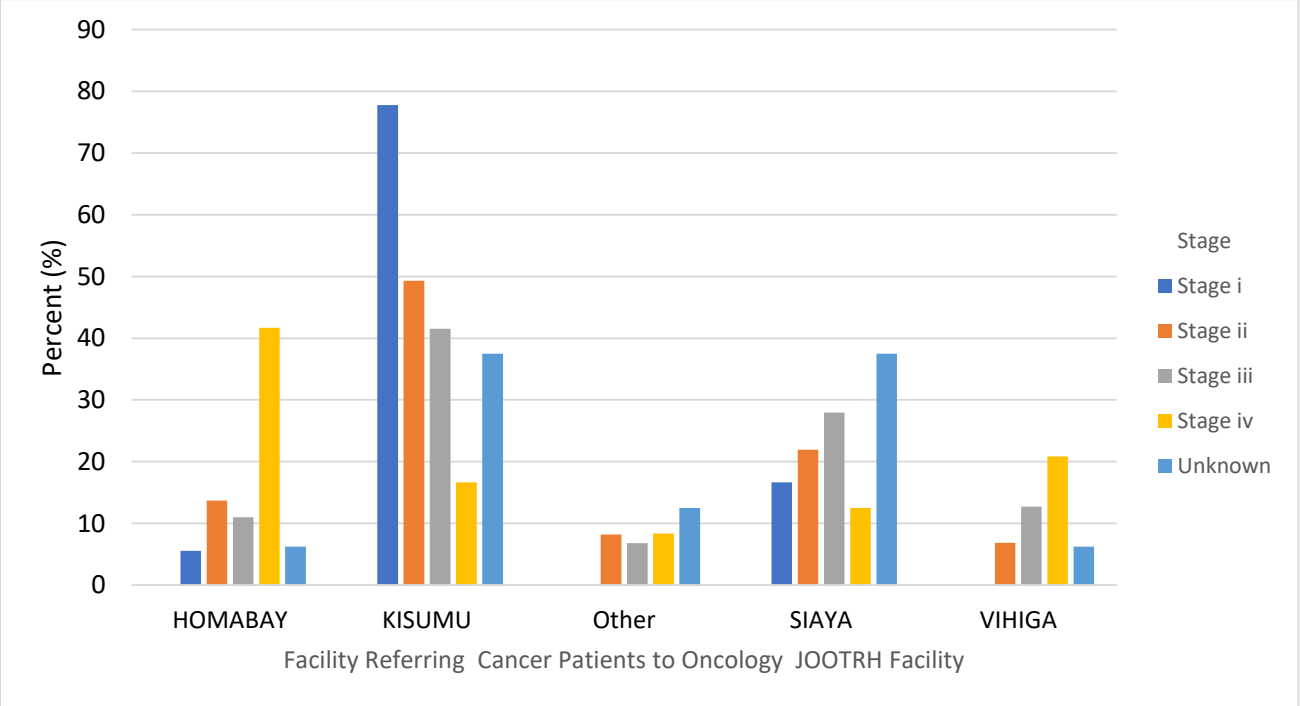


Figure 4.6 The cancer burden based on the Cancer referring and the distribution by type of cancer Patients to the JOOTRH in Kisumu Kenya.

CHAPTER FIVE: DISCUSSION

5.1 Characteristics of Cancer Patients

Data obtained from the current study shows that, majority of the study participantst were female and accounted for sixty-four percent of the study population. Most of the study population were above the midterm age, with a median age of fifty-five years. More than eighty percent of the participants were at cancer stages II and III at the time of referral to the JOOTRH cancer centre. Delay in seeking cancer management at late Stage of the condition has previously been documented (Basharat et al., 2019 ;Xolisile et al., 2022) with patient or personal delay in seeking cancer services and hospital factors being associated with such delays. Majority of the participants were married, which is synonymous with many African settings where traditional marriage even without certificate of marriage is considered legal. Approximately 79% of the patients reported to have an average low family income of approximately than ten thousand per month, given that most of them were either employed may have been in casual employment given the low wages reported and they could have delayed seeking services because of financial constraint or other unknown factors as demonstrated in other studies (Tesfaw et al., 2020 ;Wei et al., 2021) . Relatively, ninety percent of the study participants funded their cancer treatment using national insurance scheme procured through NHIF with only a few funding their treatment through out-of-pocket self-funding or family donation. This may have made it easy for most participants to access care even through overall they fall under the low-income cadre. Kisumu County was leading with the highest number of cancer participants that received services from the JOOTRH. This finding was not unusual because JOOTRH is a facility within Kisumu County and may have been the preferred choice for many but also because it's the only cancer treatment centre in the Nyanza region. This study also shows the most prevalent cancer was cervix/Ca uteri (C53/C51) followed by the oesophagus/nasopharynx (C15/C11) breast cancer (C50) prostate (C61) Colon & rectum (C25)/Anal carcinoma (C18-21) at as five major cancers in this population respectively see Figure 4.13. This is consistent with the available literature on cancer prevalence in Kenya where cervical and breast cancers are prevalent in women and prostate and oesophageal cancers in men (Wakhisi et al., 2005; Kobia et al., 2019; Asombang et al., 2019; Wambalaba F.W et al., 2019),

however, the increase in the number of oesophageal/nasopharyngeal cancers in Kenya needs to be investigated.

5.1.2 Turnaround Time Outcome from onset of illness to clinical decision

The median duration taken from onset of illness to clinical decision was twenty-one months as shown in Table 4.2 and Table 4.3. While delay in cancer management has been reported in many studies (Botey et al., 2021; Tetteh & Faulkner, 2016; Somanna et al., 2020; Walpole et al., 2022; Somanna et al., 2020) , the current study provides a unique near accurate state of cancer management delays situation in many settings in Kenya with significant delays associated with patients and health facility as seen in the TAT1 and the overall TAT. There are limited data on the actual TAT for cancer services, with best practices mostly in high income countries (Walpole et al., 2022, 2023; Otty et al., 2023) , where a standard time for cancer management is monitored and data is made available to evaluate performance of the care givers (Smith et al., 2019; Vasiliadou et al., 2021; Vasiliadou et al., 2021; Appayya et al., 2018; Diamand et al., 2020) . For the first time this study calculated delay in time taken in the cancer clinical pathways, that are associated with patient factors with delay between onset of illness and time to first visit to hospital and hospital related delay associated with time between clinical diagnosis and clinical decision. A public health action towards improvement of cancer services uptake must consider those factors that are patient associated and those that targets health system structures with the best approached being health system integration with focus on the primary healthcare. Additionally, to improve on the quality of cancer care should integrate cancer screening, diagnosis, and clinical decision in the routine hospital pathways. Studies conducted in Australia and United Kingdom have demonstrated cancer management can be effective and efficiently through integration of health services and provision of funding to support cancer management clinical pathways (Diamand et al., 2020; Chapman et al., 2020; Chapman et al 2018; . The delay between onset of illness to first hospital visit which was ten times longer than any of the timepoints with participants who had previously gone for initial screening being less likely to go to the hospital following onset of illness. These outcomes pose a question whether early cancer screening translates to increase uptake of cancer services or not or what is the social need that is still unmet on cancer screening and transitioning to care. This may mean that there could be some social barriers to seeking cancer services that needs to be explored (Chapman et al., 2020; Mimouni et al., 2021; Mutebi et al., 2018), 2018 ; Mimouni M. et al 2018 ;Chapman, Emma. J et al 2020 ;Mimouni et al., 2021 ;

‘Rendle et al., 2019), Patient related factors that lead to delay in seeking services needs to be investigated, as this may be associated with fear of the unknown or stigma as demonstrated in other studies elsewhere that found negative beliefs about cancer, fear and disregarding symptoms and use of alternative medicine (Adewumi et al., 2022; Olbodun et al., 2022;Wei et al., 2021). In analysis comparing TAT and type of cancer, there was no statistically significance in the TAT as seen in Table 4.3, however, the delay in cancer management observed was recorded in all cancer types regardless of the cancer and thus lack of statistical significance. In a meta-analysis of peer-of cancer studies, a four-week delay was associated with increased mortality in breast cancer patients, and a two-week delay in treatments was associated with disease progression to severity **(**Unger et al., 2019; Asombang et al., 2019; Basharat et al., 2019) across the various treatment options. Delay in diagnosis (TAT2) the participants with varying cancer stages were mostly less than 1 month while that delay in cancer clinical decision had a median delay of> 2 months and still remained a high TAT for cancer patients as this is a progressive condition.

5.2 Barriers to Cancer Diagnosis and Clinical Decision

In a crude and an adjust model using the Cox proportional regression analysis, it was determined that, those who were employed were less likely to visit the health facility in the event of onset of cancer illness compared to those who were unemployed leading to delay in them seeking care. This outcome is not clearly known, especially on health-seeking behavior among the employed versus non-employed, this may imply that work schedules does not allow employees to seek medical attention in time given that in Kenya, work schedules run from mostly 8,00am to 5.00pm and these are the times that most outpatient clinics close., On the other hand, patients who had TB were more likely to visit the hospital at the onset of illness compared to those who did not have TB infection. This still may be due to well-established structures for TB management and free treatments thus prompting the patients to seek medical attention See Figure 4.2. On time to clinical decision cancer patients having TB disease were twenty times more likely to received clinical decision more that those who did not have TB disease. This may imply that they were easily identified and diagnosed, and clinical decision made early enough for their cancer management. However, this outcome may have some implications on the need to for early screening for cancer cases. TB patients may have benefitted due to the robustness of the TB program with follow-ups of patients in TB clinics where any slight abnormality detected during

TB clinic visits is investigated. In a univariate analysis, female cancer patients were less likely to be diagnosed early looking at time between first hospital visitation to time of clinical diagnosis compared to the male counter parts in this study cohort this is simar to other documented findings among women with breast cancer who experienced delay of >3month (Granek Leeat, et al 2012) a study conducted in Western Kenya among community members on barriers to seeking services in a health care (Xolisile et al., 2022) setting identified fear of pain and embarrassment during pelvic examination for cervical cancer screening and lack of knowledge and discomfort discussing sensitive subjects (Adewumi, Konyin et al. 2022). Cancer patients with tertiary education when compared to those with primary level of education were less likely to have cancer diagnosis done while those who had prior cancer screening were equally less likely to be diagnosed as demonstrated in Figure 4.3 in clinical diagnosis, may be due to lack of time or awareness on cancer.

Early Identification of patients with cancer is key in bridging the gap on missed opportunities that would otherwise be early identified at the primary healthcare level. (Tsai et al., 2023; Basharat, Sarah et al.,2019). Though it's unclear why some participants staging was not classified, this could be associated with lack of skills on cancer classification and or for early detection by health care workers or just inconsistencies in maintaining or updating patients records and therefore could have been the reason associated with the 14 unknown or unclassified cancer patients. These study outcomes provide time intervals to cancer diagnosis and clinical decision and its association with cancer classification and types of cancers. To the best of the investigators knowledge, this is the first study to correctly determine the various turnaround times in the clinical pathway of cancer management and the various associated factors like staging and type of cancer see Tables 4.2 and 4.3, even though there was weak association between TAT and the type of cancer, or cancer staging across all the various cancers.

More than half of the participants had at least gone for cancer screening before visiting the hospital, for management and the remaining one third never went for cancer screening and thus considered missed opportunities. This delay or lack of taking personal initiative to go for early screening has been reported elsewhere as one patient associated factors to delay in cancer diagnosis (Mafiana et al., 2022; Petersen et al., 2022; Ubah et al., 2022; Joy J et al 2022) and as such the need for public health education on early screening, early diagnosis and early initiation

on cancer care would avert many deaths associated with adverse cancer conditions. Other studies have demonstrated that with early screening for cancers and early treatments reduces morbidity and mortality and can lead to effective treatment outcomes if done early as demonstrated in other (Baessler & Zafar, 2022; Chakravarty et al., 2023).

5.3 Cancer Distribution and Referral Networks

The cancer referral networks were within the five major counties within Kenya, mostly bordering the Kisumu County. However, Kisumu County bore the largest cancer burden followed by Siaya, Homabay and Vihiga counties respectively. More than 40% of the cancer cases were in Kisumu County. In the interview it was noted that most cancer patients were referred to Jaramogi Oginga Odinga Teaching, and Referral hospital from five major county referral hospitals namely Siaya, based Busia, Kakamega, Vihiga and Kericho based on the patients enrolled. The JOOTRH was a well-known cancer centre and therefore most intra-referral were within the country and to JOOTRH as opposed to external referral see figure 4.5 and 4.6. In the figure 4.5 we see a lot of different distribution of cancers across the counties that were referring patients to JOOTRH with prostate cancer being more dominant in Kisii and cervical cancer dominant in Busia counties. It's not clearly known, the factors that are driving the differential prevalence of the various cancers in certain regions. However, this would be interesting to conduct further research to determine why cervical cancers were more prevalent in Vihiga, Kakamega Busia and Kisumu Counties compared to the rest of the referring facilities.

CHAPTER SIX: CONCLUSION AND RECOMMENDATIONS

6.1 Conclusion

In conclusion, this study provides important information on the delay in cancer management through the clinical pathways and equally identifying the gaps associated with lack of public awareness on the need for early cancer screening. To the best of the investigator's knowledge, this is the first study to determine the actual TAT for cancer management of patients in Kenya. While cancer screening is known to help identify cancer cases at early stages, this study demonstrates that going for screening does not equate to uptake of care services for cancer, therefore, there are still gaps in ensuring that those who go for screening (and found to have abnormalities, indicative of cancer), needs to be referred for further check-up or medical attention is sought. Other factors like employment, being married, and being a woman needs to be investigated on their role in delay in cancer services uptake. Patients with TB demonstrated the need to have a robust clinical evaluation of patients through integrated health systems to avoid missed opportunities in cancer management and this would avert unnecessary deaths associated with delays or missed cancer cases in other hospital clinics. These results provided a focus that targets health systems interaction with patients at the point of entry and the need to strengthen screening for cancer at primary healthcare level and the recent established initiative by Kenyan government on use of community health worker to support primary heath would come in handy. The need for a contextualised approach on targeting special population during cancer screening remains as import as transiting those screened to access care.

6.2 Recommendations

6.2.1: Recommendations for Action

The Ministry of Health should develop key indicators for cancer management that would see delay associated with patient and healthcare system monitored and gaps closed. The extensive delay in onset of illness to first visit to the hospital is a wakeup call for the need to evaluate effectiveness of cancer screening processes on the uptake of cancer management. Social needs associated with barriers to uptake of services like stigma, or unknow reasons can be addressed through integrating psychological counselling services. Efficient cancer referral networks are needed and should be integrated in the primary healthcare system that ensures early diagnosis as

well transiting those screened to care through follow-up of cases. There is also needed to develop policies to guide the clinical management of cancer cases that include clear early identification, screening, diagnosis, and clinical decision similar to what has been done for TB and HIV management in Kenya.

6.2.2 Suggestions for Future Research

Prioritizing funding for cancer management and research would enable progressive actions alongside initiating efficiency and effectiveness operational research studies and evaluation of the impact of cancer screening services on cancer services uptake in Kenya.

Given the delay in cancer management, from onset to clinical decision, as demonstrated by this study, there is need to initiate efficient and effective operational research studies to evaluate the impact of cancer screening services on services uptake in Kenya.

There is also need for studies to address the social behavioural factors associated with the delay in cancer management in order to improve cancer screening, diagnosis, and clinical decision for cancer management of patients through integrated health systems approach.

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APPENDICES

APPENDIX I: STRUCTURED QUESTIONNAIRE

Patient unique ID number: __ __ __ - __ __ __ __

Interviewer initial : _____ Interview date : |_D_|_D_|_M_|_M_|_Y_|_Y_|_Y_|_Y_|

PART ONE: Demographic Information

1. Hospital/Clinic Location: ❑ JOOTRH Cancer Centre ❑ JOOUST Auspice)
   ❑ Other_____
2. Date of Birth (DOB) |_D_|_D_|_M_|_M_|_Y_|_Y_|_Y_|_Y_|

a. If DOB is unknown, please enter age: years _|_Y_|_Y_| Years

3. Sex: ❑ Male ❑ Female Other (Specify): _____
4. Home contact?
   County_____

   Sub-county: _____Location: _____Village/Estate: _____

5. Is your current resident same as your hope country? ❑Yes ❑No

If no please specify your current resident and indicate for how long have you lived in your current resident: Resident_____ period of stay in current resident:_____ (years/months)

6. What is your occupation

Industrial	❑Yes	❑No
Farmer	❑Yes	❑No
Service provider	❑Yes	❑No
Research	❑Yes	❑No
Mineral mining	❑Yes	❑No

   Other (specify): _____

7. State your level of education.

Not Completed Education (or some primary)	❑Yes	❑No
Completed Primary	❑Yes	❑No
Not completed secondary (or some secondary)	❑Yes	❑No
Completed secondary	❑Yes	❑No
Tertiary	❑Yes	❑No

   Other (specify): _____

8. Marital Status

Married	❑Yes ❑No
Single	❑Yes ❑No
Widowed	❑Yes ❑No
Divorced	❑Yes ❑No

Other (specify):_____

9. Religious Affiliation

Christianity	❑Yes ❑No
Muslim	❑Yes ❑No
Hindu	❑Yes ❑No

Other (specify): _____

10. What is your family/Household income?

<1,0000	❑Yes ❑No
10001-50000	❑Yes ❑No
50001- 100,000	❑Yes ❑No
100001-150000	❑Yes ❑No
>150,000	❑Yes ❑No

11. How do you fund your medical cost?

Self	❑Yes ❑No
Family Donation	❑Yes ❑No
Harambee	❑Yes ❑No

Other (Specify): _____

PART TWO: Clinical Description

12. Before you were diagnosed with this cancer, did you ever go for cancer screening? ❑Yes ❑No If yes how many times did you go for the cancer screening (Indicate the number of times) _____

13. During those times was your cancer condition detected ❑Yes ❑No

If onset date is not known, how long have you been feeling sick or having any pain or abnormal swelling? (*Pain, discharge, swelling etc)*): days/month ____

14. Date of onset of current illness: |_D_|_D_|_M_|_M_|_Y_|_Y_|_Y_|_Y_|

15. Date of first contact with health care system for this condition (*prior to this*)
|_D_|_D_|_M_|_M_|_Y_|_Y_|_Y_|_Y_|

How long did it take you to receive your cancer diagnosis?

<2 weeks	❑
≥2weeks -1 month	❑
≥1month-2 months	❑
≥2months - 3 months	❑
≥3 months – 4months	❑
≥4 months- 5 months	❑
≥5 months- 6 months	❑
>6 months	❑

16. What cancer condition were you diagnosed with? (Verify from the records to get the actual diagnosis

a.	lip, oral cavity (ICD-10 C00-08)	❑Yes ❑No ❑ Don't Know
b.	nasopharynx (C11)	❑Yes ❑No ❑ Don't Know
c.	Other pharynx (C09-10, C12-14)	❑Yes ❑No ❑ Don't Know
d.	esophagus (C15)	❑Yes ❑No ❑ Don't Know
e.	stomach anus C18-21),	❑Yes ❑No ❑ Don't Know
f.	liver (C22),	❑Yes ❑No ❑ Don't Know
g.	gallbladder (C23-24),	❑Yes ❑No ❑ Don't Know
h.	pancreas (C16),	❑Yes ❑No ❑ Don't Know
i.	colon and rectum (including (C25),	❑Yes ❑No ❑ Don't Know
j.	larynx (C32),	❑Yes ❑No ❑ Don't Know
k.	lung (including trachea, C33-34),	❑Yes ❑No ❑ Don't Know
l.	melanoma of skin (C43),	❑Yes ❑No ❑ Don't Know
m.	Kaposi sarcoma (C46)	❑Yes ❑No ❑ Don't Know

n.	female breast(C50),	❑Yes	❑No	❑ Don't Know
o.	cervix uteri (C53),	❑Yes	❑No	❑ Don't Know
p.	corpus uteri (C54),	❑Yes	❑No	❑ Don't Know
q.	ovary (C56),	❑Yes	❑No	❑ Don't Know
r.	prostate (C61),	❑Yes	❑No	❑ Don't Know
s.	testis (C62),	❑Yes	❑No	❑ Don't Know
t.	kidney (including renal pelvis and ureter, C64-66),	❑Yes	❑No	❑ Don't Know
u.	bladder (C67),	❑Yes	❑No	❑ Don't Know
v.	brain and central nervous system (C70-72),	❑Yes	❑No	❑ Don't Know
w.	thyroid (C73),	❑Yes	❑No	❑ Don't Know
x.	Hodgkin lymphoma (C81),	❑Yes	❑No	❑ Don't Know
y.	non-Hodgkin lymphoma (C82-85, C96),	❑Yes	❑No	❑ Don't Know
z.	multiple myeloma (C88 1 C90),	❑Yes	❑No	❑ Don't Know
aa.	leukaemia (C91-95)	❑Yes	❑No	❑ Don't Know
bb.	all cancers combined,	❑Yes	❑No	❑ Don't Know
cc.	Non-melanoma skin cancer (C00-97, except C44).	❑Yes	❑No	❑ Don't Know

17. When was your cancer diagnosis done? |_D_|_D_|_M_|_M_|_Y_|_Y_|_Y_|_Y_|

18. When was medical decision on your cancer determined (i.e., or radiotherapy chemotherapy, surgery? |_D_|_D_|_M_|_M_|_Y_|_Y_|_Y_|_Y_|

19. What is the cancer stage before initiation on treatment?

Stage 1	❑
Stage II	❑
Stage III	❑
Stage IV	❑

PART THREE: Risk Factors

20. Do you use tobacco (smoking or chewing)? ❑Yes ❑No ❑Don't Know if yest indicate when
21. Newly diagnosed TB ❑Yes ❑No ❑ Don't Know if yes Indicate when treatment was initiated |_D_|_D_|_M_|_M_|_Y_|_Y_|_Y_|_Y_|
22. Are you on any other long-term treatment /medication for an ailment other than cancer i.e TB, HIV or Diabetic? ❑Yes ❑No ❑ Don't Know if yest Indicate the Condition_____
23. What is your Occupation / what you do for a living? (Please indicate, this applies to the occupation held last if not currently working) occupation: _____
24. Have you ever used any family planning methods (only applicable to women) ❑Yes ❑No
    If yes go to next question
    Depo-Provera ❑
    Implant ❑
    Copper T ❑
    Pills ❑

Others: _____

APPENDIX II: DATA ABSTRACTION FORM

Patient ID	Patient Name as in the file	Date/Year of Birth	Date of Hospital Visit	Type of cancer Diagnosis	Staging	Date of Diagnosis

APPENDIX III: INFORMED CONSENT (ENGLISH)

TIME TO DIAGNOSIS AND CLINICAL DECISION FOR PATIENTS RECEIVING CANCER SERVICES AT THE ONCOLOGY UNIT AT THE JARAMOGI OGINGA ODINGA TEACHING AND REFERRAL HOSPITAL (JOOTRH), KISUMU

Date_____, 2022

Version 2

INTRODUCTION AND PURPOSE

You are being asked to take part in a medical research study being carried out through Jaramogi Oginga Odinga University of Science where does it occurs most. A medical research study can also look at ways to prevent or control a disease. The Jaramogi Oginga Odinga University of Science and Technology and the Jaramogi Oginga Odinga Teaching and Referral and Technology student, in collaboration with Jaramogi Oginga Odinga Teaching and Referral Hospital. A medical research study can look at what causes a disease or what facilitates the disease or Hospital will do this study. We are looking for about 350 participants who are undergoing cancer treatments treatment at the Oncology Centre to take part in the study.

Key Information for You to Consider

Voluntary consent. You are being asked to volunteer for a research study. It is up to you whether you choose to participate or not. There will be no penalty or loss of benefits to which you are otherwise entitled if you choose not to participate or discontinue participation.

Purpose. To understand how long, it takes a cancer patient to go through the cancer management process in an hospital set up. We shall also look at the existing referral networks for cancer patients and the barriers that exist that can hinder care provision for cancer patients.

Duration. You should expect today's assessment to take less than 30 minutes.

Procedures and activities. To participate in the study, you will have to complete questionnaires. No examinations or collection of samples (e.g., blood, urine, and vaginal fluids) will be done. If you are agree to participate in the study you will be taken through the sub-sequent questionnaire.

Risks. Like all research studies, there are limited risks to participating in this research study,

however, in this study will not subject you to any invasive procedure and will be limited to asking you questions about your health, onset of the cancer condition and some of the challenges that you have encountered the treatment pathway. We will explain this in detail later in the questionnaire.

Benefits. Taking part in this study may have no direct benefit to you. The study will not give you general medical care but findings from this study would contribute in the improving services at the cancer centers that would translate to better patient care.

Alternatives. You are free to choose not to participate in this research.

If you agree to take part in this after having been explained to the objectives of the study and how it would be conducted and you agree it indicates you suitable to take part in the study, you:

TAKING PART IS YOUR CHOICE

It is important to know that no one can make you take part in this pre-screening assessment if you do not wish to do so. You may take whatever time you need to decide if you would like to be pre-screened for this study

IF YOU CHOOSE NOT TO TAKE PART

If you have questions about this research, please contact Dr Dan Onguru at the Jaramogi Oginga Odinga University of Science and Technology or xxx (within JOOTRH Grounds, Off Kisumu-Kakamega Road, P.O. Box xx-40100, Kenya) at telephone +254-xx and

If you have questions about your rights, you can contact the secretary, JOORTH Ethical Review Committee, (P. O. Box xx-00200, Nairobi) at telephone 020-2722541 or cell phone xx / Email address ERC Admin@JOOTRH.org). The above numbers are not for emergencies. If you are having an emergency, please go to the nearest clinic.

STATEMENT OF CONSENT

I have the study procedures explained to me. I understand the purpose of the study and that a paper copy of this information offered to me. All the procedures have been explained to me and my questions have been answered.

Do you agree to take part in the study?

_____No

_____Yes_____ _ _____/_____/_____

Signature/Mark of Research Participant Date (mm/dd/yy)

_____

Printed Name of Research Participant

STATEMENT OF PERSON EXPLAINING CONSENT

I have carefully explained the purpose of this research to the volunteer. There has been an opportunity for the volunteer to ask questions about this study and this form. I have been available to answer any questions that the volunteer has about this study and this form. To the best my knowledge, she understands the purpose, procedures, risks and benefits of this research.

_____ _

_____/_____/_____

Signature of Person Explaining Consent Date (mm/dd/yy)

Printed Name of Research Person Explaining Consent

APPENDIX IV: JOOUST UNIVERSITY APPROVAL LETTER

JARAMOGI OGINGA ODINGA UNIVERSITY OF SCIENCE & TECHNOLOGY

BOARD OF POSTGRADUATE STUDIES
Office of the Director

Tel. 057-2501804
Email: bps@jooust.ac.ke

P.O. BOX 210 - 40601
BONDO

Our Ref: H153/4198/2017

Date: 10th August 2021

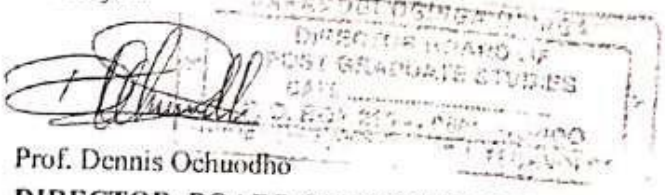
TO WHOM IT MAY CONCERN

RE: JULLY AWINO ODERO – H153/4198/2017

The above person is a bonafide postgraduate student of Jaramogi Oginga Odinga University of Science and Technology in the School of Health Sciences pursuing Master of Science in Epidemiology and Biostatistics. She has been authorized by the University to undertake research on the topic: ***"Time to Diagnosis and Clinical Decision for Patients Receiving Cancer Services at the Oncology Unit at the Jaramogi Oginga Odinga Teaching and Referral Hospital (JOOTRH), Kisumu".***

Any assistance accorded her shall be appreciated.

Thank you.



Prof. Dennis Ochuodho
DIRECTOR, BOARD OF POSTGRADUATE STUDIES

APPENDIX V: JOOTRH ERC APPROVAL LETTER

COUNTY GOVERNMENT OF KISUMU
DEPARTMENT OF HEALTH

Telephone: 057-2020801/2020803/2020321
Fax: 057-2024337
E-mail: medsuptnpgh@yahoo.com
ceo@jaramogireferral.go.ke
Website: www.jaramogireferral.go.ke
When replying please quote
GEN/21A
Ref: .....

JARAMOGI OGINGA ODINGA TEACHING & REFERRAL HOSPITAL
P.O. BOX 849-40100
KISUMU

25th January, 2022
Date .....

Jully Awino Odero

Dear Jully

RE: PERMISSION TO COLLECT DATA

Following approvai of protocol titled "Time to Diagnosis and Clinical Decision for Patients Receiving Cancer Services at the Oncology Unit at Jaramogi Oginga Odinga Teaching and Referral Hospital", you are hereby permitted to proceed with the activity.

Thank you.

Yours sincerely

DEPUTY CEO/ DIRECTOR CLINICAL SERVICES
JARAMOGI OGINGA ODINGA TEACHING &
REFERRAL HOSPITAL (JOOTRH)
P.O. BOX 849 - 40100, KISUMU
DATE:.....

DR. DEDAN ONGONG'A
DIRECTOR CLINICAL SERVICES/DEPUTY CHIEF EXECUTIVE OFFICER
JOOTRH – KISUMU

APPENDIX VI: COUNTY GOVERNMENT OF KISUMU LETTER OF APPROVAL

COUNTY GOVERNMENT OF KISUMU
DEPARTMENT OF HEALTH

Telephone: 057-2020801/2020803/2020321
Fax: 057-2024337
E-mail: medsuptnpgh@yahoo.com
ceo@jaramogireferral.go.ke
Website: www.jaramogireferral.go.ke

When replying please quote

Ref. No. IERC/JOOTRH/545/21

JARAMOGI OGINGA ODINGA TEACHING & REFERRAL HOSPITAL
P.O. BOX 849
KISUMU

Date 18th November, 2021

RE: APPROVAL: STUDY TITLE:
TIME TO DIAGNOSIS ANDCLINICAL DECISION FOR PATIENTS RECEIVING CANCER SERVICES AT THE ONCOLOGY UNIT AT THE JARAMOGI OGINGA ODINGA TEACHING AND REFERRAL HOSPITAL, KISUMU.

REF: IERC/JOOTRH/545/21

TO: Principal Investigator – Jully Awino Odero

Dear Sir/madam,

RE: STUDY TITLE

This is to inform you that JOOTRH IERC has reviewed and approved your above research proposal. Your application approval number is ***IERC/JOOTRH/545/21*** .The approval period is ***18th November, 2021 – 18th November, 2022.***
This approval is subject to compliance with the following requirements;

i. Only approved documents including (informed consents, study instruments, MTA) will be used
ii. All changes including (amendments, deviations, and violations) are submitted for review and approval by JOOTRH IERC.
iii. Death and life threatening problems and serious adverse events or unexpected adverse events whether related or unrelated to the study must be reported to JOOTRH IERC within 72 hours of notification
iv. Any changes, anticipated or otherwise that may increase the risks or affected safety or welfare of study participants and others or affect the integrity of the research must be reported to JOOTRH IERC within 72 hours

APPENDIX VII: NACOSTI APPROVAL LETTER

REPUBLIC OF KENYA

NATIONAL COMMISSION FOR
SCIENCE,TECHNOLOGY & INNOVATION

Ref No: 405913

Date of Issue: 14/February/2022

RESEARCH LICENSE

This is to Certify that Miss.. Jully Awino Odero of Jaramogi Oginga Odinga University of Science and Technology, has been licensed to conduct research in Kisumu on the topic: TIME TO DIAGNOSIS AND CLINICAL DECISION FOR PATIENTS RECEIVING CANCER SERVICES AT THE ONCOLOGY UNIT AT THE JARAMOGI OGINGA ODINGA TEACHING AND REFERRAL HOSPITAL (JOOTRH), KISUMU for the period ending : 14/February/2023.

License No: NACOSTI/P/22/15488

405913

Applicant Identification Number

Director General
NATIONAL COMMISSION FOR
SCIENCE,TECHNOLOGY &
INNOVATION

Verification QR Code

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