

**AWARENESS AND PREDICTORS OF UPTAKE OF PALLIATIVE CARE SERVICES
AMONG PATIENTS WITH ADVANCED CANCER ATTENDING KENYATTA
NATIONAL HOSPITAL.**

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**A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE AWARD OF DEGREE OF MASTER OF SCIENCE IN NURSING
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November, 2023.

DECLARATION

I hereby declare that this thesis is my original work and has not been submitted anywhere else by any other person(s) for research purposes or award of any degree or otherwise.

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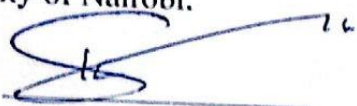
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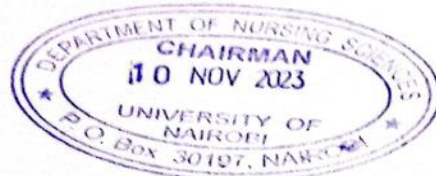
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DEDICATION.

A special dedication to my dear wife Grace Boke Chacha, my daughter Ekaterina Bisieri and son Samuel Moturi.

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ABBREVIATIONS

ADL:	Activities of Daily Living
ASCO:	American Society of Clinical Oncologists
CTC:	Cancer Treatment Center.
ECOG:	Eastern Cooperation oncology group.
ERC:	Ethics and Review Committee.
GLOBOCAN:	Global Cancer Observatory.
HRQOL:	Health related quality of life.
HOD:	Head of department.
IAE:	International Atomic Energy.
KNH:	Kenyatta National Hospital.
MOH:	Ministry of Health
NCI:	National Cancer Institute.
LMICs:	Low- and middle-income countries.
PC:	Palliative care.
UON:	University of Nairobi.
WHA:	World Health Assembly.
WHO:	World Health Organization.

OPERATIONAL DEFINITIONS

Advanced Cancer: A cancer that is unlikely to be cured or controlled with available treatment modalities, a malignancy that has metastasized to vital organs like lungs, liver or brain and distant parts from the primary organ.

Awareness: Patients' perception and having background knowledge on palliative care services.

Hospice care: This is care that is focused on comfort, quality of life and symptom alleviation for individual with life limiting condition approaching end of life care.

Life limiting condition: A condition in which there is no reasonable hope of cure whose outcome is likely to be death. Progressive disease-causing deterioration in the functional capacity of an individual resulting on the individual to be totally dependent upon others for his/her activities of daily living

Life threatening condition: A condition of which curative treatment is possible but might likely fail such as cancer

Palliative care: A specialized medical intervention for individuals and families with a life limiting condition whose aim is to alleviate pain and suffering and improve the quality of life.

Patients with advanced cancer: Patients with a clinical diagnosis of cancer stage III or IV attending care at KNH.

Supportive care: A holistic model of care that encompasses physical, psychological, social and spiritual support to individuals and family during an instance of a life limiting condition or life-threatening condition.

Uptake: Utilization of palliative care services among patients with advanced cancer.

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ABSTRACT

Background: Life-limiting cancer has a profound effect on the individual and their family member's health and well-being. The effects can range from psychological, physical, social and spiritual health of the patients leading to a diminished quality of life and poor treatment outcomes. Palliative care (PC) plays a critical supportive care role in alleviating the symptom burden, reduce the psychosocial distress and improve the health-related quality life for patients with serious and life-threatening advanced cancer. Integration of palliative care and standard oncology care have been proven to confer better survival outcomes and better quality of life for patients with cancer. Little is known about palliative care awareness and uptake among patients with advanced cancer in sub-Saharan region.

Objectives: To investigate the level of awareness, proportion of uptake, predictors of uptake and barriers of uptake of palliative care among patients with advanced cancer attending outpatient care at KNH.

Methods: This was a descriptive cross-sectional study to assess the level of awareness and uptake of palliative care among patients with advanced cancer attending care at CTC, KNH. Data was collected through a structured researcher administered questionnaire to 173 participants. The data was analyzed using SPSS version 26, presented using mean, frequency distribution, percentages and standard deviation. Multi-variate logistic regression was used to investigate the relationship between dependent and independent variables. The Kenyatta National Hospital- University of Nairobi Ethics and review committee (KNH-UON) granted ethical approval, permission to collect data granted by Head of department, cancer treatment center.

Results: The response rate was 92% with the majority of participants being female (62%). The mean age for the respondents was 54 ± 14 years. Overall, Palliative awareness was 34%. There was a significant association between the social demographic and clinical factors and awareness of PC with a ($P= 0.04$). Patients with high level of education had a high odds of PC awareness. Most 29.5% of the patients with PC awareness heard it from the attending oncologist. Majority 29% stated that the goal of palliative care is to help them cope with symptom management. Palliative care uptake was 31% among patients with advanced cancer, 60% of this were recommended by the attending oncologist. Further analysis revealed that women are likely to utilize Palliative care services. The most cited barriers for PC utilization were lack of funds for consultation fee 77% and lack of money for transport 69%.

Conclusion: The low awareness and uptake of palliative care services among cancer patients highlight the need to introduce interventions aimed at improving the general awareness and uptake of PC. We recommend implementation of models aimed at integrating PC to standard oncology care.

CHAPTER ONE: INTRODUCTION

1.1 Background

Cancer is a leading cause of morbidity and mortality worldwide, the 2020 GLOBOCAN cancer statistics indicated that the cancer incidence was about 19 million globally and reported mortality of over 10 million cases (Sung et al., 2021). The low- and middle-income countries (LMICs) disproportionately continue to bare the significant burden of the cancer contributing to about 70% of these cancer related deaths worldwide (WHO, 2022). The international atomic energy agency projected that by 2035, LMICs will account for two thirds of new cancer cases globally, a scenario that will put a humongous burden on the health care system which already overburdened and underfunded (IAE, 2019).

Sub Saharan Africa region bares a double burden of both communicable and an increasing burden of non-communicable diseases, this is coupled with a health system that greatly underfunded. The continent also presents a unique mix of common cancers a majority of them are infection related that can easily be prevented (Cancer atlas, 2018). Statistics point to an ever-increasing rate of major cancers such breast, cervix, prostate and colorectal cancer. Kimani, (2014), Onyenka (2011), noted that 95% of cancer cases in sub-Saharan region are diagnosed late more often at advanced stages, a situation that presents a unique demand for palliative care services.

In Kenya, cancer ranks as the third leading cause of morbidity and mortality (Malloy et al., 2017). WHO and GLOBOCAN cancer statistics approximate that in the year 2020, Kenya registered a cancer incidence of over 42000 and a mortality of over 27000 deaths. Report from Kenya Hospice and palliative care alliance (KEHPCA, 2014) indicated that over 80% of cancer cases were diagnosed at advanced stages with very minimal chances of curative treatment.

Patients diagnosed with cancer experience a significantly high level of physical, mental and social distress that are associated with the diagnosis of cancer, cancer morbidity and the aggressive cancer treatment regimens, and survivorship challenges (Delgado- Guay, 2018). These symptoms often impact negatively on their treatment outcomes and the health-related quality of life of the patients. It is also documented that by extension, the patient's family and family care givers also suffer the same distress and strain that is associated with the burden of giving care to the patient and the impending death of their loved one (Hui et al., 2015).

Rigorous clinical trials have shown across the world have shown that integrating palliative care with standard oncology care confers a great survival benefit through addressing the common psychosocial and physical sequelae prevalent among patients with advanced cancer hence improving the health related quality of life (HRQL) (Hui et al., 2015). Palliative care involves timely assessment, diagnosis and promptly addressing of any biological, physical, social and spiritual issues associated with cancer diagnosis, treatment and survivorship (Chang et al., 2022).

The World Health Organization acknowledges palliative care as a public health issue, its access and utilization for the deserving population is considered a human right and has implored signatory countries to incorporate it into its health systems (McIlfatrick et al., 2013). Unfortunately, only about 14% of those in need of palliative care are able to access it (McLouth et al., 2023)

Awareness of palliative care can play a critical role to promoting its uptake (Kirshbaum et al., 2011). A telephone survey conducted among the adult Irish reported that majority of the respondents had low awareness of palliative care and the terminologies used in palliative care and end of life care (M cCarthy et al., 2010). In the US, a study on public awareness of palliative care showed an inadequate, low levels of awareness (McIlfatrick et al., 2013).

In Asia, a study on awareness and palliative care uptake revealed an overall palliative care awareness at 30%, patients with high education levels, patients from middle and high income and those with a high diseases severity demonstrating a high odds of higher awareness levels. The overall utilization of palliative care was at 35% and higher among those with high awareness levels (Ozdemir et al., 2022).

The World health organization (WHO), the American society of clinical oncologists (ASCO) and European Society of Medical Oncologists (ESMO) recommend the integration of palliative care and standard cancer care, they all issue an advisory that palliative care should be initiated as soon as a cancer diagnosis is made or within 8 weeks of oncology care (Ferrell et al., 2017) . However, this model largely remains abstract and complex concept poorly understood, a report by WHO in 2020, revealed that approximately 56.8M in the world are in need of palliative care and only 14% of that population are able to access palliative care, (WHO, 2020). In sub-Saharan Africa, despite a recent surge in palliative care, the services remain largely inaccessible with only 5% of those in need able to access the services (Harding et al., 2015), with the cancer cases projected to shoot by over 400% by 2050, the need for palliative care will continue to widen.

In Kenya, the unmet need for palliative care continues to grow, it is estimated that about 800000 Kenyans are in need of palliative care, of this only a paltry 14000 can access palliative care services (MOH, 2021). This calls for a review of models of provision of palliative care, systematic audit of the health care systems and implementation of concerted strategies to reduce the large unmet need palliative care. It is against this backdrop that this study seeks to unravel the level of uptake, factors associated with uptake and the patient reported barriers on the utilization of palliative care services among patients with advanced cancer at a teaching and referral hospital in Kenya.

1.2 Problem statement

Many cancer patients endure physical, psychological, cognitive, social and spiritual impairments during a cancer diagnosis, cancer treatment and even during the survivorship phase, this impairments can eventually affect the person's mobility and ability to perform the activities of daily living (ADLs), Self-care tasks resulting to a self-care deficit, studies have demonstrated that, if this impairments are not addressed, they can lead to an impaired health related quality of life (HRQOL) and even affect health outcome (Pergoloti et al., 2017: Braithwaite et al., 2010).

Palliative care incorporates a holistic, multidisciplinary approach in addressing the above challenges. Despite the well documented evidence of the importance palliative care, there is a large unmet need for palliative care especially for patients with advanced cancer. Globally, it is estimated that only 14% of those in need of palliative care can access palliative care. A significant disparity in palliative care provision has been reported between high income countries and the Low- and Middle-income countries (LMIC). The LMIC have registered significantly low utilization of palliative care (Ozdemir et al., 2022). In Kenya, there is a large unmet need for palliative care, statistics from the ministry of health indicating that approximately 83% of individuals in need of palliative care services cannot access the service (MOH, 2020).

As a strategic intervention, the WHO, ASCO (2018) recommend early integration of palliative care to standard oncology care, a strategy that has been proven to confer a great benefit to the overall quality of life and survival outcomes for cancer patients (Sullivan et al., 2019), however in Kenya, there seems to be huge disconnect in palliative care provision to standard cancer care, pain and palliative care clinics operate as independent specialist clinics where patients are attended on referral basis. Further, Palliative care provision occurs in inherently diverse settings ranging from home care, hospice homes, private clinics with a clear lack of standardization of care

provided. This creates a problem of estimating the proportion of patients who have received palliative care, the standard of care, duration and intensity of palliative care offered and if the interventions led improved outcomes among cancer patients (Bauman et al., 2014). Thus, there is need to establish baseline information on the level of uptake of palliative care for patients with advanced cancer at the KNH.

1.3 Research questions

1. What is the level of awareness of palliative care among patients with advanced cancer at Kenyatta National Hospital?
2. What is the proportion of uptake of palliative care among patients with advanced cancer attending care Kenyatta national hospital?
3. What are the predictors of uptake of palliative care uptake among patients with advanced cancer attending care at Kenyatta National hospital?
4. What are the perceived barriers to uptake of palliative care among patients with advanced cancer attending care at the Kenyatta national hospital?

1.4 Objectives

1.4.1 Broad objective

To investigate awareness and the level of uptake of palliative care services among patients with advanced cancer attending Kenyatta national hospital.

1.4.2 Specific objectives

1. To determine the level of awareness of palliative care among patients with advanced cancer attending Kenyatta national hospital
2. To determine the level of uptake of palliative care services among patients with advanced cancer at the Kenyatta National Hospital.

3. To identify the predictors of uptake of palliative care services among patients with advanced cancer at the Kenyatta National Hospital.
4. To establish the perceived barriers of uptake of palliative care services at the Kenyatta National hospital.

1.5 Hypothesis

The social demographic factors and disease characteristics do not impact on the awareness and uptake of PC services among patients with advanced cancer at KNH.

1.6 Study Justification.

Palliative care is an express human right whose aim is to improve the quality of life for patients with life limiting and life-threatening illnesses, it addresses the spiritual, psychosocial, and physical aspects associated with the disease and its treatment, it is also incorporated to debrief family members involved in caring for patients with cancer. There is a universal call for countries to enact policies and guidelines towards increase access and uptake of palliative care as a way to attaining the sustained development goal 3, working towards universal health coverage. In order to achieve this, policy makers and stakeholders need data on the uptake, specific needs and challenges in order to formulate valuable policies on palliative care.

Data provides an understanding on service access and utilization patterns and this forms the first step towards evidence-based program improvement that will open the channel for formulation of relevant national and institutional policies that will aid service affordability, physical accessibility and acceptability across the intended users. It is anticipated that recommendations and findings emanating from this study will form a baseline for policy formulation and future research.

1.7 Study variables

1.7.1 Independent variables

A. **Patient related factors:** Social demographic factors (Age, gender, level of education, religion), Economic factors (income), patient clinical state, patient level of performance (ECOG score) type of cancer, Current staging of the disease, presence of a co morbid, symptom burden (Edmond score), patient awareness of palliative care, previous experience of palliative care.

B. **Institutional related factors:** infrastructural enablers, staffing and staff related factors, effective referral systems within the institution, consultation charges/fee, administrative support, structural set up and accessibility of the clinic, policies and guidelines on palliative care and standard cancer care, availability of services and resources for provision of palliative care.

1.7.2 Dependent variables

Awareness and uptake of palliative care among patients with advanced cancer in KNH

1.7.3 Outcome variable

Health related quality of life.

CHAPTER TWO: LITERATURE REVIEW

2.1 Symptom burden for cancer patients.

Cancer diagnosis is debilitating to the patient and family, cancer diagnosis, cancer disease progression and metastasis and cancer treatment are known to lead to varied and multi-dimensional burden of symptoms that either directly or indirectly impair the quality of life (Elmokhallalat et al., 2022). This burden of symptoms could often lead to delays in initiating treatment or if they are treatment related, they might lead to termination of treatment or may complicate survivorship phase (Cleeland, 2007).

The adverse events resulting from cancer and or cancer treatment may vary in severity from mild, moderate to severe and may change from time to time across the disease trajectory, the symptom burden may vary from person to person based on different biopsychosocial issues, the primary cancer, extent of metastasis and the different treatment modalities for the patient. In a systematic review to investigate the symptom burden experienced by cancer patients, Kim and colleagues established that the most common reported symptoms are fatigue, anxiety, pain, lack of sleep (Insomnia), dry mouth, irritability, drowsiness and mental distress (Kim et al., 2009).

In a study to examine the burden of symptoms among cancer survivors one year after diagnosis, the American cancer society (ACS) study group established that 92% of the study subjects reported of symptoms associated with cancer or its treatment modality, it was also established that patients with a primary diagnosis of cancer of the lungs, metastatic disease and an underlying commodity are likely to experience a moderate to severe cancer symptom burden (Shi et al., 2011). The study further revealed that active chemotherapy treatment contributed to the severity of the symptoms (Shi et al., 2011), this findings are in line cross sectional study by Iyer et al (2014) in which patients

with advanced metastatic non-small cell lung cancer on chemotherapy reported fatigue (100%), shortness of breath (95%), pain (93%).

On a study on persistence of symptoms, the findings established that over 90% of patients who participated in the study reported of one or more symptoms and the symptoms varied depending on the type of cancer, patients with cancer of the prostate reported fewer symptoms while those with cancer of colorectum reported of more than one symptom (Deshields et al., 2014).

In a bid to improve the clinical pathways for management of the symptom burden, scholars have attempted to cluster the symptoms, Kenne et al clustered the symptoms for patients with cancer of the breast, which yielded clusters such as the emotional, gastrointestinal, and unwellness symptom burdens (Kenne Sarenmalm et al., 2014). The symptom burden negatively impacted on the health related quality of life, (Shi et al.,2011; Kenne et al., 2014; Deshields et al 2014). Shiuann and Janet studied the impact of the burden of symptoms on the health-related quality of life, the results indicated that as many as a third of the survivors experienced the symptom burden similar to those they experienced during cancer treatment that included mood disturbances, fatigue, sleep deprivation pain, cognitive impairments and physical impairments. Literature further supports that the burden of symptoms that extends to survivorship greatly impacts on quality of life of the cancer survivor (Shiuann & Janet., 2015).

Studies on the symptom burden among cancer patients have also demonstrated that most of the symptoms are significantly under treated (Kim, 2009). Lack of treatment of the adverse effects of cancer and cancer treatment may lead to increase in patient distress levels thus having an impact on the patient functionality status (ECOG score), this may lead to dose adjustments, delay or

termination of treatment thus ultimately impairing the patient's healing process and health related quality of life (Soita, 2022).

2.2 Palliative care concept

Palliative care is a broad-based dynamic concept that builds on key foundational principles. It focuses on family centered care where attention is given to the person and not the disease with the overall objective being to improve the general health related quality of life (Tieman et al., 2010). There is a large unmet need for palliative care globally, It is estimated that approximately over forty million people with life limiting and life threatening conditions are in need of palliative care, a large percentage of this (78%) reside in the LMICs (Morley et al., 2019).

The palliative care concept is broad and dynamic, historically it is believed to have originated in the Great Britain championed by Cicely Saunders for the humane caring of terminally ill and providing care to cancer patients on the terminal stages of life in a hospice care center (Fang & Zhen, 2021). The Saunders model encompassed a multidimensional approach in which care care was provided to both the family and the patient, it included treating total pain, Saunders defined total pain as suffering that includes the physiological, sociological, psychological, spiritual, physical, and practical struggles in the terminally ill patient (Gomez et al., 2019).

Over time, the demand for palliative care has continued grow, this has necessitated innovative approaches to diversify the settings for provision of palliative care to suit the patient's needs. The settings could include homes, hospitals and hospice homes. In the USA, 50% of the States have palliative care programs in 60% of the hospitals Hughes et al., 2014), studies have also demonstrated that large academic and religious hospitals are likely to have a palliative care team (center for palliative care report, 2013). Some countries especially in Europe have also developed a robust community and home-based palliative care programs with sound policies and guidelines

on the delivery of palliative care. All these measures are geared to address the gaps in access to palliative care (Guo et al., 2012).

The world health organization defines palliative care as a comprehensive approach that improves the quality of life of patients suffering from life limiting conditions (WHO, 2020). It is a holistic approach that represents a paradigm shift from disease-based treatment interventions to patient centered family care (Funk et al., 2017, Brighton et al., 2019). Hughes et al (2014) denotes that palliative care is supplemental to other aggressive treatment, palliative care offers an extra layer of supportive care. The scope of palliative care approach is conceptualized to be beneficial across the trajectory of life limiting illness who need alleviation of symptom burden and suffering as opposed to end of life only approach (Meghan 2004).

In a systematic review on palliative care concept analysis in the USA, Wantonoro et al (2022) described palliative in the following four characteristic, holism, interdisciplinary team work, effective communication between the interdisciplinary team, patient and family to foster a compassionate care, individualized patient care and family and patient centered care. Kirkpatrick et al., (2017) further highlighted that inpatient communication, the nurse or palliative care provider must be clear, accurate and honest and must demonstrate empathy in communicating the patient's prognostication and condition. The communication ought to be therapeutic and should foster the patient's general wellbeing (Guo et al., 2012).

The hallmark of the palliative care concept is structured around symptom relief as pre text of improving the quality of care, in the context of chronic illness care continuum, a wide spectrum of symptom burden can be highlighted, Sounders described it as total pain which the WHO, (2020) further described to contain the physical, psychological, social and spiritual dimensions. Oechsle and group conducted a study to determine the prevalence of symptom burden for patients in

palliative care setting, the symptoms ranged from pain, exhaustion, psychological distress and fear and anxiety. In addressing this wide range of symptom burden, KirkPatrick et al., (2017) recommended a multifaceted approach of physical, social, spiritual and psychological therapies implemented by a multidisciplinary team to alter the trend of disease trajectory and improve the quality of life.

2.2.1 Palliative care vs hospice care

Historically, the concept of palliative care developed from the growth and expansion of hospice movement, with the similar evolution root, palliative care and hospice care have similarities in the philosophical underpinning and conceptual models. However, there are substantial differences between the two approaches of care.

Buss et al asserts that hospice care is a multidisciplinary team approach-based care comprising of a nurse, chaplain, social worker and care assistants, the care is structured in a way that there are aggressive symptom management approach to control unwanted symptoms to ease the process of transition to death, the aim is not halt the process of death or cure the disease but to ensure that the process of death is painless and comfortable (Buss et al., 2016). Hospice care is an integral component of palliative care that has a specific eligibility criterion for admission that admission to the hospice care requires that two practicing physicians certify that the patient has less than 6 months to live (Swami et al., 2018). Buss further states that palliative care differs from hospice care in that any patient with life limiting chronic condition can be enrolled to palliative care at any stage of the disease trajectory (Buss et al., 2016)

2.2.2 The concept and growth of palliative care in Kenya.

Uganda and Kenya Kenya have been heralded as leaders in Africa that have championed the growth and development of palliative care worldwide. In an international ranking, Kenya was

ranked 63rd in the growth, access and utilization of palliative care by the economist newspaper, the ranking is based on the quality and availability of service (Line, 2015).

The key advances of palliative in Kenya is based on the advancement in palliative care education, evidence gathered from a study Fraiser et al., (2017), it was demonstrated that Kenya has integrated palliative care to education curriculum of health care providers. Focus has also been put on post graduate level training for palliative care for health care providers. Despite the great advances in palliative care education, Malloy et al., (2011) noted there is an acute shortage of human resource trained on palliative care.

Kenya has also made significant strides on the availability of palliative care infrastructure like narcotics, a report from Kenya hospice and palliative care association noted that Kenya has adopted the WHO essential list of essential drugs, a list which contains about 14 palliative care medications (KEHPCA, 2019). The government through the ministry of health has facilitated the development palliative care guidelines and palliative care policy that were launched by the first lady and the ministry of health to guide the standardized implementation of palliative care in Kenya (Fraise et al., 2017, Ali et al., 2022,)

Despite strides in palliative care training, advocacy, and availability resources to that have facilitated a considerable growth of palliative care in Kenya, palliative care remains largely inaccessible to a vast majority of those in need, and with the increasing in prevalence of cancer and HIV, its estimated that the demand will outpace the supply and this calls for implementation of strategies to promote accessibility of palliative care (Mwangi et al., 2014).

In 2021, the MOH through the then first Lady launched a palliative care policy, it has been heralded as the new dawn in the provision of palliative care in Kenya, the policy highlighted on models of

government funding and integration of palliative and supportive care to universal health coverage, according to the report by KEHPCA, 2021, the policy provides a framework for improved advocacy, training and deployment of palliative care specialists as ways of health system strengthening to offer patient centered palliative care.

2.3 Availability and uptake of palliative and supportive care among cancer patients.

Pain and symptom management are key quality antecedents for quality cancer care (Harding & Higginson, 2005), it is in this backdrop that the WHO regards palliative care as a human right and a critical component of compressive cancer care (Ferrell et al., 2017). It is an additional layer of supportive care to standard aggressive targeted oncology care that the 67th world health assembly recommended integrating it to health care systems (WHO, 2014).

In recent times, the demand for palliative care has been increasing steadily and this trend is likely to continue in this future (Hughes et al., 2004). This fact is attributed to the surge in prevalence of both communicable and non-communicable illnesses secondary to an aging population and increase in global population. This poses an increased need for palliative care (Musema et al., 2014).

There is a huge disparity in palliative care for cancer patients across the globe, the high-income countries such as the USA have a wider coverage of palliative and supportive care hence easy accessibility for those in need of the service. A study in the USA to assess the availability palliative care in cancer centers revealed that National Cancer institute (NCI) cancer centers are more likely to have palliative and supportive care programs at 98% and each palliative care program has a palliative care specialist (74%) and an inpatient palliative multidisciplinary team (92%) and an outpatient palliative care clinic (59%), the study concluded that however most facilities reported availability of a palliative care program, the state of integration in the standard cancer care varied

widely across the care centers (Hui et al., 2010). On pediatric palliative care program, study findings also revealed that services are widely spread across the USA, it was established most pediatric cancer centers had availability of palliative care team (58%), psychosocial support programs (80%), pain management (90%), hospice services (60%) and bereavement services (59%) (Johnston et al., 2008) This findings were correlated by findings of the report on palliative care in the USA in which it was established palliative care services have been established in over 72% of USA hospitals that serve over 87% of hospitalized patients (Morrison et al., 2011).

The United Kingdom (UK)'s National health system (NHS) has adopted a two-pronged approach as a strategy to increase access and uptake of palliative care, the hospital-based approach and the community based approach, a retrospective study that was conducted to measure to uptake of palliative care among cancer patients established that 64% of participants were able to access comprehensive palliative care, the average contact in six weeks was twice. Generally, community palliative care approach was associated with more uptake as compared to hospital based and for a longer duration.

In the sub-Saharan region, there seems to be a large unmet need for palliative care, documented evidence indicates that only 5% of those in need of palliative care can access the services, leaving a large population with a high unmet need (Harding et al., 2013). With the ever-increasing aging population, cancer prevalence and the prevalence of other non-communicable diseases, the demand for palliative care will continue to outpace the supply in the sub-Saharan region (Fraiser et al., 2015). In Africa, Uganda is deemed to be the leader in provision of palliative care, in an audit conducted, Uganda has approximately 226 accredited centers with a majority being public centers offering specialized palliative care. This translates to an average population coverage of 88.5%. Even with the impressive coverage, the uptake of palliative care shows a dwindling number

due to the usual barriers of lack of means of transport, loss to follow up and sometimes lack of resources to run the facilities (Kagarmanova et al., 2022). Even with the impressive figures from Uganda, the rest of the continent, access and uptake of palliative care remains significantly low (Fraser et al., 2017).

2.4 Incorporation of palliative care to standard oncology

In the recent past, there have been significant innovations and advancements in the scientific approaches to cancer care, this has included measures such as early screening, diagnosis and treatment of cancer and cancer related illness (Greer et al., 2013). These advancements have yielded an overall increase in the patient survival years and better patient outcomes. With the increase in prevalence and number of survivors in need of survivorship care, the World health organization recommends an early initiation of palliative care to address the emerging symptom burden due to cancer diagnosis and cancer treatment, it also addresses psychosocial, physical and other existential elements across the cancer care continuum (WHO,2013, WHO, 2020, Greer et al., 2013 & Hui et al., 2017).

There have been a number of randomized controlled studies comparing concurrent standard oncology and palliative care to standard oncology alone, Zimmerman studied the inclusion of palliative care breast and lung cancer patients in a prognosis of 6-24 months, the statistical results favored concurrent palliative with standard oncology to standard oncology alone, parameters such as the quality of life, symptom management, patient mood, patient overall satisfaction and communication all were improved in patients on palliative care (Zimmerman et al., 2014) Temel et al., studied lung patients in USA outpatient clinics, Maltoni et al (2016) studied patients with pancreatic cancer, all these studies resonate with the aspect of improved quality of life, mood, communication and the overall survival for the patients on concurrent palliative care.

Studies have also been conducted to do cost analysis for patients on an integrated palliative care model with standard oncology, it was noted that there were reduced health care costs on patients on the palliative care program, palliative care minimized the need for futile interventions and investigations and hospitalizations associated with end-of-life care (Hui et al., 2018). In another study among the inpatients, noted that inpatient palliative care consultations reduced costs significantly (Morrison et al., 2008). A systematic review study amalgamating over 40 studies also concluded that cost was significantly reduced to patients on concurrent palliative care (Smith et al., 2009).

Ferrer et al in the summary of ASCO recommended that patients with advanced cancer, in any setting that may include, outpatient, inpatient or home should receive dedicated palliative care interventions in the disease trajectory concurrently with standard oncology care as a complementary intervention (Ferrer et al., 2017).

2.5 Barriers to palliative care service delivery in oncology

As early alluded to, the WHO recognizes palliative care as a basic human right to all in need of it, as a strategy to increase uptake, a recommendation from the 14th WHO assembly proposed integrated approach of delivery of palliative care to patients with life limiting diseases such as cancer (Lellan & Cai, 2022). Notwithstanding the enormous body of evidence of the benefits of palliative care in the patient related quality of life, there are document evidence of low uptake of palliative care, it is estimated globally that only 14% of patients with chronic and life limiting conditions have access to palliative care (WHO, 2020).

Several studies have sought to unravel the perceived barriers and enablers to the uptake of palliative care, it is worthy to note that most of the literature emanates from the western world and developed nations. Choy (2017) noted that most low and middle level income countries have not

established or are in the process of establishing a health care system (Choy, 2017). In literature, the perceived barriers and enablers can be categorized into three categories namely, health care related factors, patient related factors and health system related factors.

Herrmann et al., (2019) conducted a study in Australia to elicit the general practitioners (GP) perception perceived barriers and enablers of palliative care, the GPs reported a number of barriers that included time constraints related to the complex nature of palliative care that involves emotionally draining GP, patient and family communication, they highlighted a lack of evidence to guide family interactions and a lack of clear cut roles between the multidisciplinary team in palliative care. Kilcullen and Ireland (2018) studied the nurses perceptions in Australia and elicited staff related factors such a lack of training, skills and emotionally draining provider patient communication relationship, this results were in tandem by a study by den Herder-van der edern et al (2017) who studied the IPC leaders in seven European countries in which lack of knowledge, lack of skills and lack of collaborations among staff was highlighted as major barriers.

The lack for knowledge and skills seems to be an overriding component across many countries, study in the USA, other components such as desire for aggressive treatment, family member's resistance to hospice and end of life care (Rhodes et al., 2017). From the oncologist perspective Horlait et al., (2016) conducted a study in Belgium and noted the oncologist hesitant to refer patients to palliative care, a preference for aggressive treatment and a lack of knowledge on patient prognosis as key barriers.

In Iran, a systematic review on the patient related factors donated factors as financial related issues, cultural and religious factors on end-of-life care, obstacles initiated by the family and relatives as the major impending factors to uptake of palliative care (Azami- Angdash et al., 2015). A study in rural Indiana State in the USA, it was noted that patient perceptions and misconceptions, lack of

funds and insurance, geographical barriers in accessibility to palliative care, lack of awareness and family beliefs and attitudes on palliative care as key driving barriers to utilization of palliative care (Lellani & Cai, 2022).

Ismaili et al., sought to study the system related barriers to provision of palliative care, his findings pointed to a lack of government funding and support, lack of requisite policy and standard guidelines, infrastructural barriers and lack of enough staff trained and deployed for palliative care as major barriers in Tanzania (Ismaili et al., 2018). These findings resonate to a study by Rhodes et al., (2017) and Horlait et al., (2016) in which the oncologist reported a lack of requisite policy, training, awareness creation by health system managers and guidelines to guide delivery of palliative care.

2.6 Theoretical Framework

This study is based on the social support framework as conceptualized by (Fitch, 2008)

The supportive framework is based on the basis that a cancer diagnosis potentially affects the patient's ability to meet and satisfy their needs across the different domains of their life resulting to distress and psychological disequilibrium (Fitch, 2008). Within the context of continuum cancer care, the patient will experience multiple changes, the supportive care framework theorizes that the changes will occur across 7 major domains that include physical, social, mental, psychological, spiritual, informational and practical domains (Fitch, 2008). The framework is underpinned on the assumption estimate that all cancer patients will require some form of supportive care while less than 50% will require intensive specialized oncology care. Supportive care is best provided under the palliative care settings.

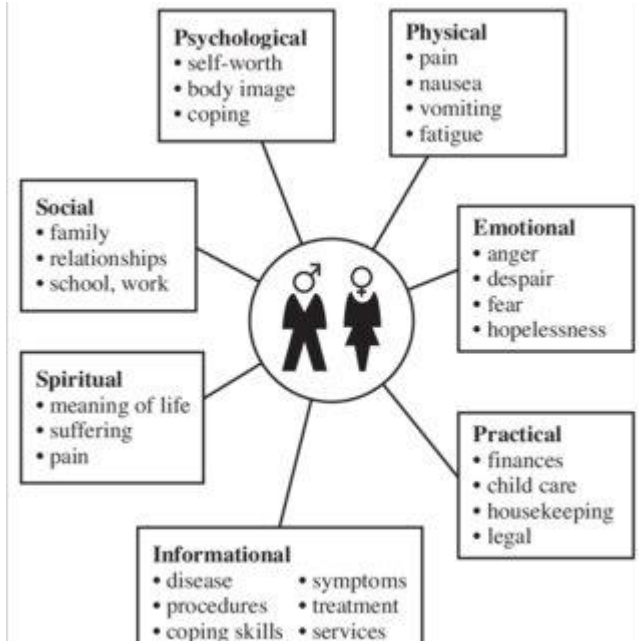


Fig 2.1: Theoretical framework adopted for Fitch (2008)

2.6 Conceptual framework

Independent variable

Intervening variable

Dependent variable

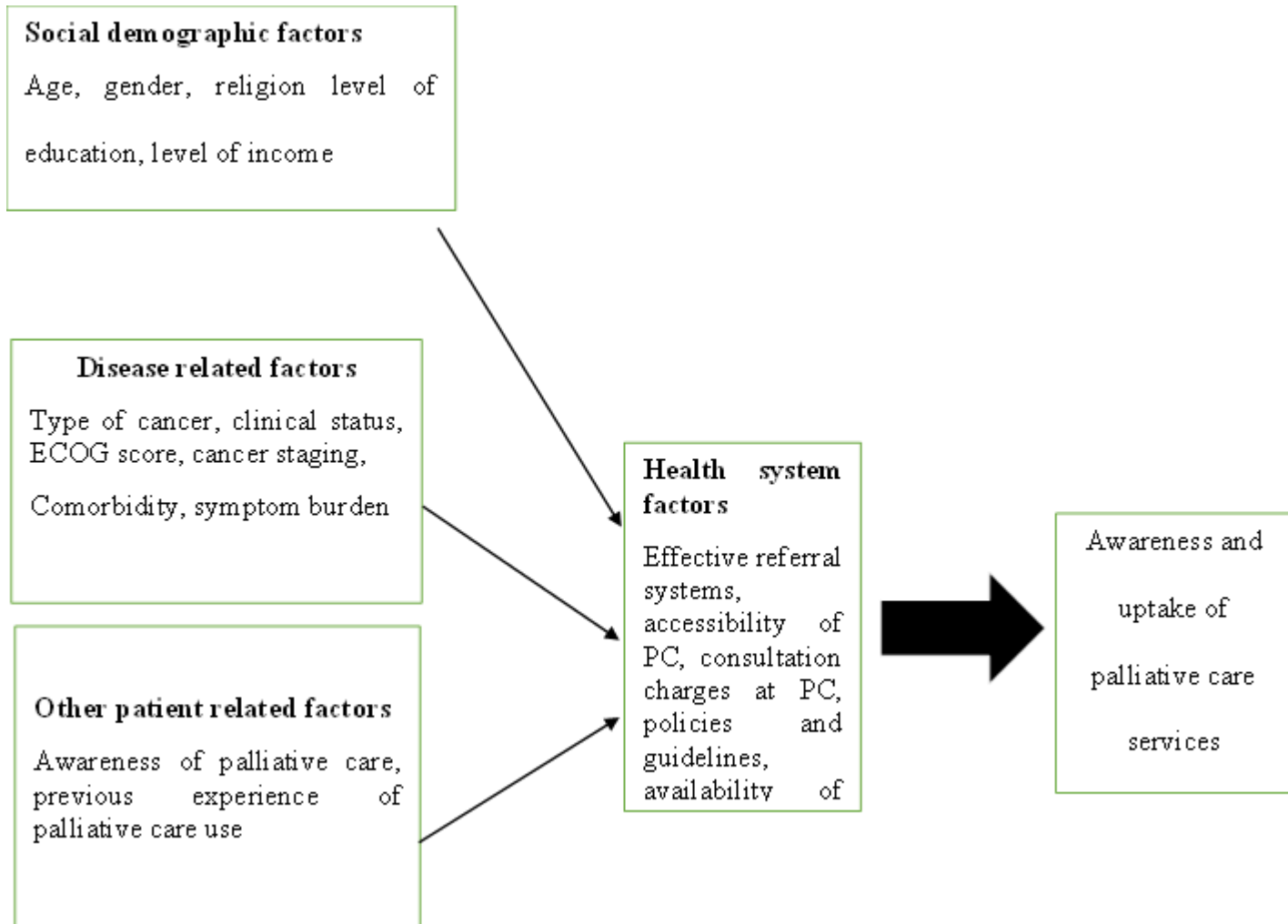


Fig 2.2: Conceptual model

CHAPTER THREE: METHODOLOGY

3.1. Study design

The study adopted a hospital based cross sectional descriptive study to assess awareness and uptake of palliative care services among patients with advanced cancer attending care in KNH. The descriptive cross-sectional design was preferred as the investigator aimed to identify the level of awareness and uptake of palliative care among patients with advanced cancer, factors affecting uptake and the barriers to uptake at the point in time and described.

3.2. Setting

The study was conducted at KNH. KNH is a public hospital that was established as a state cooperation in 1987 under a legal notice of government and accorded the mandate to serve as a level six referral hospital for patients requiring specialized care within and outside Kenya, it is also mandated to provide facilities for medical education for the UoN for research either directly or indirectly, to provide facilities for training in nursing and other health fields and to participate as a national referral hospital in national health planning. It is the largest public hospital with a bed capacity of 2500 averaging 90% bed occupancy daily. It also has a variety of specialized outpatient clinics, specialized day care centers and an accident and emergency department, all this average over 100,000 outpatient visits per year.

The hospital is located in Upper hill region in Nairobi County, around 3 KM from the central business district and accessible by both public and private transport services.

Data collection was collected at the Cancer treatment Center (CTC). The CTC is a department within the KNH that offers specialized cancer treatment. The services offered include ambulatory outpatient care, nuclear medicine services, radiotherapy services, survivorship and care follow-up

clinic, treatment planning and treatment follow up clinic, outpatient chemotherapy center and also includes the GFD, inpatient unit. Statistics from the division statistics and health information indicate that averagely there are 400 to 500 patients seen at the CTC per week.

3.3.Target population

The target population composed all cancer patients with metastatic or locally advanced disease with pathological or clinical staging III and IV or with poor performance status attending care at the outpatient cancer treatment centers.

The table below provides a summary of patients with cancer stage III and IV as summarized from attendance registers at the registration desk.

Clinic attendance register (physical count of stage III and IV)

Cancer stage	March, 2023	April, 2023	May, 2023	June, 2023	Average
Stage III	202	199	187	207	198
Stage IV	157	137	168	151	153
Total	359	336	355	358	352

Table 3.1: 4-month summary of the clinic register

The targeted sample was based calculated average clinic attendance of patients for the four months estimated at 352.

3.4. Eligibility criteria

3.4.1. Inclusion criteria

- a. All patients with a diagnosis of advanced cancer either clinical or surgical histopathology report of cancer stage III and stage IV
- b. Poor functional status (Eastern Cooperative Oncology Group (ECOG score of 3 &4)).

- c. The patients who assented and gave a signed consent to participate in this study.

3.4.2. Exclusion

- a. New patients being seen at the CTC for the first time. Palliative and supportive care is part of the treatment plan that need to be integrated to the standard oncology care. It is assumed that the treatment plan for patients being seen at CTC for the first time has not yet been established hence excluded from participating in this study.
- b. Patients who did not assent and thus declined to sign consent form to participate in the study.

3.5. Sample size determination

The sample size was calculated using the Yamane formula according to Yamane (1967). The formula is as follows

$$n = \frac{N}{1+N(e)^2}$$
$$= 356/1+ 356/(0.05)^2$$

188 patients.

The estimated population of patients with advanced cancer seen at the Cancer Treatment Center based on statistics from the health information and statistics department is averagely 356 per month.

3.6. Sampling procedure

The participants were sampled consecutively till the target number was attained. Every eligible participant who consented to participate was recruited and a provider administered questionnaire administered. The process was repeated until the required sample size was attained.

3.7. Study instrument tool

3.7.1. Questionnaire

A structured provider administered questionnaire was used to collect data. The questionnaire appendix (III) contains 4 parts. part 1 consisted of the participants social demographic data, part 2 contained the awareness of palliative care, part 3 contains information on uptake of palliative care and part 4 contains patient reported barriers to uptake of palliative care.

3.8.Data collection and data management

Data collection was done by three research assistants and the researcher, a one-day training for the study assistants on the purpose, objectives of the research and procedures was organized. A practical hands-on training on data collection through demonstration using a real participant.

The collected data was cleaned, incomplete questionnaires were excluded. Data was uploaded to the Microsoft excel, coded and then exported SPSS software of data analysis. Descriptive statistics were used to analyze the social demographic characteristics, clinical characteristics and the level of awareness and uptake of palliative care among patients diagnosed with metastatic or locally advanced cancer attending care at KNH and presented using the mean, frequency distribution, standard deviation and percentages. Multivariate logistical regression used to establish association independent and dependent variables of the study.

3.9.Quality assurance

The study proposal was reviewed by 2 allocated supervisors from the department of nursing, UoN faculty of health sciences. After their approval, the research proposal was submitted to KNH-UON ERC for review the proposal and granted approval for the study (attached on the appendices).

3.10. Ethical considerations

The scientific and ethical approval was granted by the joint Kenyatta National Hospital ethics and review committee. Permission to conduct the study was granted by the research office, KNH and the Head of department, CTC to carry the study.

Recruitment to participate in the study was voluntary, the research participants were taken through an individual, comprehensive consenting procedure where each component of the study was explained to the participants. Those who consented to participate appended their signature on the consent form.

A unique participant number was issued and no direct patient identifiers were used in order to keep anonymous, data collected was stored in a lockable shelf accessible to only the researcher to ensure it remained private and confidential. Transcribed data was kept under protected password accessible to the statistician and researcher. The study did not involve any invasive procedure.

CHAPTER 4: RESULTS

4.1 Introduction

The section outlines the findings with regards to the study objectives. The study assessed the awareness and determinants of uptake of palliative care services among patients with advanced cancer attending care at Kenyatta National Hospital. Among 188 participants who were enrolled in the study, 173 questionnaires were completely filled and returned for analysis representing 92% response rate. 15 questionnaires were incomplete as the participants withdrew from the study hence were not considered for analysis.

4.2 Participants' social demographic profile.

The Table below provides a summary of the social demographic characteristics of the participants. The majority of the participants were female 62.4% (n= 108). The average age of the participants was 54 years (SD ± 14 years). Majority of the participants were married 65.9% (n=114) and most of them were Christians 92.5 % (N= 160). Most patients (97.7%) had varying levels of formal education of which 44.5% (n= 77) had high school level of education, 33.5% (n=58) had primary level of education and 19.1% had a tertiary level of education. Very few 12.7% of the participants were in the formal employment and a majority of the participants 50.9% (n= 88) had monthly income of between Ksh. 10000- 25000. Most (93.1%) of the participants had enrolled in social health insurance fund (NHIF) which part of their treatment costs.

Social demographic characteristics of the participants.

Table 4.1: social demographic characteristics of participants

		Count (N=173)	%
Gender	Male	65	37.6
	Female	108	62.4
Age	Mean	54	100
	Median	53	
	Standard dev	14	
Marital Status	Single	19	11.0
	Married	114	65.9
	Divorced	1	0.6
	Separated	13	7.5
	Widowed	26	15.0
Level of education	Primary	58	33.5
	Secondary	77	44.5
	Tertiary	34	19.1
	No education	4	2.3
Religion	Christian	160	92.5
	Muslim	12	6.9
	Hindu	0	0.0
	Traditional	0	0.0
	Pagan	1	0.6
Occupation	Self-employed	79	45.7
	Employed	22	12.7
	Not on Employment	57	32.9
	Any other	15	8.7
NHIF availability	Yes	161	93.1
	No	12	6.9

4.3 Disease characteristics of the respondents

4.3.1 Stratification of the types of cancer

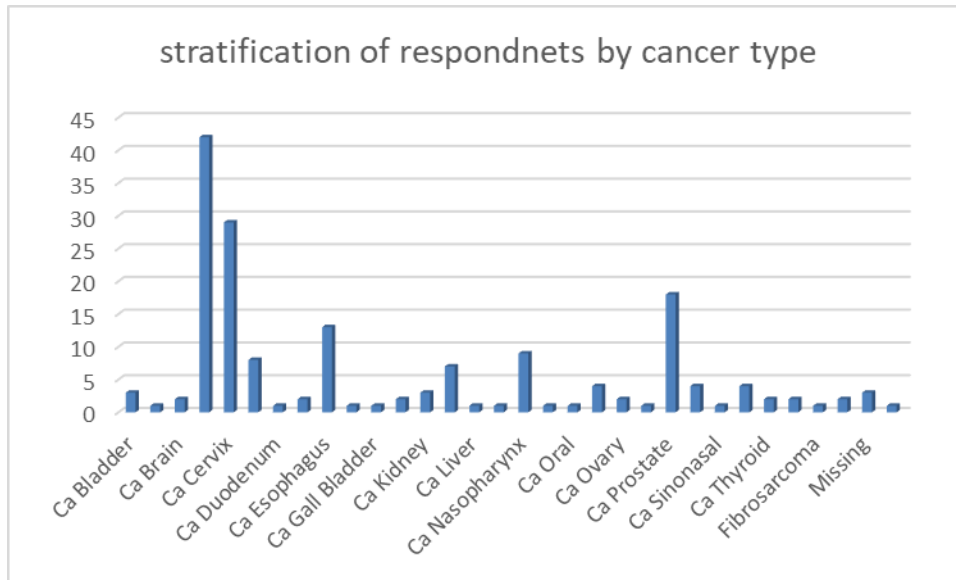


Figure 4.1: Stratification of respondents by cancer type

The study sought to investigate the stratification of patients by cancer type, most participants had cancer of the breast (24.3%) closely followed by cancer of the cervix (16.8%) and cancer of the prostate (10.4%)

4.3.2 Disease staging

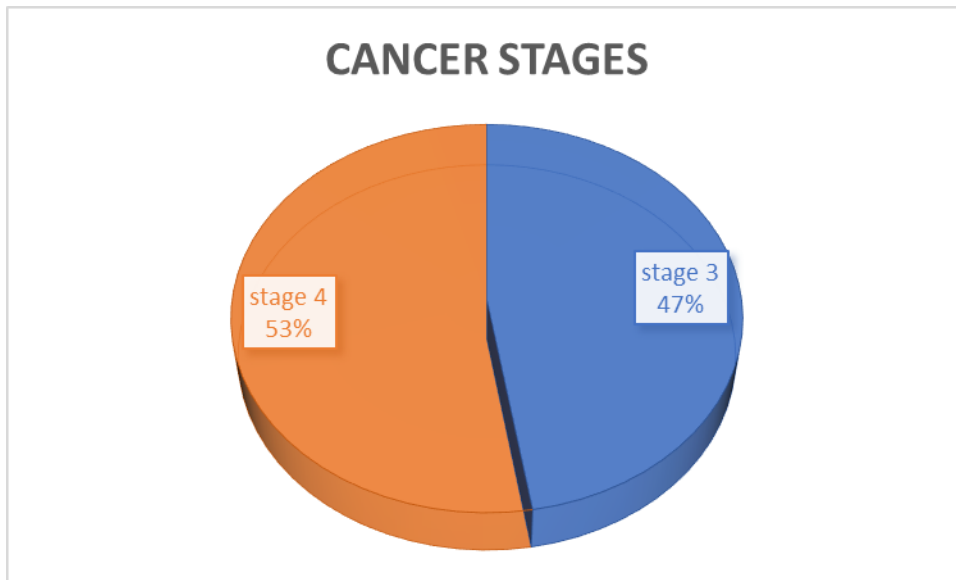


Fig 4.2 characterization by stage

All the 173 participants had advanced cancer described as locally advanced stage III or metastatic diseases stage IV. Most participants 53% n=91 had stage 4 metastatic cancer disease.

Table 4.2 Patients clinical factors

Disease characteristics	Frequency	Percentage
Type of treatment		
Chemotherapy	101	58.4
Radiotherapy	11	6.4
Chemoradiotherapy	34	19.7
Survivorship care	27	15.6
Level of physical performance		
ECOG 0	16	9.2
ECOG 1	37	21.4
ECOG 2	67	38.7
ECOG 3	44	25.4
ECOG 4	9	5.2

58.4% (n= 101) of the study participants were getting chemotherapy, the level of function using the Eastern Cooperative Oncology Group (ECOG score) majority 38.7% n= 67) scored 2. The average time since diagnosis was 26.9 (SD ±15) months.

4.4 Awareness of palliative care among patients with advanced cancer.

4.4.1 Proportion of participants who have heard of palliative care.

Most of the respondents 66% have never heard of palliative care as indicated in fig 4.3 below.

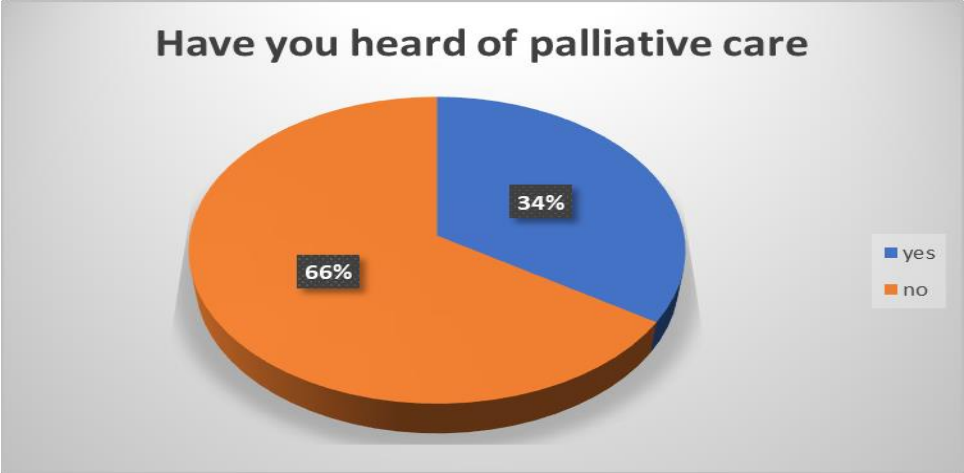


Figure 4.3: Awareness of palliative care among patients with advanced cancer at KNH.

4.4.2 Source of information about palliative care among patients with advanced cancer at KNH.

Of those who reported of awareness of palliative care (n= 59), majority 29.5%, heard it from their oncologist while 11% of them have used palliative care. 6.4% of them stated that they heard about it from a health care provider outside the Cancer treatment center, KNH, cumulatively, 9.8% have heard of palliative care either from the media or read about it online. 3.5% received information about from a family member.

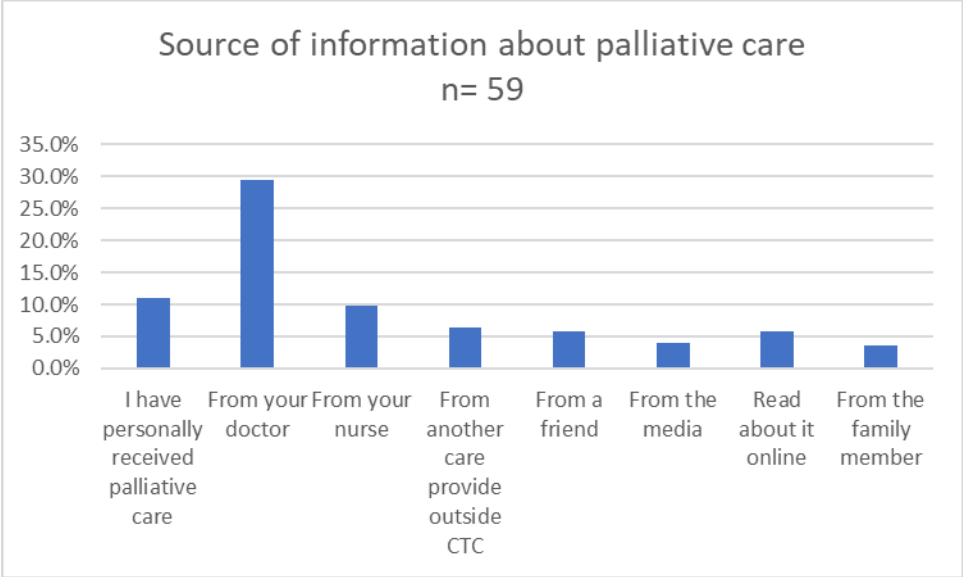


Fig 4.4 Source of information about palliative care

4.4.3 Perception of participants on the goal and period of initiation of palliative care.

Majority of the participants 28.3% stated that the goal of palliative care is to help patients cope with adverse effects of treatment, 26.6 % highlighted that palliative care helps to improve the quality of life. 6.4% stated that the goal of palliative care is not curative treatment and 11% of the responses alluded to palliative care as end-of-life care.

The study also revealed that majority of participants 50.3% (n= 82) did not know when to initiate palliative care, 19.7% felt that palliative care can be initiated during diagnosis and 13.3% indicated that it can be initiated during any time of the disease’s trajectory.

Table 4.3 below summarizes the findings on the perception of patients on palliative care.

Table 4.3: Perception of patients on palliative care.

Goal of Palliative care		Frequency	Percentage (%)
The goal of palliative care is to address any psychological issues brought up by serious illness	Yes	23	13.3
Palliative care can help people manage the side effects of their medical treatment	Yes	49	28.3
Palliative care is exclusively for people who are in their last stages of their life	Yes	19	11
A goal of palliative care is to help people better understand their treatment options	Yes	23	13.3
Palliative care encourages people to stop treatment aimed at curing their illness	Yes	11	6.4
A goal of palliative care is to improve a person's ability to participate in daily activities	Yes	25	14.5
Palliative care helps the whole family cope with a serious illness	Yes	14	8.1
Palliative care helps to improve the quality of life of the patient	Yes	46	26.6
When people receive palliative care, they must give up their other doctor	Yes	2	1.2
People must be in the hospital to receive palliative care	Yes	3	1.7
When should people/patients receive palliative care?	Any time	23	13.3
	At the time of diagnosis	34	19.7
	At end-of-life care.	11	3.5
	Don't know	82	50.3

4.5 Predictors of Awareness

4.5.1 Association between social demographic features and awareness of palliative care among patients with advanced cancer.

We conducted a one-way ANOVA to investigate whether there was a significant difference between the social demographic factors and the disease clinical factor to awareness of palliative care among patients with advanced disease. The findings revealed that there was a significant difference in the social demographic factors ($F= 3.385$, $P= 0.004$)

Table 4.5: Association between social demographic features and awareness of palliative care

ANOVA^a

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	4.656	6	.776	3.385	.004 ^b
	Residual	33.462	146	.229		
	Total	38.118	152			

.

a. Dependent Variable: Have you heard of palliative care?

b. Predictors: (Constant), What is the level of patient's performance? What is the stage of your cancer diagnosis? What is your highest level of education? What is your gender? What is the treatment you are currently receiving? What is your age in years?

4.5.2 Relationship between the social demographic characteristics and the awareness of palliative care

From the multivariate linear regression analysis, only the level of education had a significant association with the level of awareness of palliative care among patients with advanced cancer attending care at KNH. Patients with a higher level of education were more likely to have awareness to palliative care as compared to those with low levels of education.

Table 4.6: Linear regression analysis for social demographic factors to level of awareness.

Coefficients ^a		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	95.0% Confidence Interval for B	
Model		B	Std. Error	Beta			Lower Bound	Upper Bound
	(Constant)	0.982	0.39		2.519	0.013	0.212	1.752
	What is your gender?	0.143	0.087	0.136	1.647	0.102	-0.029	0.315
	What is your age in years?	0.004	0.003	0.124	1.387	0.168	-0.002	0.011
	What is your highest level of education?	-0.163	0.05	-0.266	-3.237	0.001	-0.263	-0.064
	What is the stage of your cancer diagnosis?	0.082	0.074	0.09	1.111	0.268	-0.064	0.228
	What is the treatment you are currently receiving?	0.033	0.039	0.067	0.837	0.404	-0.045	0.11
	What is the level of patient's performance?	0.016	0.041	0.032	0.396	0.693	-0.065	0.098
a Dependent Variable: Have you heard of palliative care?								

4.6 Uptake of palliative care

4.6.1 Proportion of uptake of palliative care services among patients with cancer

The study established that few participants 31% had utilized palliative care services and 69% had never utilized as shown in fig 4.4 below.

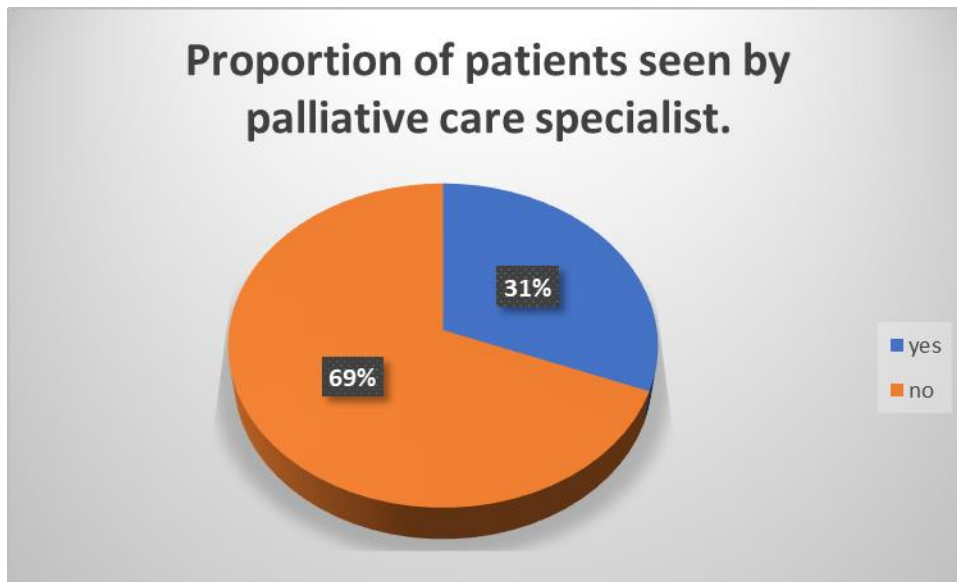


Fig 4.4: proportion of participants seen by a palliative care specialist

4.6.2 Referral systems to palliative care

The study established that 60% of those who had utilized palliative care services were referred by the attending oncologist at the cancer treatment center as illustrated in fig 4.5 below.

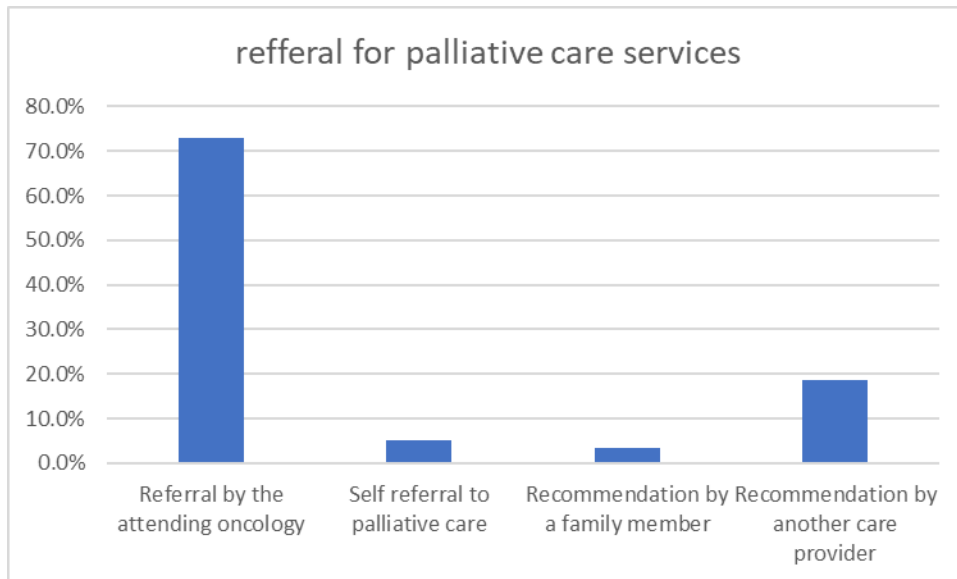


Fig 4.5: Sources of referral for patients with advanced cancer to palliative care specialist.

4.7 Palliative care services patients received

The study sought to determine the specific palliative care services utilized, nutritional services (90.8%) and pain management 80.9% were the most sought-after service while cancer rehabilitation, sexual counselling and psychiatric consultation were the least sought-after services.

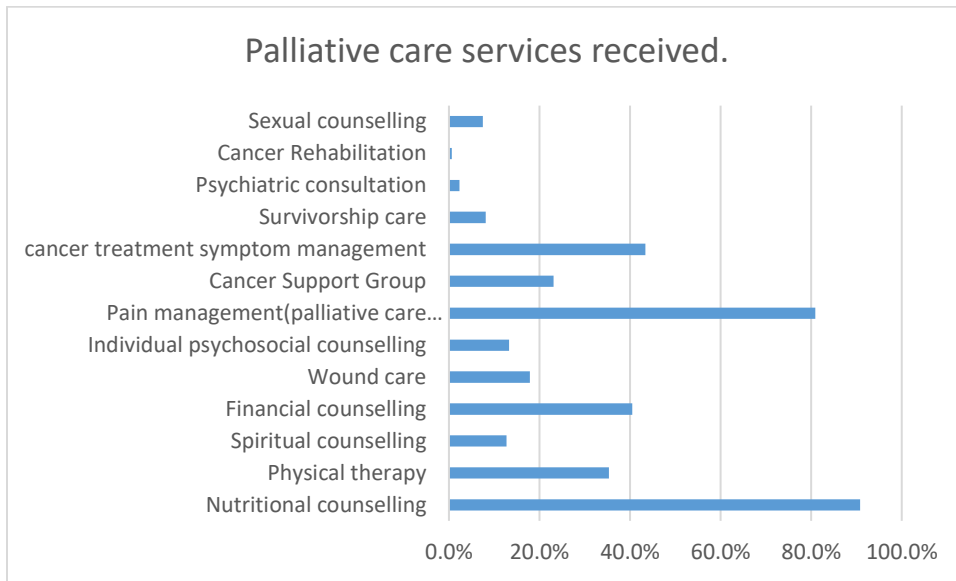


Fig 4.6: Variety of palliative care services utilized by patients with advanced cancer.

4.8 Access to palliative care services

4.8.1 Place of palliative care service delivery

85% (n=147) reported that they received the above supportive care services at the cancer treatment center, 15.6% had received them in another facility outside the Kenyatta National Hospital while 12.7% had been referred to specialist palliative care clinic at the Kenyatta National hospital as illustrated in table 4.7 below.

Table 4.7- service delivery point for supportive care therapies

Place where supportive care received	Frequency	Percentage
Cancer Treatment Center, KNH	147	85
Specialized palliative care clinic	22	12.7
Referred to other clinic	7	4.0
Other facility outside KNH	27	15.6
At home	1	0.6

4.8.2 Timing of palliative care services

Many of the participant 37.6% received the services more than six months prior to this study as illustrated in table 4.8.

Table 4.8: Timing of palliative care

Timing of palliative care	Frequency	Percentage
< 1 month ago,	30	17.3
1-3 months ago	38	22
4- 6 months ago	36	20.8
>6 months ago	65	37.6

4.8.3 Frequency of utilization of palliative care.

Majority 69.9% also reported that they received the service once. As shown in figure 4.7

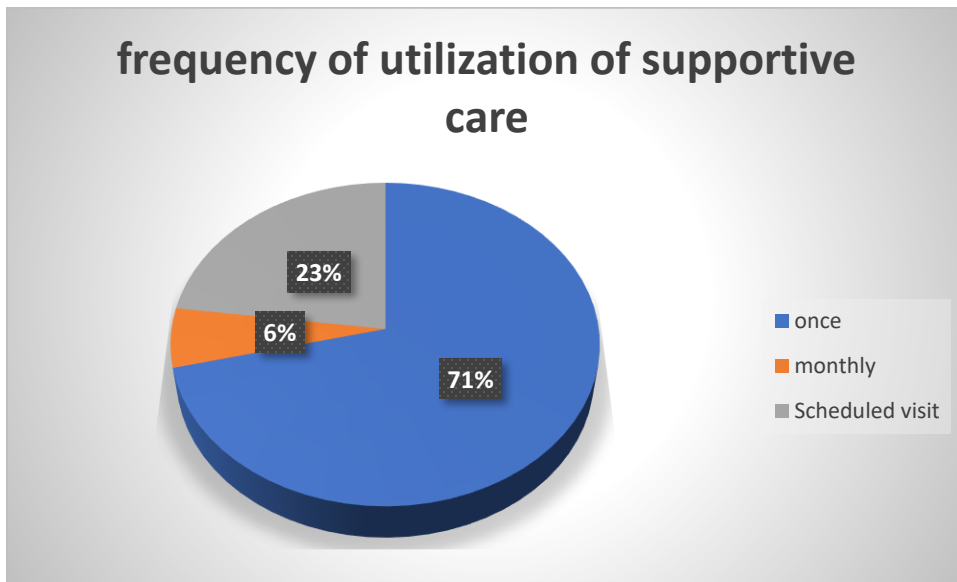


Fig 4.8 Frequency of utilization of palliative care

4.9 Level of satisfaction with services received

A five-point Likert scale was used to measure the level of satisfaction of the palliative care services utilized, majority 49.1% of the participants were generally satisfied with the services received while 19.7% of the participants were neither satisfied nor dissatisfied with the services received. 8.1% were dissatisfied with the services received.

Table 4.9: Level of satisfaction with the services received

If you have used any of the services listed above, how satisfied are you with this palliative and supportive care services in helping you deal with the impact of cancer or its treatment:	Very unsatisfied	1	0.6
	Dissatisfied	14	8.1
	Neither dissatisfied or satisfied	34	19.7
	Satisfied	85	49.1
	Very much satisfied	32	18.5

4.10 Determinants of uptake of palliative care services

4.10.1 Association between social demographic factors and uptake of palliative care.

Multivariate logistical regression was done to find out whether there was a difference in the uptake of palliative care based on social demographic and clinical status of the patient. At 95% CI, the findings were not statistically significant (P=0 .061).

ANOVA^a

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	3.238	7	.463	1.984	.061 ^b
	Residual	31.935	137	.233		
	Total	35.172	144			

4.10.2 Pearson linier correlation coefficient of the level of uptake of palliative care services and social demographic factors

A Pearson linier correlation efficient revealed that only gender $p < 0.03$ was statistically significant to the uptake of palliative care among patients with advanced cancer.

Table 4.10: Association of social demographic factors to uptake of palliative care

Coefficients ^a		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	95.0% Confidence Interval for B	
Model		B	Std. Error	Beta			Lower Bound	Upper Bound
	(Constant)	1.132	0.422		2.683	0.008	0.298	1.966
	What is your gender?	0.227	0.103	0.217	2.195	0.03	0.022	0.431
	What is your age in years?	0.004	0.003	0.122	1.294	0.198	-0.002	0.011
	What is your highest level of education?	-0.093	0.053	-0.153	-1.774	0.078	-0.197	0.011
	What is the stage of your cancer diagnosis?	-0.022	0.077	-0.024	-0.287	0.775	-0.175	0.131
	What is the treatment you are currently receiving?	0.068	0.041	0.145	1.679	0.095	-0.012	0.149
	What is the level of patient's performance?	-0.042	0.044	-0.082	-0.947	0.345	-0.13	0.046
	What is your primary diagnosis? (Confirm from	0.005	0.006	0.091	0.921	0.358	-0.006	0.017

4.11 Perceived Barriers to uptake of palliative care

The study sought to identify the patient perceived barriers on the uptake of palliative care services. Majority of the participants (76.9%) agreed that money for consultation fee was major hindering factor to uptake of palliative care services, lack for money for fare was also highly linked as a major barrier at 69.9% hindering uptake of palliative care services. 65.9% of the respondents also expressed that time is a limiting factor to combining standard oncology care to palliative care. Some participants (50.3%) Lack of oncologist to refer deserving patients for palliative care hindering factor.

Table 4.11. The patients’ perceived barriers to uptake of palliative care services.

		Count	%
Time limitations	Agree	114	65.9
	Disagree	15	8.7
Accessibility of services	Agree	107	61.8
	Disagree	29	16.8
Money for consultation fee/expenses	Agree	133	76.9
	Disagree	12	6.9
Lack of means of transport/fare	Agree	121	69.9
	Disagree	15	8.7
Lack of referral from oncology physicians	Agree	87	50.3
	Disagree	9	5.2
Lack of palliative care awareness and knowledge on palliative care	Agree	44	25.4
	Disagree	11	6.4
Patient's lack capacity to make decisions on goals of care	Agree	46	26.6
	Disagree	14	8.1
Stigma and discrimination	Agree	26	15.0
	Disagree	75	43.4
Lack of family awareness on palliative care	Agree	31	17.9
	Disagree	78	45.1
Reluctance of family to be referred	Agree	5	2.90

CHAPTER FIVE

DISCUSSION, CONCLUSION AND RECOMMENDATION.

5.0 Introduction.

Palliative care is a critical and essential component in management of patients with life limiting and life-threatening conditions. This study sought to determine the level of awareness and uptake of palliative care among patients with advanced cancer attending care at Kenyatta National Hospital, as well as explore the patient perceived barriers to uptake of palliative care in a tertiary health facility. The discussion is organized into social demographic health factors, awareness of palliative care, uptake of palliative care and barriers to uptake of palliative care.

5.1 Discussion.

5.1.1 Social demographic factors.

The average age of the study participants was 54 years with an SD of 14 years and more than half of the participants were female. These findings depict similar trends with previous findings that have shown a high prevalence of cancers individuals between the age of 50- 60 years (Nayak et al., 2017, Ranjbar et al., 2018). The findings are also consistent with other studies conducted in the same setting, a study by Bosire et al., 2020, Soita et al., 2021 & Machaki et al., 2018) all indicated a high prevalence of cancer among patients within the age distribution on 50-60 years and among women.

The study findings further revealed that more than three quarters of participants were married, more than half of the participants had a secondary level of education and a majority were unemployed. Studies have shown that the incidence of cancer is twice as great among individuals with no or low levels of education and low socio economics as compared to those with high levels

of education. Damian (et al., 2015) indicated that individuals with a higher level of education and good income are more likely to go for early screening. Matiba in her study postulated that women of low socio economic, with low education may experience delay in seeking health services and the status may push them to seek alternative therapy instead of conventional methods (Matiba et al., 2020).

5.1.2 Disease characteristics of the participants

The study established that the common types of cancer among the participants were breast cancer, cancer of the cervix and cancer of the prostate that cumulatively was seen in over half of the participants. The findings are consistent with the GLOBOCAN 2020 statistics that have shown that Breast cancer has the highest incidence followed by cancer of the cervix and prostate in developing countries (Sung et al., 2021).

More than half of the participants had stage IV cancer staging and approximately a third were receiving chemotherapy. The findings are consistent with most epidemiological patterns where patients present with advanced disease due to delayed diagnosis (Kabura, 2020). The study also established that over a third of the patients were receiving palliative chemotherapy. Systematic chemotherapy is a preferred mode of treatment to local treatments such as radiotherapy for advanced disease (Abinya et al., 2014; MOH, 2018) The study also established that the disease characteristics of the patients did not have any significant association with the awareness and uptake of palliative care services among patients with advanced cancer.

5.1.3 Awareness of palliative care

The study indicates that generally the level of awareness of palliative care among the study participants was low with approximately a third indicated awareness to palliative care. The study further revealed that level of education is significantly associated with awareness of palliative care,

patients with a higher level of education had a higher odd of being aware of palliative care as opposed to patients with low levels of knowledge.

The findings of the study are consistent with the results from a study in 4 countries in Asia in which awareness of palliative care service was 30% (Lin et al., 2020), However, this is significantly lower compared Singapore where awareness was 44% (Ozdemir et al., 2022)

Health care providers play a critical role in increasing awareness of palliative care, the study established that about a third of the respondents heard about palliative care from their primary doctor. Educational interventions targeting the oncology care providers to increase their familiarity with the concepts of palliative care will subsequently increase patient awareness of palliative care.

There seemed to be a large disconnect between end-of-life care and palliative care. Our study revealed that about 1/10 of the participants equated palliative care to end of life care and further 6% believed that palliative care is aimed at managing the disease beyond cure. These findings are consistent with a qualitative study by Cammila et al., (2016) in which most patients and care givers stated that palliative care is often associated with a negative stigma associated with death. Another qualitative study in Ireland revealed that quite often conceptualized to mean terminal care.

5.1.4 uptake of palliative care

About 1/3 of the participants had utilized the palliative care of palliative care services among patients with advanced cancer. This trend is consistent with literature from other low- and middle-income countries where the uptake of palliative care among cancer patients was equally low (34%) and 19% in China (Lin et al., 2022; Ozdemir et al, 2022). However, the findings have stark difference from a study in high income countries that reported a higher utilization of palliative

care, in the US Hui et al., (2014) reported 46% uptake of palliative care while Chang reported 50% uptake of palliative care in Britain.

The users of palliative care in this study were more likely to have a higher level of education, this trend is similar to literature correlating higher levels of education to higher utilization and better treatment outcomes. Patients with low levels of education exhibit low health literacy thus may have a information gap regarding the benefit of palliative care to standard oncology care. Gender was also significantly associated with the uptake of palliative care where women are more likely than men to utilize palliative care services. This concurs with the study by Kimani et al., (2021) that females are more likely to report more comorbidities than men. This can also be associated to biological and social differences between the different genders.

Health care providers play a critical role in utilization of health services, the study revealed that more than half of the patients utilizing palliative care were referred by the attending oncologist. These findings are consistent with the findings in a study by Hui et al., (2014) done in the US that revealed that almost all patients seen at the palliative care clinic had a consult request from other specialized clinic

Pain and Nutritional services among the palliative and supportive care services that patients were seeking and a more than half of the received these services at the Cancer treatment Center. This explains the justification for further integration of palliative care services with the standard oncology care.

5.1.5 Barriers to uptake of palliative care.

The study explored the patient perceived barriers to uptake of palliative care among patients with advanced cancer, the major findings revealed that lack of money to cover transportation costs, time

constraints inaccessibility of services and lack of referrals from attending oncologist were identified as the major barriers to uptake of palliative care services among patients with advanced cancer. The findings are consistent with the findings from a qualitative study done in Ethiopia in which 4 themes ranging from referrals, cost constraints, accessibility and effectiveness of the services were highlighted (Abate et al., 2023).

The WHO (2018) highlighted that one in every three major barriers in uptake of palliative care are related to lack of integration within the health system. The major barriers identified by WHO include lack of supportive policies, lack of a hands-on training for health care providers and lack of accessibility for palliative care services (WHO, 2018).

5.2 Study Limitations

Some respondents declined to take part in the study and others withdrew from the study before conclusion of the data collection process. The incomplete questionnaires were excluded from further processing hence did not form part of data analysis. However, this did not affect the strength of the study as the response rate was over 90%.

This is an institutional study hence the findings of this study might not be generalized to other settings.

5.3 Conclusion

The study revealed that patients with advanced cancer generally had low levels of awareness on palliative care, this is compounded by low levels of uptake of palliative care among patients with advanced cancer.

The findings of the study also demonstrated that level of education as the social demographic factor affecting the level of awareness of palliative care among patients with advanced cancer

attending care at Kenyatta National hospital. Regression analysis revealed that the social demographic factors did not have significant impact on the uptake of palliative care services.

The study further showed that pain management and nutritional therapy were the major palliative and supportive care services received and generally patients were satisfied with the services they received.

On the barriers to uptake of palliative care, money for consultation fee, lack of money for transport and a lack of referral by the attending oncologist as the major barriers to uptake of palliative care.

5.4 Recommendation

Our findings suggest that measures should be put in place to increase awareness and uptake of palliative care among patients with cancer attending care at Kenyatta National hospital. In view of the above, the following recommendations are made: -

1. Integrating of specialist palliative oncology care services with the standard oncology services at the Cancer treatment Center, Kenyatta National Hospital
2. Health care providers play a critical role in awareness creation and increasing uptake of health service utilization. We therefore recommend in-service training on palliative care on oncology for the staff working at the Cancer Treatment Center, KNH.
3. As a long-term plan, it is recommended that in the scheduled curriculum review, Palliative care to be incorporated as an integral component in the training curriculum for various specialist courses for oncology.
4. We also recommend that policy makers to include an evidence-based guideline on palliative oncology with key recommendations to foster uptake of the services.

5.5 Further research

We recommend further research on examining different models of integrating palliative care to standard oncology care at Kenyatta National Hospital.

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APPENDICES

Appendix i: Informed consent for the patient

Title of the study: Uptake of palliative care services among patients with advanced cancer at Kenyatta National Hospital.

Principal investigator: Solomon Mirera Omare, Msc. Nursing (Oncology), Year II

Institution: University of Nairobi, P.O Box 30197- 00400 Nairobi

Introduction

My Name is Solomon Mirera Omare, I am a student at the faculty of health sciences, department of Nursing, pursuing a Master of Science degree in nursing specializing in Oncology Nursing. I am conducting a study titled; Awareness and uptake of palliative care services among patients with advanced cancer at the Kenyatta National Hospital. You are cordially invited to participate in this study that is being done at the Cancer Treatment center.

This consent form gives you detailed information about the study, the benefits and risks associated with this study, and the process of participation will also be explained to you. Once you understand the study and agree to participate in this study, you will be requested to append your signature or put the thumb print on this form.

Purpose of study

The purpose of the study is to determine the uptake of palliative care services among patients with advanced cancer at the Cancer treatment Center, KNH. To achieve this broad objective, the study will seek to determine the proportion of uptake of palliative care among patients with advanced cancer, Patient related factors associated with the uptake of palliative care, health system related

factors associated with the uptake and the patient reported barriers to uptake of palliative care among patients with advanced cancer in KNH.

Time

While participating in this study, it will take **20-30 minutes** of your time through the guidance of the researcher or research assistant.

Benefits

There is no direct monetary benefit for participating in this study. However, the results from this study will be useful in informing key stakeholders in restructuring and reorganizing the care process to optimize patient experiences in delivery of quality health care services tailored to meet the patient needs.

Risks

There are no directly foreseen risks for participating in this study, however, you will take some time of (20-30) minutes of your time to respond to the questionnaire, also, in the process of responding to this questionnaire, there is a potential risk of disclosing some of your personal information that might trigger some levels of anxiety, measures will be taken to reassure you and might be referred to the counselor for management.

Confidentiality

The Data you are going to provide, together with other participants will be stored in safe, locke cabinets. Your data will be labelled with a unique study code and you will not be required to use your name, your identity will be held in confidentiality, any additional information you provide, it

will remain confidential. The electronic data generated during data cleaning, will be password and fire wall protected computers.

Participation

Participation in this study will be voluntary, you retain a right to withdraw from the study at any time without any consequence and you may skip some questions as you may deem though you are encouraged to complete all. Refusal to participate will not in any way jeopardize the quality of care you receive while seeking care in this hospital.

Sharing the results

The results of this study may be presented during scientific and academic forums and be published in academic and scientific journals.

Contact person

If you have any questions regarding this study during or after the research, you may contact the principal investigator, the supervisors or KNH/UoN Ethics and Research committee on the contacts provided bellow.

1. Principal Investigator

Name: Solomon Mirera Omare

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Physical address: Department of Nursing, University of Nairobi, faculty of health sciences, KNH campus.

3. KNH/UoN ethics and Research committee

Dr Beatrice Amugune

Secretary, KNH/UoN ERC

Phone number: +254 722 802 074

Tel extension: 44102

Email: knhuonerc@uonbi.ac.ke

Physical address: Department of pharmacy, University of Nairobi, faculty of health sciences, KNH campus.

Appendix iii: Consent form

I hereby confirm that I have full knowledge of the study being undertaken, I also confirm that I have read and understood the information sheet provided and the study investigator/ research assistant has informed me about the nature, process, conduct, benefits and potential risks of the study.

I am also aware that my participation in this study is voluntary and I can withdraw from participating should I wish so. It is also in my knowledge that the information I will be giving will be confidential and that the results of this study will be anonymously processed. I have been provided sufficient time to ask questions regarding this study and declared myself prepared to participate in this study

I agree to participate in the study

Signature..... Date

I (investigator/ research assistant) confirm that I have clearly explained to the participant the nature, process, conduct benefits and potential risk of the study and the contents of this consent form in details and that the participant has decided to participate voluntarily without coercion or undue pressure

Investigator/ Research assistant

Signature..... Date

Appendix iii: Ruhusa ya ridhaa kwa wagonjwa

Mada ya utafiti: Uhamasishaji na matumizi ya huduma za kwa wagonjwa walio na saratani iliyokidhiri wanaopata huduma katika Hospitali ya Kitaifa ya Kenyatta.

Mtafiti: Solomon Mirera Omare, Mwanafunzi wa mwaka wa pili, Shahada ya uzamili ya Uuguzi (Uuguzi wa saratani).

Taasisi ya utafiti: Chuo Kikuu cha Nairobi.

Utangulizi

Jina langu ni Solomon Mirera Omare, mimi ni mwanafunzi katika kitivo cha sayansi ya afya, idara ya Uuguzi, ninasomea Shahada ya Uzamili ya Sayansi katika uuguzi, taaluma katika Uuguzi wa Oncology. Ninafanya utafiti unaoitwa; Uhamasishaji na utumiaji wa huduma za matibabu kwa wagonjwa walio na saratani iliyokithiri waanohudhuria matibabu katika Hospitali ya Kitaifa ya Kenyatta. Umealikwa kwa moyo mkunjufu kushiriki katika utafiti huu unaofanywa katika kituo cha Tiba ya Saratani.

Fomu hii ya idhini ni ya kukupa maelezo ya kina kuhusu utafiti, faida na hatari zinazohusiana na utafiti huu, na mchakato wa kushiriki pia utafafanuliwa. Mara tu unapoelewa utafiti na kukubali kushiriki katika utafiti huu, utaombwa kuambatisha sahihi yako au kuweka alama ya kidole gumba kwenye fomu hii.

Kusudi la kusoma

Madhumuni ya utafiti huu ni kubaini utumiaji wa huduma za tiba shufaa miongoni mwa wagonjwa walio na saratani iliyokithiri katika Kituo cha matibabu ya Saratani, KNH. Ili kufikia lengo hili

pana, utafiti utatafuta kubainisha uwiano wa uchukuaji wa huduma shufaa miongoni mwa wagonjwa walio na saratani iliyokithiri, mambo yanayohusiana na uchukuaji wa huduma shufaa, mambo yanayohusiana na mfumo wa afya yanayohusiana na uchukuaji huo na Vizuizi jinsi vilivyoripotiwa na juu ya uchukuaji wa huduma shufaa miongoni mwa wagonjwa walio na saratani iliyokithiri wanaohudhuria matibabu katika hospitali kuu ya KNH.

Wakati

Utakapokubali kushiriki katika utafiti huu, itachukua dakika 20-30 za muda wako kupitia mwongozo na usaidizi wa mtafiti au msaidizi wa utafiti kukamilisha dodosho ya utafiti.

Faida

Hakuna faida ya moja kwa moja ya fedha kwa kushiriki katika utafiti huu. Hata hivyo, matokeo ya utafiti huu yatakuwa na manufaa katika kufahamisha washikadau wakuu katika kurekebisha na kupanga upya mchakato wa utunzaji ili kuboresha uzoefu wa mgonjwa katika utoaji wa huduma bora za afya zinazolengwa kukidhi mahitaji ya mgonjwa.

Hatari

Hakuna hatari zilizotabiriwa moja kwa moja za kushiriki katika utafiti huu, hata hivyo, utachukua muda wako (dakika 20-30) za muda wako ili kujibu dodoso, pia, katika mchakato wa kujibu dodoso hili, kuna uwezekano wa kufichua baadhi ya taarifa zako za kibinafsi ambazo zinaweza kusababisha viwango fulani vya wasiwasi, hatua zitachukuliwa ili kukutuliza na zinaweza kutumwa kwa mshauri kwa usaidizi.

Usiri

Data utakayotoa, pamoja na washiriki wengine itahifadhiwa katika makabati salama, yenye kufuli. Data yako itawekewa msimbo wa kipekee wa kujifunza na hutahitajika kutumia jina lako, utambulisho wako utahifadhiwa kwa usiri, maelezo yoyote ya ziada utakayotoa, yatakuwa siri.

data ya elektroniki yanayotokana wakati wa kusafisha data, itakuwa password na moto ukuta ulinzi kompyuta.

Kushiriki

Kushiriki katika utafiti huu kutakuwa kwa hiari, ni haki yako kujiondoa kwenye utafiti huu wakati wowote bila matokeo yoyote na unaweza kuruka au kutojibu baadhi ya maswali kama unavyodhani ingawa unahimizwa kukamilisha yote. Kukataa kushiriki hakutahatarisha kwa vyovyote vile ubora wa huduma unayopata unapotafuta huduma katika hospitali hii.

Matokeo

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

Mawasiliano

Ikiwa una maswali yoyote kuhusu utafiti huu wakati au baada ya utafiti, unaweza kuwasiliana na mpelelezi mkuu, wasimamizi au kamati ya Maadili na Utafiti ya KNH/UoN kuhusu anwani zilizotolewa hapa chini.

1. Mpelelezi Mkuu

Jina: Solomon Mirera Omare

Nambari ya simu: +254727765981

Barua pepe: solomare87@gmail.com

Anwani ya eneo: Idara ya Uuguzi, Chuo Kikuu cha Nairobi, kitivo cha sayansi ya afya, Idara ya uuguzi iliyomo KNH.

2. Wasimamizi

i. Samuel Kimani (PhD) Dk.

Nambari ya simu: +254722384917

Barua pepe: tkimani@uonbi.ac.ke

Anwani ya eneo: Idara ya Uuguzi, Chuo Kikuu cha Nairobi, kitivo cha sayansi ya afya, KNH.

ii. Sabina Wakasiaka (PhD)

Nambari ya simu:+254727438359

Barua pepe:swakasiaka@gmail.com

Anwani ya eneo: Idara ya Uuguzi, Chuo Kikuu cha Nairobi, kitivo cha sayansi ya afya, chuo kikuu cha KNH.

3. **Kamati ya maadili na Utafiti ya KNH/UoN**

Dr. Beatrice Amugune

Katibu, KNH/UoN ERC

Nambari ya simu: +254 722 802 074

Ugani wa simu: 44102

Barua pepe: knhuonerc@uonbi.ac.ke

Anwani ya eneo: Idara ya maduka ya dawa, Chuo Kikuu cha Nairobi, kitivo cha sayansi ya afya, chuo kikuu cha KNH.

Appendix iv: Fomu ya Idhini

Ninathibitisha kwamba nina ufahamu kamili wa utafiti unaofanywa, pia ninathibitisha kuwa nimesoma na kuelewa karatasi ya maelezo iliyotolewa na mpelelezi wa utafiti/msaidizi wa utafiti ameniarifu kuhusu asili, mchakato, mwenendo, manufaa na hatari zinazoweza kutokea za utafiti huu.

Pia ninafahamu kuwa ushiriki wangu katika utafiti huu ni wa hiari na ninaweza kujiondoa katika kushiriki iwapo nitapenda hivyo. Pia ni katika ufahamu wangu kwamba maelezo nitakayotoa yatakuwa ya siri na kwamba matokeo ya utafiti huu yatachakatwa bila kujulikana. Nimepewa muda wa kutosha kuuliza maswali kuhusu utafiti huu na kujitangaza kuwa tayari kushiriki katika utafiti huu

Ninakubali kushiriki katika utafiti

Sahihi..... Tarehe

Mimi (mchunguzi/msaidizi wa utafiti)

nathibitisha kwamba nimemweleza mshiriki kwa uwazi asili, mchakato, manufaa na hatari inayoweza kutokea ya utafiti. na yaliyomo katika fomu hii ya idhini kwa maelezo na kwamba mshiriki ameamua kushiriki kwa hiari bila shuruti au shinikizo lisilofaa.

Mtafiti/ Msaidizi wa Utafiti

Sahihi.....

- a. Chemotherapy { }
- b. Chemo radiotherapy { }
- c. Radiotherapy { }
- d. Survivorship care { }

14. What is the level of patient’s performance level (ECOG score)

descriptive	Score	tick
Fully active; no performance restrictions, (able to perform activities of daily living independently)	0	
Strenuous physical activity restricted; fully ambulatory and able to carry out light work.	1	
Capable of all self-care but unable to carry out any work activities. Up and about >50% of waking hours.	2	
Capable of only limited self-care; confined to bed or chair >50% of waking hours.	3	
Completely disabled; cannot carry out any self-care; totally confined to bed or chair.	4	

SECTION TWO: AWARENESS AND UPTAKE OF PALLIATIVE CARE SERVICES FOR PATIENTS WITH ADVANCED CANCER.

a. Awareness of palliative

15. Have you ever heard of palliative care

choices	tick
yes	
no	

16. If yes, from where did you get information about it. Tick all that apply

Choices	Tick
I have personally received palliative care	
From your doctor	
From your nurse	
From another care provide outside CTC	
From a Friend	
From the Media	
Read about it online	
From the family member	

17. What do you think or believe of palliative care, tick all that apply

Choice	tick
The goal of palliative care is to address any psychological issues brought up by serious illness	
Palliative care can help people manage the side effects of their medical treatment	
Palliative care is exclusively for people who are in the last stages of life	
A goal of palliative care is to help people better understand their treatment options	
Palliative care encourages people to stop treatments aimed at curing their illness	
A goal of palliative care is to improve a person's ability to participate in daily activities	
Palliative care helps the whole family cope with a serious illness	
Palliative care helps to improve the quality of life of the patients	
When people receive palliative care, they must give up their other doctor	
People must be in the hospital to receive palliative care	

18. When should people/patients receive palliative care?

choice	tick
Any time during the disease	
At the time of diagnosis	
At the time of death	
At the time of death	
Don't know	

b. Uptake of palliative care.

19. Have you ever been seen by a palliative care doctor or nurse for your routine cancer care?

Choice	tick
Yes	
No	

20. If yes to the question above, how did you get to go for the service

Choice	Tick
Referral by the attending oncologist	
Self-referral to palliative care	
Recommendation by a family member	
Recommendation by another care provider	
Recommendation by a friend	

21. Please complete the table below about the supportive therapies you have used in relation to your cancer? (Tick all that apply)

Health service	Tick here for the service received
Nutritional counselling	
Physical therapy	
Spiritual counselling	
Financial counselling	
Wound care	
Individual psychosocial counselling	
Pain management (Palliative care consultation)	
Cancer support group	
Cancer treatment symptom management	
Survivorship care	
Psychiatric consultation	
Cancer rehabilitation	
Sexual counselling	

22. If yes to any of the services above, where did you receive the service

- a. Cancer treatment Center { }
- b. Was referred to the palliative clinic { }
- c. Was referred to relevant specialist clinic { }
- d. Different facility other than KNH { }
- e. At home { }

23. If yes to any of the services, when did you start receiving these services

- a. Less than a month ago
- b. One to three months ago
- c. Four to six months ago
- d. Over 6 months ago

24. If you ticked any of the above services, how often do you use the services

- a. once
- b. Monthly
- c. Scheduled visit

25. If you have used any of the services listed above, how satisfied are you with this palliative and supportive care services in helping you deal with the impact of cancer or its treatment?

Tick one that applies to your level of satisfaction

Scale	Very unsatisfied	Dissatisfied	Neither dissatisfied or satisfied	Satisfied	Very much satisfied
Tick where applicable					

SECTION THREE: PERCEIVED BARRIERS TO UPTAKE OF PALLIATIVE CARE.

Instruction

What are some of the difficulties you experience that could possibly hinder you from using palliative care with your standard cancer care.

Perceived barrier	agree	disagree
Time limitations		
Accessibility of services		
Money for consultation fee/ expenses.		
Lack of means of transport/ fare		
Lack of referral from oncology physicians		
Lack of palliative care awareness and Knowledge on palliative care		
Patient's lack s capacity to make decision on goals of care		
Stigma and discrimination		
Lack of family awareness on palliative care		
Reluctance of family to be referred		
Language barriers		
Any other, specify		

Appendix viii: Approval letter from KNH-UON ERC



UNIVERSITY OF NAIROBI
FACULTY OF HEALTH SCIENCES
P O BOX 19615 Code 00202
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Twitter: https://twitter.com/UONKNH_ERC



KENYATTA NATIONAL HOSPITAL
P O BOX 20723 Code 00202
Tel: 720399-9
Fax: 725272
Telegrams: MEDSUP, Nairobi

30th August



Ref: KNH-ERC/A/459

Solomon Mirera Omare
Reg. No. H5640511/2021
Dept. of Nursing Sciences
Faculty of Health Sciences
University of Nairobi

Dear Solomon,

ETHICAL APPROVAL-RESEARCH PROPOSAL: AWARENESS AND UPTAKE OF PALLIATIVE CARE SERVICES AMONG PATIENTS WITH ADVANCED CANCER ATTENDING KENYATTA NATIONAL HOSPITAL (P421/04/2023)

This is to inform you that KNH-UoN ERC has reviewed and approved your above research proposal. Your application approval number is P421/04/2023. The approval period is 30th August 2023 –29th August 2024.

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 KNH-UoN ERC.
- 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 KNH-UoN ERC 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 KNH-UoN ERC within 72 hours.
- v. Clearance for export of biological specimens must be obtained from relevant institutions.
- vi. Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. Attach a comprehensive progress report to support the renewal.
- vii. Submission of an executive summary report within 90 days upon completion of the study to KNH-UoN ERC.

Protect to discover

Prior to commencing your study, you will be expected to obtain a research license from National Commission for Science, Technology and Innovation (NACOSTI) <https://research-portal.nacosti.go.ke> and also obtain other clearances needed.

Yours sincerely,



PROF. BEATRICE K.M. AMUGUNE
SECRETARY, KNH- UoN ERC

c.c. The Dean, Faculty of Health Sciences, UoN
The Senior Director, CS, KNH
The Chairperson, KNH- UoN ERC
The Assistant Director, Health Information Dept., KNH
The Chair, Dept. of Nursing Sciences, UoN
Supervisors: Prof. Samuel Kimani, Dept. of Nursing Sciences, UoN
Dr. Sabina Wakasiaka, Dept. of Nursing Sciences, UoN


Protect to discover

Appendix ix: Approval to collect Data from KNH Research department.

Appendix x: Research Permit from NACOSTI

REPUBLIC OF KENYA
NATIONAL COMMISSION FOR SCIENCE, TECHNOLOGY & INNOVATION
Ref No: 699776
Date of Issue: 11 September 2023

RESEARCH LICENSE




This is to Certify that Mr. SOLOMON Mwiru OMARE of University of Nairobi, has been licensed to conduct research as per the provision of the Science, Technology and Innovation Act, 2015 (Rev.2014) in Nairobi on the topic: Awareness and uptake of palliative care among patients with advanced cancer attending care at Kenyatta National Hospital for the period ending 11/September/2024.

License No: NACOSTI/P/25/29387

Applicant Identification Number: 699776

Director General
NATIONAL COMMISSION FOR SCIENCE, TECHNOLOGY & INNOVATION

Verification QR Code



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See overleaf for conditions

THE SCIENCE, TECHNOLOGY AND INNOVATION ACT, 2013 (REV. 2014)
Legal Notice No. 108: The Science, Technology and Innovation (Research Licensing) Regulations, 2014

The National Commission for Science, Technology and Innovation, hereafter referred to as the Commission, was established under the Science, Technology and Innovation Act 2013 (Revised 2014) herein after referred to as the Act. The objective of the Commission shall be to regulate and assure quality in the science, technology and innovation sector and advise the Government in matters related thereto.

CONDITIONS OF THE RESEARCH LICENSE

1. The License is granted subject to provisions of the Constitution of Kenya, the Science, Technology and Innovation Act, and other relevant laws, policies and regulations. Accordingly, the licensee shall adhere to such procedures, standards, code of ethics and guidelines as may be prescribed by regulations made under the Act, or prescribed by provisions of International treaties of which Kenya is a signatory to
2. The research and its related activities as well as outcomes shall be beneficial to the country and shall not in any way:
 - i. Endanger national security
 - ii. Adversely affect the lives of Kenyans
 - iii. Be in contravention of Kenya's international obligations including Biological Weapons Convention (BWC), Comprehensive Nuclear-Test-Ban Treaty Organization (CTBTO), Chemical, Biological, Radiological and Nuclear (CBRN).
 - iv. Result in exploitation of intellectual property rights of communities in Kenya
 - v. Adversely affect the environment
 - vi. Adversely affect the rights of communities
 - vii. Endanger public safety and national cohesion
 - viii. Plagiarize someone else's work
3. The License is valid for the proposed research, location and specified period.
4. The license any rights thereunder are non-transferable
5. The Commission reserves the right to cancel the research at any time during the research period if in the opinion of the Commission the research is not implemented in conformity with the provisions of the Act or any other written law.
6. The Licensee shall inform the relevant County Director of Education, County Commissioner and County Governor before commencement of the research.
7. Excavation, filming, movement, and collection of specimens are subject to further necessary clearance from relevant Government Agencies.
8. The License does not give authority to transfer research materials.
9. The Commission may monitor and evaluate the licensed research project for the purpose of assessing and evaluating compliance with the conditions of the License.
10. The Licensee shall submit one hard copy, and upload a soft copy of their final report (thesis) onto a platform designated by the Commission within one year of completion of the research.
11. The Commission reserves the right to modify the conditions of the License including cancellation without prior notice.
12. Research, findings and information regarding research systems shall be stored or disseminated, utilized or applied in such a manner as may be prescribed by the Commission from time to time.
13. The Licensee shall disclose to the Commission, the relevant Institutional Scientific and Ethical Review Committee, and the relevant national agencies any inventions and discoveries that are of National strategic importance.
14. The Commission shall have powers to acquire from any person the right in, or to, any scientific innovation, invention or patent of strategic importance to the country.
15. Relevant Institutional Scientific and Ethical Review Committee shall monitor and evaluate the research periodically, and make a report of its findings to the Commission for necessary action.

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Innovation(NACOSTI),
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