THE PRACTICE OF ADVANCE CARE PLANNING AMONG AMBULATORY CANCER PATIENTS RECEIVING TREATMENT AT KENYATTA NATIONAL HOSPITAL

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A DISSERTATION SUBMITTED IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTER OF MEDICINE IN INTERNAL MEDICINE.

STUDENT DECLARATION

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ABBREVIATIONS AND ACRONYMS

ACP	Advance Care Planning
AD	Advance Directives
AIDS	Acquired Immunodeficiency Syndrome
CPR	Cardiopulmonary Resuscitation
DPOAH	Durable power of attorney for health
HIV	Human Immunodeficiency Virus
HPV	Human Papilloma Virus
IBM	International Business Machines
KEHPCA	Kenya Hospices and Palliative Care Association
KNH	Kenyatta National Hospital
KHSSP	Kenya Health Sector Strategic and Investment Plan
MDT	Multidisciplinary Team
NCD	Non-communicable disease
SPSS	Statistical Package for the Social Sciences
USA	United States of America

DEFINITIONS OF TERMS

Advance care planning: is an iterative process through which adults at any stage of health have conversations with healthcare workers that aid in understanding their values, preferences and goals regarding future medical care and thus align healthcare provision with these goals and preferences.

Advance directives: Written instructions regarding medical preferences that take effect when patients lose their decision-making capacity. There are two kinds of documents that serve as advance directives: the durable power of attorney for health and the living will.

Cancer patient: A person receiving medical treatment for a malignant growth or tumour.

ABSTRACT

Background: Advance care planning (ACP) is of relevance in the outpatient cancer population. Insight into the current practice of ACP canidentify high priority areas to direct interventions aimed at improving the process. This study aimed to assess the current practice of ACP in the ambulatory cancer units of a Kenyan hospital.

Objective: To assess the practice of ACP among ambulatory cancer patients at Kenyatta National Hospital (KNH).

Methodology: This was a descriptive cross-sectional mixed method study conducted in the outpatient oncology clinics at KNH. The study tools were:interviewer administered questionnaire and in-depth interviews of key informants.

Results: We recruited 387 participants (78.55% females) for the quantitative arm of the study and conducted 27 in-depth interviews. Most participants agreed that it was important to discuss end-of-life wishes with family (89.4%) and doctors (90.96%) and to record wishes in an advance directive (67.44%). Few had discussed end-of-life wishes with family (28.68%); with doctors (19.63%); appointed a surrogate decision maker (27.13%); completed an advance directive (1.55%) and discussed life expectancy with a doctor (27.39%). Among those who had not participated in ACP, most were willing to discuss life expectancy (71.9%); discuss end-of-life wishes with family (81.2%) and a doctor (85.1%); complete an advance directive (68%); and appoint a surrogate decision maker (75.9%) in the next one month. There was a high rate of documentation of ACP discussions in participants medical records (88.89%).A knowledge gap on the concept of ACP was noted but participants demonstrated positive attitudes towards ACP with a preference for family involvement. Doctors were the most preferred to initiate ACP discussions. Factors that positively correlated with uptake of ADs included- ECOG status, how well a patient understood their cancer diagnosis, discussion with family and with doctors.

Conclusion: A discrepancy exists between the documentation of ACP discussions in participants medical records and self-reported participation in ACP activities pointing to a gap in the current practice of ACP.

CHAPTER ONE: INTRODUCTION

1.1 Background Information

Advance Care Planning (ACP) is an iterative process through which adults at any stage of health have conversations with healthcare workers that aid in understanding their values, preferences and goals regarding future medical care and thus align healthcare provision with these goals and preferences[1]. The processes of ACP may lead to documentation of these preferences and instructions in legal documents known as advance directives; with the healthcare proxy designation also known as a durable power of attorney for healthcare and the living will serving as the primary instruments for documentation of advance directives. Advance directives are effected only when a person becomes incapacitated and thus unable to make decisions on their own[1].

Undertaking ACPs confers benefits to the individual, the family as well as the health care professionals. In the case of the individual, these include: increasing a person's autonomy, receiving treatment based on the person's preferences, improved quality of life and higher satisfaction with the level of care at the end of life as well as reducing the healthcare costs at the end of life. For family members: it decreases their decisional burden, and eases stress, anxiety and depression experienced after death among other outcomes. It also decreases healthcare workers' moral distress and ethical dilemmas encountered in end-of-life care[2].

Cancer ranks as the third leading cause of death in Kenya with about 32,987 cancer deaths recorded in 2018[3], yet there is a paucity of data on the practice of ACP and uptake of advance directives. The unmet need for palliative care remains huge with about 14,552 Kenyans accessing these services of the 800,000 in need of it[4]. The national healthcare budget has stagnated between 5.5% and 9.5% which is lower than the recommended 15% outlined in the Abuja declaration[3]. These aspects indicate a need to understand the practice of ACP among cancer patients in a bid to develop culturally sensitive initiatives that could improve uptake and aid in realizing the benefits associated with ACP processes in the context of a low resource set-up.

This study assessed the practice of ACP and determined the uptake of advance directives among ambulatory cancer patients at the Kenyatta National Hospital.

1.2 Problem Statement and Justification

The uptake of ACP and advance directives among cancer patients at Kenyatta National Hospital remains low despite ACP and advance directives being stipulated as part of standard practice in the National Palliative Care Guidelines 2013 and being part of the Kenya Palliative Care Policy 2021–2030. Much is unknown about the practice of ACP among ambulatory cancer patients despite them being particularly relevant to oncology.

Previous studies have elucidated that the low uptake may be related to religious and cultural factors, race, ethnicity, lack of governing laws, economic status, level of education and physician inertia[5]. This study will bridge the existing knowledge gap in the practice of ACP and the uptake of ADs among ambulatory cancer patients at Kenyatta National Hospital. The results will form a basis to guide strategies for early implementation of ACP and advance directives and improve knowledge delivery and advocacy for increased utilization of advance directives. In resource-limited settings with a growing burden of cancer, increased uptake of advance directives has the potential to reduce the cost of end-of-life care as well as to improve the quality of care at the end of life for cancer patients.

1.3 Research Question

What is the practice of advance care planning among ambulatory cancer patients at Kenyatta National Hospital?

1.4 Objectives

1.4.1 Broad Objective

To assess the practice of advance care planning and uptake of advance directives among ambulatory cancer patients at Kenyatta National Hospital.

1.4.2 Primary Objectives

i) To determine the proportion of patients who have adopted advance directives among ambulatory cancer patients at Kenyatta National Hospital.

ii) To evaluate the proportion of ambulatory cancer patients participating in advance care planning discussions at Kenyatta National Hospital.

iii) To explore the knowledge, attitudes, preferences and perceived importance of advance care planning among ambulatory cancer patients at Kenyatta National Hospital.

1.4.3 Secondary Objectives

To determine factors associated with uptake of advance directives among ambulatory cancer patients at Kenyatta National Hospital.

CHAPTER 2: LITERATURE REVIEW

2.1 Overview and Epidemiology of Cancer in Kenya

Cancer is a large group of diseases characterized by the development of abnormal cells that divide uncontrollably, go beyond their usual boundaries to invade adjoining parts of the body and/or spread to other organs [6].

Cancer is ranked as the third leading cause of death in Kenya following infectious and cardiovascular diseases. Between 2012 to 2018, the annual incidence of cancer rose from 37,000 to 47,887 cases [7]. Altogether, annual cancer deaths rose from 28,500 to 32,987 during the same period, representing an almost 16% increase in mortality [7]. Cases of cancer are expected to rise by more than 120% in the next 20 years [3]. The rising cancer incidence particularly notable in the ageing population may be attributable to several factors including the adoption of unhealthy lifestyles, an increase in life expectancy, and an improvement in diagnostic capabilities and reporting systems [3].

About 70–80% of cancer cases in our set-up are diagnosed late because of ignorance, shortage of adequate facilities to aid in the diagnosis, the high cost of medical services including diagnostic as well as treatment facilities and high poverty levels [8]. The top five causes of cancer in Kenya are breast, cervical, prostate, oesophageal and colorectal cancer. Cervical cancer accounts for the highest number of cancer deaths followed by breast, oesophageal, colorectal and prostate cancers [3].

The following are risk factors associated with cancer in Kenya – genetic predisposition, behavioural factors (smoking, alcohol use), physical inactivity, environmental carcinogens (e.g., asbestos) and infections (viral infections – HPV, Hepatitis B and C virus, HIV; bacterial infections – *Helicobacter pylori*)[9].

2.2 General Principles of cancer management

The Kenya National Cancer Treatment Protocols 2019 outlines four key principles of cancer management[7]. First, a multidisciplinary team of clinical and non-clinical staff is required for comprehensive management of cancer from pre-treatment assessment to rehabilitation and beyond. This team comprises oncologists, physicians, surgeons, dermatologists, pathologists, nurses, dieticians and palliative care specialists among others based on the cancer type and management plan. Second, early diagnosis and timely referral of patients to the appropriate health facility where required services are available. Recommended timelines include immediate referral within hours for oncological emergencies, urgent referrals (within 14 days) from time of referral to patient assessment at a cancer centre and a 31-day standard from the time of diagnosis to treatment including cases of recurrent disease. Third, communication between the patient and the medical team. Communication ought to be clear and concise. Patients should be made aware of their diagnosis, multidisciplinary team discussions, clinic appointments, treatment plan, reviews, prognosis, decisions on change of care plans and end-of-life planning. Fourth, assessment and management encompassing several stages: assessment and diagnosis, MDT meeting, treatment planning, pre-treatment assessment, treatment (options may include surgery, chemotherapy, radiotherapy, supportive care, palliative care, rehabilitation), follow up and surveillance.

2.3 Advance Care Planning

ACP is "a process of assessment and person-centred dialogue to establish an individual's needs and goals of care and if a person wishes to document these preferences for future care and treatment before losing decisional capacity" [10]. This process may encompass documentation of care goals in a legal document or the appointment of a surrogate decision maker though this is not the principal goal of ACP discussions.

ACP discussions should match a patient's readiness to talk about their medical care and should be reviewed with changing life circumstances and health status. These discussions should consider sociocultural aspects and the patient's relationships as these are key drivers of specific decisions [11].

Advance directives are written instructions regarding medical preferences that take effect when patients lose their decision-making capacity. There are two kinds of documents that act as advance directives: the durable power of attorney for healthcare/ healthcare proxy designations and the living will [11].

ACP is of utility and helps make certain that patients get the care that is in line with their preferences, it also guides the family and thus reduces their decisional burden about whether they are adhering to these preferences. It reduces the moral distress and ethical dilemmas among healthcare providers as well [11].

ACP has significantly improved multiple outcomes in end-of-life care. These include increased completion rates of ADs [12,13], a higher likelihood that clinicians and families know and comply with patient wishes [12], lower rates of end-of-life hospitalization [14], receipt of less intensive treatments at the end of life [14], higher rates of utilization of hospice services [14], increased likelihood that patients will die at their place of choice [15], contentment with the quality of care [15], reduced levels of stress, depression and anxiety in surviving relatives of deceased persons [12], and reduction in the cost of care without increasing mortality[14].

2.3.1 Engagement in Advance Care Planning

There is increased awareness of the complexity of the processes that go into the end of life decisions. ACP discussions are not just focused on the completion of advance directives, but discussions centred around educating patients on their health problem/ diagnosis, treatment options, prognosis and eliciting their values and preferences and aligning these with healthcare goals. These discussions are also a function of relational, emotional and social factors and are undertaken in the context of a longitudinal relationship between the patient, their families and the healthcare team [16].

Engagement in ACP discussions among cancer patients is still low. Waller et al conducted a cross-sectional study among a heterogenous group of medical oncology outpatients and noted that only 11% had discussed their wishes with a doctor, despite 66% of those who had not engaged in ACP discussions reporting that they were willing to take part in ACP discussions [16].

Bar-Sela et al, 2020 in a cross-sectional study that applied both quantitative and qualitative methods to assess the perceptions and attitudes of Israeli cancer patients with regards to ACP found that 45% of their study population completed ACP documents. These patients noted that the key enabling factors for ACP completion were gaining access to information (80%), and free communication with their family members (67%) and medical staff (78%). The main purpose of the completion of ACP documents was to ensure that sound medical decisions would be made

(88%) and avoid unwarranted medical procedures (69%). Among the group that failed to complete ACP forms, it was stated that not having a close enough relative who would accept the obligation to make decisions as well as the timing (most of these patients were younger and had hope that they would beat cancer) and the ability to have faith in close relatives were key barriers[17]. These findings underscore the importance of engagement of the various stakeholders in the ACP process in facilitating decision-making on end-of-life care preferences.

2.3.2 Uptake of Advance Directives

In a systematic review of studies that were published in the period 2011-2016 to determine the proportion of US adults with completed advance directives (defined as a living will, healthcare power of attorney or both); among 795,909 people in the 150 studies under review, 36.7% had completed advance directives[18]. 29.3% of adults in this study had living wills. There was no significant difference in the rates of completion of ADs between patients (38.2%) and healthy adults (32.7%). Of note is that 63.6% of the study population was female, 80.6% were 65 years and older, 65.1% were white, and 62.6% were nursing home residents. These findings may have been due to the large-scale educational programs as well as legal efforts aimed at promoting the completion of advance directives in this population [18].

In a prospective multicentre study in Australia conducted among older adults aged 65 and above, 29.8% of the patients had completed advance directives. It was noted that greater functional impairment and residing in an aged care facility correlated with higher advance directive completion rates [19]. The rates of completion of advance directives among the general population in Germany are much lower at around 10% and 2% among the Spanish population [20]. The rates of completion of advance directives are lower in other countries with rates of 0.5% in Hong Kong and 7% in the adult population of the Netherlands [21,22].

Numerous studies have been conducted on various dimensions of advance care planning and advance directives in patients with cancer with notable differences in the findings from those seen in population-based studies on the uptake of ACP and advance directives. Amol et al reviewed data from the Health and Retirement Study in the USA between 2000 and 2012 on the trends of ACP in patients with cancer. There was an increase in the use of the durable power of attorney assignments from 52% to 72% without a significant change in the use of living wills

(49% to 40%) or end-of-life discussions (68% to 60%) [23]. Kubi et al, 2020 noted that of the inpatient cancer patients with solid tumours in both medical and surgical units recruited in their study, only 50.5% had completed an advance directive despite 91.5% of the study participants reporting that having a written advance directive was of utility [24]. Berkowitz et al in a retrospective cross-sectional study that reviewed data from 2 cohorts of patients referred for palliative care dichotomized as those with cancer and those without cancer noted that patients with a cancer diagnosis were less likely to be DNR/DNI status (37% vs 53%) and were less likely to have a completed advance directive (53% vs 73%); however, rates of surrogate decision makers were similar (92.8% vs 94.5%) [25].

In a retrospective survey that reviewed 216 medical records of terminally ill patients at a tertiary healthcare facility in Kenya, Omondi et al found a prevalence of 41.2% of advance directives in this study population [26]. The high AD completion rates in this private healthcare setting were attributed to the fact that an institutional policy on ACP and AD existed at this facility as well as records under review being those of terminally ill patients in whom a palliative care consult was most likely sought [26].

The differences in uptake of advance directives across different countries can be accounted for by differences in cultural practices and economic status. The presence of laws governing advance care planning in a country may also significantly improve the uptake of advance directives. The factors that correlate with an individual's uptake of advance directives are diverse and include the patient, cultural, institutional, legal, caregiver and religious factors [5].

Lovell et al in a systematic review of studies majority of which were drawn from the United States and the United Kingdom summarize factors that positively correlate with the signing of ADs in palliative care as a being diagnosed with cancer, older age, white race, college education, past illness, an individual's knowledge and attitude, laws on ADs, accessibility of hospice care and specialist palliative care treatment [5].

Being African American, concerns about completion of ADs resulting in the withdrawal of care, having dementia, failure to acknowledge death and dying, having dependent children, and lack of laws that facilitated AD were key barriers to the uptake of advance directives[5]. The presence of a religious conviction may increase the likelihood of not wanting to complete an AD [21].

Omondi et al noted that having a discussion on AD with a patient's caregiver and patients' functional impairment were the only factors with a statistically significant association with completion of AD. Other factors that were noted to be associated with AD completion though failed to meet statistical significance on the multivariable analysis included a history of endotracheal intubation and a speciality team taking care of the patient. It is worth noting that certain findings from this study were different from those seen in previous studies from other setups; for instance, there was no association between a terminally ill patient having a diagnosis of cancer and AD completion and neither an association between the family dynamic (being a patients marital status and whether they had children or not) and completion of AD. Because this was a retrospective study, other factors that affect AD completion like knowledge and attitude could not be assessed. The study could not elicit patients' involvement in the AD discussions which further strengthens the need for a prospective study. It is also worth noting that the study participants were well-educated, middle and high-class clients, most of whom had insurance cover and may thus not have been representative of the Kenyan population [26].

2.3.3 Knowledge of Advance Care Planning

A paucity of knowledge on ACP and advance directives has been identified as a consistent factor affecting uptake [5]. Kermel-Schiffman and Werner et al, 2017 in a systematic literature review noted that research participants in 17 studies (45.9%) were partially knowledgeable about advance directives and demonstrated knowledge deficits for other aspects of ACP. It is worth noting that only seven studies (18.9%) reported moderate to high levels of knowledge regarding ACP as a whole [2].

Ayman Barakat et al, 2013, conducted a study on knowledge and documentation of ACP in hospitalized cancer patients in the US and found that 97% of the study participants knew what a living will was [27]. There is a positive association between the level of knowledge and increased uptake of ACP. Sittisombut et al, 2008 reported a reduced preference for cardiopulmonary resuscitation after information was put forward to terminally ill patients in the medical inpatient unit [28]. Thus notable that lack of knowledge is a key barrier to the uptake of ACP and advanced directives completion. Factors associated with levels of knowledge include age, ethnicity, religion, and education [2].

Across the world, there has been growing interest in the field of ACP in recognition of its potential benefits. Yet there is a paucity of studies examining the domain of knowledge on ACP and advance directives. This may be due to the relative infancy of the concept of ACP in various countries as well as the legal status of ACP with only a few countries implementing laws to govern ACP; the changing dimensions in the conceptual definition of ACP over the years and the lack of universally acceptable tools to aid in the measurement of knowledge [2].

2.3.4 Attitudes and Preferences on Advance Care Planning

Toguri et al, 2020 noted that nearly all patients and family members demonstrated a positive attitude toward ACP in a study that assessed the views of patients with advanced cancer, oncologists and families on initiating and engaging in ACP. On the timing of ACP discussions, the majority of the participants stated that ACP should occur soon after the cancer diagnosis was made. Participants expressed their belief that it was the physician's responsibility to initiate ACP discussions. Participants also preferred to know their prognosis at an earlier stage. Aspects of care considered especially important were early access to palliative care services and the prospect of transitioning care to a home-based setting [29].

Kubi et al, 2020 in a cross-sectional survey on patient preferences for personnel and timing of ACP discussions noted that 43.5% of cancer patients preferred to have ACP discussions with their primary care practitioners and that only 7% selected their surgeon and 5.5% selected their oncologist as the preferred provider to engage in ACP discussions with; 94% of their study population noted a preference to have ACP discussions early before their prognosis worsened [24].

2.3.5 Legal Status of Advance Care Planning

The topic of advance care planning is relatively novel in many countries across the globe. In Brazil, living wills are governed by a resolution that was published by the Federal Council of Medicine in August 2012 [2]. In Israel, ACP is documented in the "dying patient act" (2005) and also promoted by the Health Ministry [17]. In Portugal, the national living will registry was legislated in July 2012 [2]; while in the US the Patient Self Determination Act was enacted in 1991 with a lot of public health initiatives to promote uptake of ACP including reimbursement of physicians who engage in ACP discussions [21,30].

Kenya does not have a law on ACP or advance directives and in cases where it is practised, it is usually under an institution's policy [26]. There has been increased recognition of the need to create a legal framework to set the stage for national implementation of advance care planning and advance directives as stated in the Kenya palliative care policy 2021–2030 (4).

The unmet need for palliative care in Kenya remains huge, with only 14,552 Kenyans accessing palliative care services of the 800,000 who need it [4]. Since 2005, strategic partnerships between the Ministry of Health, The African Palliative Association and the Kenya Hospices and Palliative Care Association (KEHPCA) have attained significant strides in the implementation of palliative care services as part of Universal Health Care for the citizenry of Kenya [8].

One of the key achievements was the documentation of the first National Palliative Care Guidelines (2013) that included a section on end-of-life care thus providing healthcare providers with a framework for initiation of the much-needed end-of-life discussions. An excerpt from those guidelines stated: "*care providers shall discuss issues regarding advance directives with patients giving guidance as well as enquire about the presence of an ethical will*" [31] In October 2021, the Ministry of Health released the Kenya palliative care policy 2021–2030; establishment and implementation of guidelines on end of life care, advance directives and DNR requests have been identified as key action points in the spectrum of palliative care [4].

National policies that have aided the integration of palliative care as part of the healthcare system have been documented in national policies, health plans, guidelines and strategies [8]. Of note are the following policy documents that have included palliative care as a fundamental component with guidelines on end-of-life care being stipulated in most of them:

i. National Strategy for Prevention and Control of Non-communicable Diseases 2015–2020
ii. National Palliative Care Guidelines 2013
iii. Cancer Prevention and Control Act
iv. National Guidelines for Cancer Management
v. The First Cancer Management Guidelines
vi. Legal Aspects in Palliative Care
vii. Kenya Palliative Care Policy 2021–2030

The KEHPCA inculcated legal aspects into its program through partnering with the Kenya Legal and Ethical Issues Network for HIV and AIDS among other human rights bodies. These programs have trained healthcare providers as paralegals and thus established a network of over 300 pro bono staff who have played a key role in assisting patients and their families seeking guidance on end-of-life issues like making of a will, and power of attorney and patients' rights. They have also sensitized lawyers on the key end-of-life issues and thus aided in establishing a referral system for patients who may need legal services in documenting ADs. An array of educational pamphlets by KEHPCA on ACP have been a notable effort in bridging the knowledge gap that exists [32].

Ethical issues may arise during the implementation of ACP. The most common ethical framework for reasoning is called "principlism" after four guiding principles in medical ethics [11]—autonomy (respecting patients' right to take part in making decisions), beneficence (directs clinicians to act in the patient's best interest), non-maleficence (directs clinicians to do no harm) and justice (all people must be treated fairly and have equitable distribution/ utilization of health resources).

In the current healthcare system, these four principles are insufficient in guiding medical decision-making. This is due to several factors and advances in the field of medicine including advances in medical technology that may provide life-sustaining interventions, a longer life expectancy even among patients with a high disease burden and functional impairment, and differences in individuals' needs as influenced by religion, culture, economic status and education and shifts in the medicolegal environments [11].

2.3.6 Relevance of Advance Care Planning

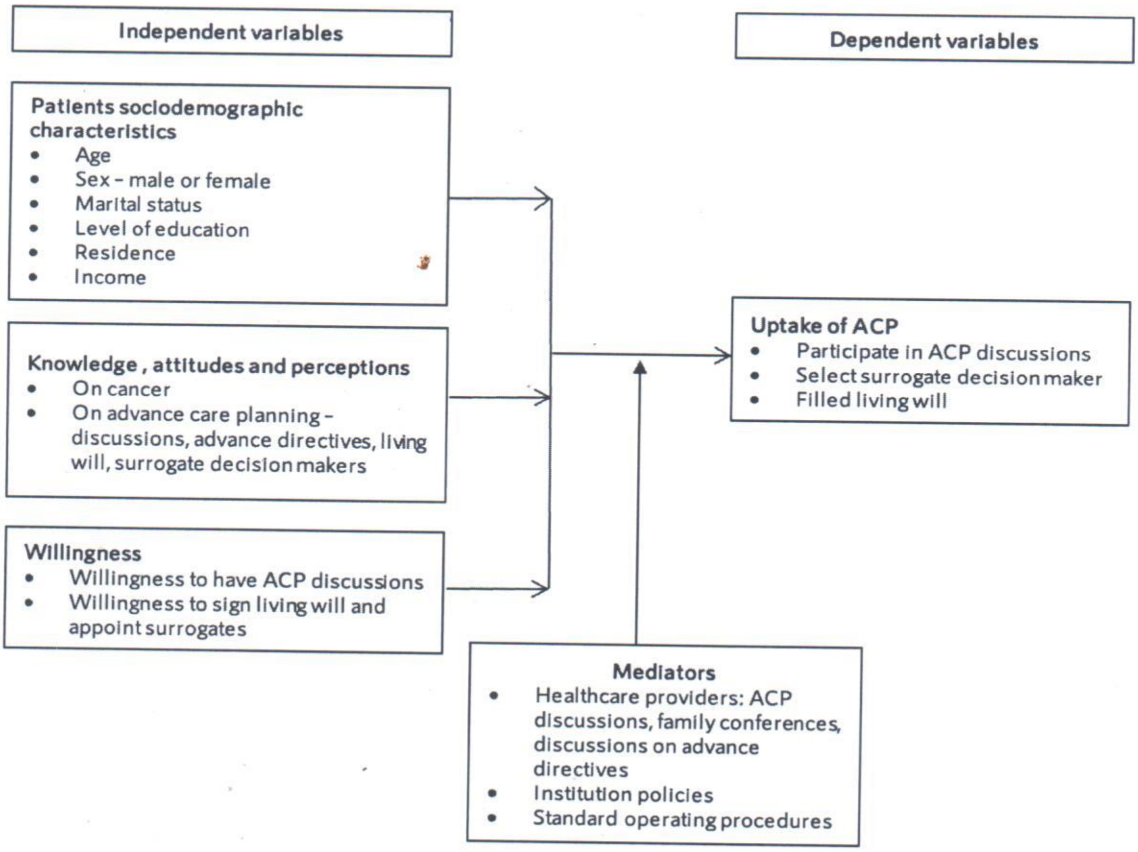
How relevant advance care planning and advance directives would be in a low-income set-up is a valid question and that of great concern. Healthcare systems that are already overstretched by the burden of disease and limited healthcare resources driven largely by the trends in healthcare financing that are subpar with international standards are the hallmark of most low-income countries. Thus, the question of whether these directives against which patients would sign could even be applicable in the first place given that critical aspects to facilitate the end of life care including critical care services are largely unavailable in most cases. Yet a counterargument can be made in that implementation of advance care planning may aid in the redistribution of limited healthcare resources to persons that may benefit most from them. Each year, approximately 40 million people need palliative care; 78% of them are residents of low- and middle-income countries [33].

The relevance of advance care planning in our setup can be drawn from a population-based street survey that examined preferences and priorities for end-of-life care in Kenya in 2014. It was noted that up to 51.1% of the study population chose home as their preferred place of death. Additionally, 61.4% of those interviewed preferred quality over quantity of life. In this study, 47.8% of the respondents said they would like to make decisions about their care if they had the decisional capacity while 55.7% preferred those medical decisions be made by a relative[34]. The results of this study underscore the importance of ACP in our set up despite socio-cultural practices, economic status, level of education and the fact that discussions on death and dying are frequently frowned upon in Africa, individuals still give thought to their end-of-life wishes. The findings of a qualitative study in South Africa further highlighted the relevance of ACP in Africa. "A vast majority of the study participants agreed that ACP was relevant in their local context including formalizing conversations and preferences through living wills and appointing proxy decision makers" [35].

In the context of the field of oncology where the uptake of ACP has been particularly high compared to other fields of medicine, there is an even greater need for ACP. Of note is the fact that nearly 70–80% of those diagnosed with cancer in our set-up present late [8] which confers a poorer prognosis with intent to palliation in such circumstances as opposed to intent towards cure or remission with an earlier presentation. It is thus particularly relevant to introduce ACP discussions early to elicit patients' own goals of care as opposed to waiting for crises such as critical care admissions or terminal illness to introduce advance care planning discussions.

It is worth noting that ACP discussion does not impacton the level of hope. Many healthcare practitioners defer ACP discussions, particularly when presented with cases of advanced cancer citing that these discussions might lead patients to lose hope at the end of life which is associated with adverse outcomes. Cohen et al, 2020 found that hope was equivalent among patients who had or had not completed the three important domains of ACP [36].

2.4 Conceptual Framework



CHAPTER THREE: METHODOLOGY

3.1 Study Design

The study used a descriptive cross-sectional mixed methods design. We applied both quantitative and qualitative methods. The use of both methods aided in achieving our study objectives. Quantitative data was collected from ambulatory cancer patients to determine the uptake of ADs, the rate of participation in ACP discussions, who should initiate ACP discussions, the prevalence of ACP documentation and willingness to participate in ACP activities.

Data collected through the quantitative arm of the study was triangulated with qualitative data collected through in-depth interviews of key informants, who included participants with the leading cancers in Kenya. The qualitative arm explored the participants' knowledge, attitudes and preferences for ACP as well as the perceived relevance of ACP, which helped to better understand the findings of the quantitative arm of study as well as provide insights into participants perspectives of ACP, which is key in strengthening the advanced care planning process especially in the study setting.

3.2 Study Setting

This study was conducted at the Kenyatta National Hospital Outpatient Oncology Clinics. KNH is a teaching and national referral hospital established in the year 1901. It is in Nairobi County, approximately three kilometres from the central business district. The medical oncology department has three specialist doctors who head a team of allied professionals. The outpatient medical oncology clinic is situated on the ground floor, clinic number 23. The outpatient medical oncology clinic runs every Monday and attends to about 80 to 100 patients (both new and old). The radio-oncology department has eight specialist doctors. The radio-oncology clinic is situated on the first floor of the old hospital at the cancer treatment centre and runs from Monday to Thursday. An average of 30 to 70 patients are seen daily at the outpatient clinic in the cancer treatment centre. KNH is the only public health facility where cancer patients can access comprehensive cancer treatment.

3.3 Study Population

Patients with an established diagnosis of cancer aged 18 years and above attending the outpatient oncology clinics at Kenyatta National Hospital.

3.4 Case Definition

A cancer patient was defined as a patient with any form of cancer confirmed by histology or cytology.

3.5 Inclusion and Exclusion Criteria

3.5.1 Inclusion Criteria

The study included:

i) cancer patients attending the oncology clinic at Kenyatta National Hospital and were on treatment or follow-up after completion of treatment
ii) respondents who were 18 years and above
iii) respondents who provided informed written consent

3.5.2 Exclusion Criteria

The study excluded:

i) Respondents who declined to give informed written consent
ii) Respondents who were too sick to participate in the interviews
iii) Persons with known psychiatric disorders

3.6 Sampling and Sample Size Estimation

3.6.1 For the Quantitative Study

The sample size for a single proportion was calculated using Cochran's formula for descriptive studies [37]:

$n = (Z2 \times P \times (1 - P))/e2$

Where:

- Z = value from standard normal distribution corresponding to desired confidence level ($Z=1.96$ for 95% CI)
- P is the expected true proportion
- e is desired precision (half desired CI width)

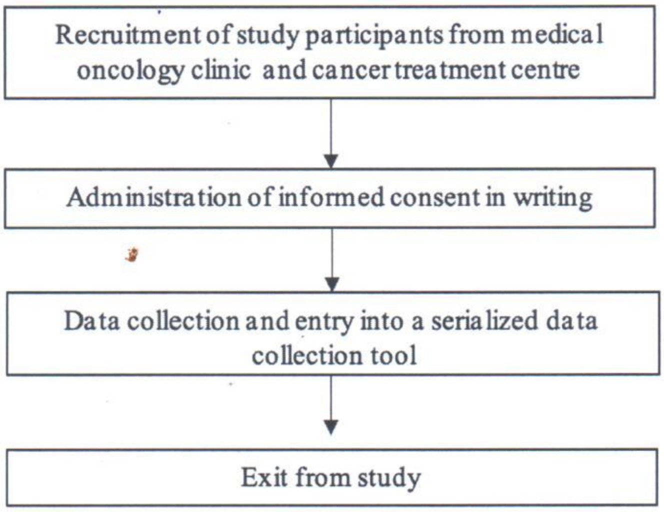
Based on the findings of a systematic review, an estimated proportion of patients with advance directives of 36.7% was used [18]. In addition, due to a small population of 3908 $({}^{7817}/{}_{2})$ /4296—the estimated number of cancer patients seen at the clinic—the sample was adjusted so that $n(adj) = (Nxn)/(N+n)$; where $n(adj)$ is the final adjusted sample size for the finite population, N is the finite population and n is the calculated sample for an infinite population. Thus, the final sample was estimated at 328/330 participants. After further adjustment of 10% to account for ineligible participants, the final sample was 363 participants.

Consecutive sampling was applied to recruit the study participants for the quantitative arm of the study. We recruited approximately 50 participants each week allowing the final sample to be met within the eight weeks of data collection.

3.6.2 Participants in the Qualitative Study

Purposive sampling was applied to select key informants for the qualitative arm of the study. The study targeted participants who had lived with cancer for at least one year, which made them have some level of experience with the disease and could provide insights that could help address the study objective on knowledge, attitude and preferences on ACP better. In addition the study sought to recruit participants from diverse socioeconomic and cultural backgrounds to promote inclusivity and minimise potential bias. We included participants who consented to undertake in-depth interviews regardless of cancer type. Overall, a minimum sample size of 40 participants was recruited to be interviewed to gain deeper insights into knowledge, attitude and preferences of advance care planning. In addition, collected data was analysed concurrently to ensure data saturation. In depth interviews were conducted over a period of eight weeks (designated for data collection). Of note is data saturation was detected after conducting 27 in depth interviews.

3.7 Flowchart of Quantitative Study Participants' Recruitment



3.9 Study Variables

3.9.1 Outcome Variables

The main outcome variables were the prevalence of ACP documentation, uptake of ADs, participation in ACP activities, knowledge, attitudes and preferences of ACP, perceived importance of ACP and willingness to participate in ACP discussions.

Participation in ACP activities was defined as the proportion of the study population who gave a "Yes" response to questions on participation in the activities in various domains of ACP.

Prevalence of ACP documentation was defined as the proportion of the study population with evidence of documentation of ACP discussions in their medical records either as a completed family conference document or other forms of documentation of ACP discussions.

The uptake of advance directives was defined as the proportion of the study population with either self-reported living wills or surrogate decision-makers.

The perceived importance of participating in ACP activities was defined as the proportion of the study population whose responses were "strongly agree" and "somewhat agree" to the questions assessing the perceived importance of ACP.

Knowledge, attitudes and preferences of ACP were elicited from in-depth interviews of key informants.

3.9.2 Baseline Characteristics

The baseline characteristics included age (respondent's age at the time of the study in completed years), sex (defined as researcher-observable sex, either male or female), diagnosis, stage and year of diagnosis, county of residence (as defined in the constitution of Kenya—at the time of the study), place of residence (urban or rural), religion, household income, level of education (highest level of education categorised as no formal education, primary, secondary, or tertiary level of education), and employment status (Employed (formal and informal), self-employed, unemployed or others e.g., retirement).

3.10 Data Collection Tool

A study proforma was used to collect data on demographic variables including age, gender, sex, marital status, religion and level of education from eligible participants.

A structured interviewer-administered questionnaire was used to obtain data on the perceived importance of participating in ACP activities, willingness to participate in ACP activities in the next one month, self-reported participation in ACP activities, and on who should initiate ACP discussions.

The data collection tool was adopted from a study by Amy Waller et al, based in a medical oncology outpatient set up in Australia [16] and was available in English and Kiswahili for the respondents. It contained five sections: **section A** which had one statement on self-reported health status in the past week, **section B** with four statements on the perceived importance of participating in ACP activities, **section C** with five statements on willingness to participate in ACP in the next month, **section D** with five statements on self-reported participation in ACP and **section E** with four statements on who should initiate ACP discussions.

A study proforma was used to record the documentation of ACP discussions in the participants' medical records. This was documented by either the presence of a completed family conference document, other forms of documentation or no documentation.

A semi-structured interview guide with relevant questions on knowledge, attitudes and preferences for ACP was used to guide the in-depth interviews. Data was collected by the principal investigator and a qualified qualitative research assistant trained in in depth interviews. This was conducted through face to face interviews lasting about 45-60 minutes. The in depth interviews were recorded using a voice recorder and a note taker documented important observations such as the participants mood and affect.

Being that questions on ACP and end-of-life were sensitive issues we had counselling services available for any of the participants who needed them at any point of the interviewing process with the provision to drop out of the interview process as per the participant's request.

3.11 Data Management

Quantitative data collected was entered into a Microsoft Excel sheet. Data Cleaning and analysis was done using SPSS version 25/25 statistical software for Windows (IBM). Cleaning involved checking and cleaning data in terms of duplicate records, missing values, internal consistencies, renaming variables and generating new variables.

Audio recordings from the in-depth interviews were transcribed and translated verbatim. Transcripts were reviewed and uploaded to Dedoose for analysis.

3.12 Data Analysis

Cleaned data was imported to SPSS version 25 for analysis. Frequencies and percentages were used to describe the respondents' baseline characteristics. Frequencies and percentages were used to describe self-reported participation in ACP, level of uptake of advance directives, the perceived importance of participating in ACP activities and willingness to participate in ACP. The Pearson Chi-square test of association and multivariable logistic regression were used to assess the association between respondents' characteristics and uptake of advance directives. Statistical significance will be considered at a $P<0.05$.

For the qualitative study, audio recordings of the in-depth interviews were transcribed and translated verbatim after each of the interviews. Transcripts were reviewed and uploaded to Dedoose for analysis. Two researchers—principal investigator and research assistant independently read and reread the transcripts to gain in-depth understanding of the interview. Each of the researchers then independently developed a codebook to guide the data analysis process. The codebooks were then be discussed, and a unified codebook agreed on for use in the analysis. Transcripts were then be coded line by line using both an inductive and deductive approach guided by the codebook. Emerging themes were reviewed and agreed on as analysis processes. The codebook was also updated as new codes were generated. After the analysis of all transcripts, themes and subthemes were constantly compared for similarities and differences until final themes and subthemes were agreed upon. The supervisors were involved at interval to provide feedback on emerging themes and subthemes. The final themes and subthemes were reported with illustrative quotes/excerpts.

3.13 Quality Assurance

Research assistants were trained on the tool to be used in this study through role play and simulation sessions. They were taught how to approach study participants, how to take informed consent, administer the questionnaire and maintain confidentiality throughout the data collection process.

The principal investigator held debrief meetings with the qualitative research assistant prior to commencement of data collection to review process of taking consent and patient confidentiality. The objectives of the qualitative arm of the study were rediscussed as well as the overall procedures to be conducted during the in depth interviews, data handling and review of recordings. Of note is no further training on conducting in depth interviews was warranted as the qualitative research assistant has background training in qualitative research with vast experience in qualitative research in the field of medicine.

3.14 Ethical Considerations

Approval was sought from the Department of Clinical Medicine and Therapeutics, the University of Nairobi (UoN) and the KNH/UoN Ethics and Research Committee. Thereafter, authorization was sought from the head of department oncology clinic to undertake research activities within the unit. Respondents were identified with the help of the oncology clinical team. Written and informed consent was obtained from study participants before administering the questionnaire.

Anonymity of the research participants was observed as we did not collect any identifier details from the participants like names and hospital numbers. Data collected was not used for any other purpose other than to meet study objectives. Data collected was stored in a safe box under lock and key and electronic data was password protected. The study proforma materials will be stored by the principal investigator for a period of 5 years.

The findings, conclusions and recommendations of this study will forwarded to the head of department, oncology unit after presentation of results to the Department of Clinical Medicine and Therapeutics.

CHAPTER FOUR: RESULTS

4.1 Descriptive statistics of practice of ACP at KNH

We screened and found a total of 400 participants who were eligible to participate in the quantitative study of whom 387 gave written consent and were enrolled. The interviews were conducted over 8 weeks (26 September 2022 to 11 November 2022).

4.1.1 Socio-demographic characteristics

Among the 387 participants interviewed, majority were females 78.5% (304/387) while 21.5% (83/387) were males. The ages ranged from 18 years to 92 years with a mean age of 51.6 years (S.D. 13.7). A total of 61 (15.8%) had attained tertiary education. 381 participants (98.5%) were Christians and 249 (64.3%) were unemployed with a majority of study participants reporting an estimated monthly income of <5,000 Kenya shillings (56.6%). 58.7% were of rural residence

Table 1: Baseline characteristics

Variable	Category	Number (n=387)	Percent (%)
Age (in years)	Mean (SD)	51.6 (13.7)	
	Median (IQR)	50 (43–62)	
	Range	18–92	
Gender	Male	83	21.5
	Female	304	78.5
Marital status	Not-in-a-union	129	33.3
	Married / in-a-union	258	66.7
Highest level of education	No formal education	12	3.1
	Primary	164	42.4
	Secondary	150	38.8
	Tertiary	61	15.8
Religion	Christian	381	98.4
	Muslim	5	1.3
	Traditional	1	0.3
Employment status	Employed	38	9.8
	Self employed	86	22.2

	Unemployed	249	64.3
	Other	14	3.6
Residence	Urban	160	41.3
	Rural	227	58.7
Estimated monthly income	<5000	219	56.6
	5000–10000	73	18.9
	10001–25000	58	15.0
	25001–50000	32	8.3
	>50000	5	1.3

4.1.2 Participants clinical characteristics

The most common cancer type was breast cancer (31.0%) followed by cervical cancer (22.5%) while 5.7% of the study participants had oesophageal cancer. Majority of study participants had early stage cancer (stage 0, 1, and 2) at diagnosis (47.8%) while 22.7% had locally advanced disease at diagnosis with 22.0% having had metastatic disease at diagnosis. Overall, 28.4% of participants had been diagnosed with cancer less than six months at the time we conducted the interviews while 24.8% of participants had been diagnosed more than two years prior to the time we interviewed them.

21.2% of the participants were at ECOG 0 functional status with a majority (60.0%) being at ECOG 1. Only 2 participants were at ECOG 4 performance status. It is worth noting that only 4.9% of the study participants reported that they understood their cancer diagnosis very well.

Table 2: Clinical characteristics of study participants

Variable	**Category**	**Number**	**Percentage (%)**
Diagnosis **(n=387)**	Breast cancer	120	31.0
	Cervical cancer	87	22.5
	Oesophageal cancer	22	5.7
	Colorectal cancer	20	5.2
	Lymphoma	16	4.1
	Prostate cancer	15	3.9
	Nasopharyngeal carcinoma	10	2.6

	Gastric cancer	10	2.6
	Ovarian cancer	8	2.1
	Leukemia	8	2.1
	Endometrial cancer	7	1.8
	Multiple myeloma	7	1.8
	Kaposis sarcoma	5	1.3
	Vulval cancer	3	0.8
	Pancreatic cancer	3	0.8
	Cholangiocarcinoma	3	0.8
	Meningioma	3	0.8
	Others	39	10.1
	I don't know	1	0.003
Months since diagnosis	<6 months	110	28.4
	≥6–12 months	111	28.7
	≥12–24 months	70	18.1
	≥24 months	96	24.8
Stage at diagnosis	Early	185	47.8
	Locally advanced	88	22.7
	Metastatic disease	85	22
	Not documented	29	7.5
Performance status (ECOG)	0	82	21.2
	1	232	60.0
	2	60	15.5
	3	11	2.8
	4	2	0.5
How well do you understand your cancer	Not at all	38	9.8
	A little	87	22.5
	A little more	79	20.4
	Averagely	110	28.4
	Well	54	14.0
	Very well	19	4.9

4.2 Participants reported importance of participating in ACP activities

The majority of participants strongly agreed that it was important to discuss end of life wishes with family (89.4%). Most strongly agreed it was important to discuss end of life wishes with their doctor (91.0%) and to formally choose a surrogate decision maker (85.5%). Fewer participants strongly agreed that it was important to record end of life wishes in a written document i.e., an advance directive (67.4%)

Table 3: Patients views about the importance of participating in each of the ACP activities

ACP activities	Strongly agree	Somewhat agree	Somewhat disagree	Somewhat disagree
	N (%)	N (%)	N (%)	N (%)
Talk to your family about the type of end of life care you would want to receive	346 (89.4)	10 (2.6)	14 (3.6)	17 (4.4)
Talk to your doctor about the type of end of life care you would want to receive	352 (91.0)	11 (2.8)	12 (3.1)	12 (3.1)
Record the type of care you would want to receive in a document i.e., an advance directive)	261 (67.4)	25 (6.5)	31 (8.0)	70 (18.1)
Formally choose someone to make decisions about your care on your behalf (i.e., a surrogate decision maker)	331 (85.5)	13 (3.4)	17 (4.4)	26 (6.7)

4.3 Self-reported participation in ACP activities

28.7% of patients (n=111) had already discussed the type of end of life care they would want to receive with their family, however, only 19.6% (n=76) had already discussed this with their doctor. 27.3% of the participants (n=106) had discussed their life expectancy with a doctor. 27.1% (n=105) of the participants had appointed a surrogate decision maker. Very few patients, 1.5% (n=6) had documented their end of life wishes in a written document (an advance directive)

Overall, 200 participants (51.7%) had not participated in any ACP activity.

Table 4: Self-reported participation in ACP activities

ACP activities: have already	Yes	No	Unsure
	N (%)	N (%)	N (%)
Talked with your family about the type of end of life care you would want to receive	111 (28.7)	274 (70.8)	2 (0.5)
Talked with your doctor about the type of end of life care you would want to receive	76 (19.6)	309 (79.8)	2 (0.5)
Recorded the type of care you would want to receive in a written document (i.e., an advance directive)	6 (1.5)	380 (98.2)	1 (0.3)
Formally chosen someone to make decisions about your care on your behalf (i.e., a surrogate decision maker)	105 (27.1)	280 (72.4)	2 (0.5)
Discussed how cancer may affect the length of your life (your life expectancy) with your doctor	106 (27.4)	267 (69.0)	14 (3.6)

4.3 Willingness to participate in ACP activities

Among participants who had not participated in each ACP activity, 81.2% wanted to talk to their family about the type of end of life care they wanted to receive; 85.1% wanted to talk to a doctor about the type of end of life care they wanted to receive while 75.9% wanted to choose a surrogate decision maker. Fewer participants (68%) wanted to record the type of end of life care in an advance directive. 71.9% of the participants wanted to discuss life expectancy with their doctor.

Table 5: Willingness to participate in ACP activities

ACP activities	Yes	No	Unsure	Total
	n (%)	n (%)	n (%)	N
Talk to family about the type of end of life care s/he would want to receive	224 (81.2)	38 (13.8)	14 (5.1)	276
Talk to doctor about the type of end of life care s/he would want to receive	265 (85.1)	33 (10.7)	13 (4.2)	311
Record the type of care s/he would want to receive in a written document	259 (68.0)	95 (24.9)	27 (7.1)	381
Formally choose someone to make decisions about care	214 (75.9)	46 (16.3)	22 (7.8)	282

on his/her behalf				
Discuss life expectancy with his or her doctor	202 (71.9)	57 (20.3)	22 (7.8)	281

4.4 Who should initiate ACP discussions

Participants were asked about their opinion on who should initiate ACP discussions. On this question we got responses from majority of the study participants interviewed with some reporting that they neither agreed nor disagreed with each of the responses given and thus not captured. 70.9% of study participants who responded strongly agreed that the doctor should initiate ACP discussions while 57.4% of respondents strongly agreed that the patient was best suited to initiate ACP discussions. Of the participants who gave responses only 22.9% strongly agreed that family should initiate ACP discussions. When asked whether having other participants initiate ACP discussions; of those who responded, 93.5% strongly disagreed that other parties should initiate ACP discussions.

Table 6: Participants views on who should initiate ACP discussions

	Strongly agree	Somewhat agree	Somewhat disagree	Strongly disagree	Total
	n (%)	n (%)	n (%)	n (%)	N (%)
Patient	210 (57.4)	76 (20.8)	13 (3.6)	67 (18.3)	366
Family	81 (22.9)	118 (33.3)	21 (5.9)	134 (37.8)	354
Doctor	266 (70.9)	43 (11.5)	10 (2.7)	56 (14.9)	375
Other	12 (5.6)	2 (0.9)	0	201 (93.5)	215

Of the 12 respondents who strongly agreed that other participants should initiate ACP discussions, they listed friends (n=3), community health workers (n=1), counsellors (n=3) and pastors (n=5) as the preferred parties who could initiate ACP discussions.

4.5 ACP documentation in participants medical records

Of the 387 participants we found that 88.9% has evidence of documentation of ACP discussions in their files; these were in form of the Clinical Navigation tools and doctors' documentation of family conference discussions.

We did not find any completed official hospital family conference tool nor surrogate decision maker appointment orders nor a living will in any of the files that we audited.

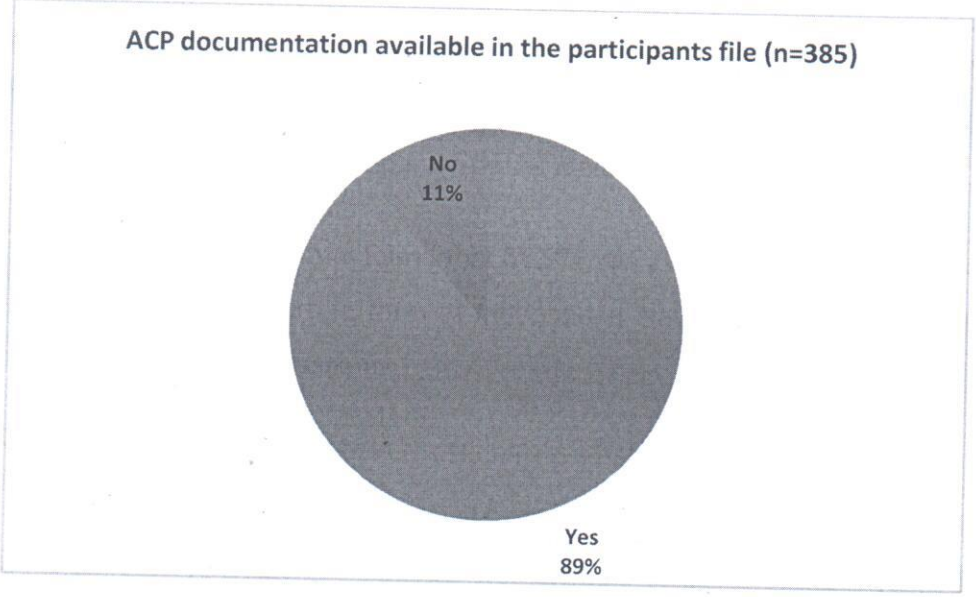


Figure 1. ACP documentation in participants medical records

4.6 Results of key informant interviews

40 participants were recruited to participate in in-depth interviews to assess the knowledge, attitude, perceptions and preferences for advance care planning. A total of 27 in depth interviews were conducted before saturation was detected. We interviewed 10 male and 17 female participants on follow up at the cancer treatment centre and the radio-oncology units. We found that advance care planning was an unfamiliar concept among majority of the patients on follow up at the outpatient cancer clinics; however, patients were keen on being guided through the ACP process by their doctors. Interviews were recorded and transcribed verbatim and content analysis was conducted to arrive at the themes as summarized in the table below.

Table 7: Themes and subthemes arising from in-depth interviews

Theme	Subthemes	Quote
Knowledge of ACP	Lack of awareness of ACP	*"I haven't heard about it yet; I've just heard about it right now."* *"We are usually not told what we're done for or what it is they do to us. They themselves know how they will treat us."*
	Creating awareness about ACP	*"If our people are educated (on ACP) and the information keeps spreading, it will help many people."*
Attitudes towards ACP	Patients are interested in ACP	*"I think it makes sense because a patient has a right to choose out of the varieties of treatment after discussing, they come up with the best for him ... so to me it is a good idea."*
Perceptions of ACP	Relevance of ACP	*"Yes, it is (relevant), it gives the patient freedom to decide what they want"*
	Involvement of family and other parties in the ACP process	*"I can have my husband and family members (involved) so that when I am home, they will understand me better when I am not able to do some things, they understand the challenges we experience."* *"There are spiritual guides, pastors, priests; they are important parties so that they can encourage you with prayers and you can include a few friends you trust"*
Preferences for ACP	Timing of ACP discussions	*"It is immediately the disease is diagnosed."*
	Doctors should facilitate ACP discussions	*"Obviously the doctor because he is the one who is knowledgeable."*

A narrative of the patients' perspective on ACP cutting across the domains of knowledge, attitudes, perceptions and preferences have been summarised as subthemes.

1.Lack of awareness of advance care planning among cancer patients

Patients were not aware of the concept of advanced care planning especially as process of communicating preferences, goals, and values of their treatment journey.

> *"I haven't heard about it yet; I've just heard about it right now."* **IDI 5, Male participant**

Some expressed the need to get more information to help them understand the concept better as they struggled to answer further questions during the discussion.

> *"You know I have not first understood it (ACP). We are usually not told what we're done for or what it is they do to us. They themselves know how they will treat us."* **IDI 15, Female participant**

> *"Interviewer: In your views, what should be done to make the (ACP) process better? Did you understand the process as I explained?*
>
> *Respondent: I understood but I am finding the questions to be tough."* **IDI 22, Female participant**

2. Patients are interested in ACP and feel others would also be interested

All the participants interviewed for this study showed interest in ACP and would welcome the discussion between themselves and their doctors (Healthcare providers). They believe ACP would give them the ability to be involved in their own care.

> *"I think it makes sense because a patient has a right to choose out of the varieties of treatment after discussing, they come up with the best for him ... so to me it is a good idea."* **IDI 21, Male participant**

> *"Sometimes in my opinion... the doctor can tell you something and you just follow without knowing what it is. But if you're given an option, you can ask questions and you can say, "I choose this instead of this"*. **IDI 3, Female participant**

Patients often felt that they did not have an option and often the decisions were made for them by the doctors and ACP would be beneficial in bridging this gap.

> *"I asked myself some questions because they had already removed the kidney and I was no longer in pain, I wondered what else they were going to treat. I agreed because the doctor had said and I did not have an option or say, because he had probably seen something that I did not see and so I agreed to continue with treatment. <u>But as I continue</u>*

and I am almost finishing, if it was upon me, I wouldn't want to continue with the chemo and I just be coming for reviews." ***IDI 27, Female participant***

3. Creating awareness about ACP would get more patients interested

The lack of awareness about ACP is a hindrance to patients receiving cancer treatment participating.

> *"If our people are educated (on ACP) and the information keeps spreading, it will help many people.*" **IDI 24 – male participant**

> *"A good thing sells itself and for example how we have talked with you, if you tell me something that doesn't suit me, I will go spreading wrong information and another person will not agree to participate in the process. But when you tell me something good, I can be able to tell another person about it and encourage them to participate."* **IDI 20 – Female participant**

> *"I think the most part is to educate about it and maybe make it public. I am not sure, but there should be a system on how the message can reach many patients so that they can make their own decisions so that it can be helpful for them in the future.*" **IDI 21 – male participant**

4. Timing of ACP discussions

After learning about ACP, participants felt that the best time to initiate the process is as soon as they had been diagnosed.

> "*I think it should be introduced as soon as you get aware of that sickness ... It should be introduced at the very beginning, although sometimes as human beings someone after a couple of sessions may not even want to hear what is being said*" **IDI 17 – male participant**

> *"It is immediately the disease is diagnosed. Yes, immediately they have done their research and seen that the disease is there, they should start immediately because the patient doesn't know anything about this disease.*" **IDI 13 – male participant**

5. Doctors are best placed to facilitate ACP discussions

The majority of patients reported that doctors would be best placed to facilitate the ACP process. They further added that doctors need to be very honest and have ample time to take patients through the process.

> *"Obviously the doctor because he is the one who is knowledgeable."* ***IDI 14, Female participant***

> *"It requires someone who is real. Someone who tells you the truth, something you can understand and something that this person can take ample time to explain, not something that is done hurriedly for the sake of following the process .... You know, a patient normally has a lot of faith in the doctor. The patient knows everything the doctor explains to them is right"* ***IDI 25, Female participant***

> *"Because he is the one who is conversant with the kind of disease I am suffering from, and he can come up with the best option and we can exchange views with him based on his knowledge."* **IDI 21 – male participant**

6. Relevance of ACP discussions

Participants believed that others would be interested in advance care planning and that it would be beneficial to them.

> *Interviewer: Do you think this process is relevant to you and other patients?*
>
> *Respondent: "Yes, It gives the patient freedom to decide what they want"* ***IDI 27, Female participant***

7. Involvement of family and other parties in the ACP process:

Most of those interviewed were keen on having close family members who are involved in their treatment journey involved.

> *"I can have my husband and family members (involved) so that when I am home, they will understand me better when I am not able to do some things, they understand the*

challenges we experience. There are drugs that affect the blood, I was transfused at one time and so they even understand the kind of food you need" **IDI 26, Female participant**

"*My child and the health care provider, the time we meet they will be able to help me somewhere, she can help me in thinking through and I can tell her what I want for the future*" **IDI 20, Female participant**

Others proposed that they could have their spiritual leaders involved in ACP, especially those who perceive that they could be burdening their family members by the ongoing treatment or those that felt spiritual support would be useful.

Interviewer: "who will you prefer to be with you as you undergo that process (ACP)?

Respondent: A patient's process is a bit tough because many people do not understand your mental health during the process. Even the family may sometimes not understand you. You know the cancer disease costs a lot of money. In human nature, a person may have the desire to help you but when they get fed up, they won't tell you. You will see them disappear for different reasons, but you can tell that they are fed up. That also stresses the patient a lot, they feel that their ailment has brought a lot of stress to friends and even the family. I don't know what can be done but that's my opinion in my experience that someone can get exhausted and once they are fed up, they won't tell you, instead they will come up with many reasons ...

"*Someone like a pastor. A pastor or a priest. Someone with a feeling with the process you are undergoing. You can feel very safe with such a person*" **IDI 25, Female participant**

"*There are spiritual guides, pastor, priests, they are important parties so that they can encourage you with prayers and you can include a few friends whom you trust.*" **IDI 9, Female participant**

CHAPTER 5: DISCUSSION

5.1 Discussion

ACP is increasingly recognised as standard care in the spectrum of cancer management and has been incorporated in practice guidelines and policy documents[4,7,31]. This study was a descriptive cross-sectional survey to determine the practice of ACPamong a heterogenous population of ambulatory cancer patients in a low resource set up.

We found that a very small proportion of our study participants had adopted advance directives with less than one third of the participants having appointed surrogate decision makers and only 1.5% reporting to have completed living wills. This finding may be in part due to the shift in focus in the field of ACP from the completion of ADs to a greater focus on having patients hold more comprehensive ACP discussions with their health care workers and aid them in understanding their values, preferences and goals of care[1,11,16]. This was also supported by the finding that 88.9% of participants medical records under review had evidence of documented ACP discussions thus supporting this current shift in practice. The reliance of our study on recall may have also negatively affected our findings of the uptake of advance directives.

The low uptake of living wills may be related to the lack of national laws governing advance directives as well as the lack of an institutional policy that would lay a framework for healthcare workers to guide patients in the completion of these documents[26,38]. The notable knowledge deficits on the concept of advance care planning as noted in our qualitative study may have contributed to the low uptake of living wills as past studies have demonstrated lack of knowledge as a consistent factor negatively impacting uptake of advance directives[2,28]. It was notable that in comparison to the other domains of ACP, of those participants who had not participated in ACP activities, fewer participants (68%) were willing to document their end of life wishes in an advance directive.Documentation of end of life wishes may be deemed to lead to withdrawal of care or that one might not be able to change written instructions at will[38].

Despite a higher proportion of participants reporting that they had appointed surrogate decision makers(27.1%), this number remains low although was similar to the findings of Waller et al. (28.1%) in an oncology outpatient setting[16]. This comparably higher uptake of surrogate decision maker appointments may be related to the more family-centred approach to the management of chronic illnesses in our set up. Across all the domains that we interrogated in our study there was a preference to have family involvement in ACP and a positive attitude towards holding ACP discussions with family members as well as discussing end of life wishes with family. We noted that 28.7% of study participants had talked to family about the type of end of life wishes majority of whom had appointed surrogate decision makers and it is thus possible that their SDMs were mostly family members although our study did not specifically review the relationship of the SDM to the study participants. It is also possible that rather than documenting their own end of life wishes participants preferred to shift this decisional burden to another party in order to lay their focus solely on their treatment journey. Bar-Sela et al noted that not having a close enough relative who would make decisions on a patients behalf negatively imparted the completion of ACP documents in an Israeli outpatient cancer centre[17].

88.9% of participants files audited had a documentation of an ACP discussion. These were in the form of documented family conference discussions, clinical notes and clinical navigation tools. We did not find any completed family conference tools in the audited files. Despite the high rates of documentation of ACP discussions found in medical records this did not translate into a high rate of self-reported participation in ACP discussions. Only 28.7% of participants reported that they had discussed their end of life wishes with family, 19.7% reported that they had discussed their end of life wishes with a doctor and only 27.4% reported that they had discussed issues around life expectancy with a doctor; all of which constitute important elements of ACP discussions. This discrepancy between self-reported participation in ACP discussions and documented ACP discussion may point to a gap in our current practice of ACP. The current ACP documents available in the ambulatory cancer clinics focus on discussing patient diagnosis and cancer stage, as well as treatment options and their side effects and seek to find the psychological impact of cancer diagnosis on the patients. As noted in our results, only one participant was not aware of their cancer diagnosis demonstrating that the current tools availed to clinicians are well utilised for discussion of the stated domains. However, there is an underutilisation of the family conference tools that have encompassed some discussions points on end of life wishes including opting out of critical care admissions as well as code status. The failure of utilisation of family conference tools may partly explain the inadequacies noted in the ACP discussions. A lack of standardisation of the ACP process may have also contributed to the low self-reported participation in ACP as this is a key promoter of ACP implementation[38].Our participantsreported willingness to participate in ACP discussions although there was a lower preference for documentation of living wills; they had a positive attitude towards ACP and were inclined towards doctor led ACP discussions with family involvement all of which are enabling factors for ACP as seen in past studies[5].

There was a lack of awareness of the concept of ACP among majority of the participants of the qualitative study with most reporting that they had not heard of it. Lack of standardisation of the practice of ACP in our set up may contribute to this paucity of knowledge as no uniform communication strategy has been set in place for communicating ACP terminology and discussions. Despite this however, following a brief explanation of what ACP was, participants demonstrated a positive attitude towards ACP and expressed that it was relevant and important to them. This finding was similar to what Toguri et al noted in a population on oncology patients with advanced cancer where majority of participants also stated that ACP should occur soon after cancer diagnosis was made[29], a view that was shared by our study population. There was a preference for doctor initiated discussions and this may be due to the novelty of the concept of ACP with participants preferring to be guided through the process by doctors; a finding that was consistent in both the qualitative and quantitative arms of the study. Flo E et al noted that the physician was an important agent for initiation of ACP and this role was a key component of the successful implementation of an ACP program[38]. The findings on knowledge, attitude and preferences on ACP among our patients can thus form a basis for educational programs to improve awareness on ACP and provide healthcare workers with a basis upon which to decide on timing of ACP discussions regardless of cancer stage.

Factors that positively correlated with the uptake of advance directives included: the ECOG status, how well a participant understood their cancer diagnosis, overall self-rated health status, having a discussion with family and having a discussion with a doctor. Similar to what Omondi et al found in a population of terminally ill patients in a tertiary facility, participants who had discussed preferences of end of life care with their family were more likely to have completed an ADs ($p < 0.001$) This finding supports the role of early involvement of family in the ACP process as a possible means to improve on uptake of ACP. A discussion with the doctor on a participants end of life wishes may have meant that they got an opportunity to acquire knowledge on the ACP process that may have culminated in the completion of ACP discussions. Participants who were more stable at ECOG zero and who reported an excellent state of health in the past week were more likely to have AD, this raises the question as to whether clinicians deferred ACP discussions with sicker patients with the notion that these discussions may negatively impact on their outcomes or make them lose hope. It has been seen previously that clinicians tend to withhold ACP discussion for sicker patients and thus may serve as a limitation for the uptake of ACP in such patients who may benefit most from ACP. Our findings were not in accord with those of Omondi et al who noted that greater functional impairment was associated with a higher uptake of ACP although the differences in our study populations may explain the differing findings. In the case of Omondi et al, their study looked at terminally ill patients majority of who were unable to make decisions on their own and thus advance directives were completed by relatives while our participants were in the ambulatory clinics and had autonomy over their health decisions. There may be a need to conduct further assessment and institute measures like education of clinicians in order to facilitate ACP discussions and introduction of advance directions across all patient groups regardless of health status. The finding that participants who had a poor understanding of their cancer diagnosis were more likely to have an AD may mean that this population of patients may have appointed surrogate decision makers earlier following cancer diagnosis and thus reported a higher uptake of Ads despite not having participated in ACP discussions themselves. We did not, however, find any association between uptake of AD and age, level of education and religion; factors which have been seen to be associated with the uptake of AD in other studies[5].

5.2 Conclusion

The uptake of advance directives among ambulatory cancer patients remains low despite widespread recognition of its benefits in end of life care. There was a preference for appointment of surrogate decision makers over completion of living wills. This requires education initiatives to demystify misconceptions about living wills and to further strengthen education on SDM appointments in a bit to improve uptake.

There is a notable discrepancy between the proportion on those who had ACP documentation in medical records versus self-reported participation in ACP discussions pointing to a gap in the current practice. Standardisation of the ACP process and initiatives to educate health care providers on the same may improve this.

Despite a positive attitude towards the concept of ACP there is a knowledge gap on ACP among patients that needs to be bridged through widespread education initiatives. Awareness creation in our ambulatory cancer clinics should be deemed a high priority area.

Enhanced participation of doctors and family in ACP may improve the uptake. Factors that were associated with uptake of AD mirrored those from past studies although age, level of education and religion were not associated with uptake of AD as seen in Western studies.

Early initiation of ACP and clear communication of its legal ramifications is a high priority area in our set up and may help mitigate the crisis situations encountered in end of life care.

5.3 Limitations

1. The reliance of recall for the data on the domains of ACP may have impacted negatively on the results we obtained. Data collected on uptake of AD was also not verifiable
2. Our sample constituted a heterogenous population of cancer patients at different disease stages and on different treatment strategies and may not be generalizable to a specific demographic of cancer patients e.g. patients with advanced cancer

5.4 Recommendations

1. Develop institutional guidelines on advance care planning to standardise the process
2. Have in place education initiatives to create awareness on the concept of ACP
3. Advocate for national laws that govern advance care planning and advance directives
4. Conduct an interventional study to assess how ACP discussions correlate with uptake of Ads
5. Conduct a study to determine healthcare provider factors that may affect ACP and AD uptake

3.16 Timeframes

	May 2022	Jun 2022	Jul 2022	Aug 2022	Sept 2022	Oct 2022	Oct 2022
Protocol presentation	■						
Ethical approval		■					
Data collection			■	■			
Data analysis					■		
Results presentation						■	
Corrections will then be handed in for marking							■

3.17 Budget

Item	**Cost Per Item**	**Total Cost**
Study assistant	KES 1000 per day for 60 days	60,000
Statistician	45,000	45,000
Stationery and printing		15,000
Ethics fee		2,000
Contingencies (counsellors' fees and other miscellaneous costs)		40,000

REFERENCES

1. Sudore RL, Lum HD, You JJ, et al. Defining Advance Care Planning for Adults: A Consensus Definition From a Multidisciplinary Delphi Panel. J Pain Symptom Manage. 2017 May;53(5)
2. Kermel-Schiffman I, Werner P. Knowledge regarding advance care planning: A systematic review. Arch GerontolGeriatr. 2017 Nov;73.
3. Cancer on a global stage: Incidence and Cancer-Related Mortality in Kenya -The ASCO Post. Available from: https://ascopost.com/issues/february-25-2021/cancer-on-the-global-stage-incidence-and-cancer-related-mortality-in-kenya/.
4. Kenya-Palliative-Care-Policy-2021-2030. Available from https://www.health.go.ke/wpcontent/uploads/2021/10/Kenya-Paliative -Care-Policy-2021-2030.pdf
5. Lovell A, Yates P. Advance Care Planning in palliative care: A systematic literature review of the contextual factors influencing its uptake 2008–2012. Palliat Med. 2014 Sep;28(8)
6. Cancer. Available from: https://www.who.int/health-topics/cancer#tab=tab_1.
7. I Kenya National Cancer Treatment Protocols II Kenya National Cancer Treatment Protocols; 2019. Available from: https://www.health.go.ke/wpcontent/uploads/2019/09/National-treatment-protocols-2019.pdf,
8. Kamonyo ES. The Palliative Care Journey in Kenya and Uganda. Journal of Pain and Symptom Management. 2018 Feb 1;55(2)
9. Macharia LW, Mureithi MW, Anzala O. Cancer in Kenya: types and infection-attributable. Data from the adult population of two National referral hospitals (2008-2012). *AAS* Open Research. 2019 Nov 14;1:25.
10. Musa I, Seymour J, Narayanasamy MJ, Wada T, Conroy S. A survey of older peoples' attitudes towards advance care planning. Age Ageing. 2015 May;44(3)
11. Advance care planning and advance directives - UpToDate. Available from: https://www.uptodate.com/contents/advance-care-planning-and-advance-directives?search=ACP%20relationship&source=search_result&selectedTitle=1~150&usage_type=default&display_rank=1
12. Detering KM, Hancock AD, Reade MC, Silvester W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. BMJ. 2010 Mar;23; 340
13. Hammes BJ, Rooney BL. Death and End-of-Life Planning in One Midwestern Community. Arch Intern Med. 1998 Feb 23;158(4).
14. Teno JM, Gruneir A, Schwartz Z, Nanda A, Wetle T. Association Between Advance Directives and Quality of End-of-Life Care: A National Study. J Am Geriatric Society. 2007 Feb;55(2).
15. Molloy DW, Guyatt GH, Russo R, et al. Systematic Implementation of an Advance Directive Program in Nursing Homes. JAMA. 2000Mar 15;283(11).

16. Waller A, Turon H, Bryant J, Zucca A, Evans TJ, Sanson-Fisher R. Medical oncology outpatients' preferences and experiences with advanced care planning: A cross-sectional study. BMC Cancer. 2019 Jan;19(1).

17. Bar-Sela G, Bagon S, Mitnik I, et al. The perception and attitudes of Israeli cancer patients regarding advance care planning. Journal of Geriatric Oncology. 2021 Nov;12(8).

18. Yadav KN, Gabler NB, Cooney E, et al. Approximately One In Three US Adults Completes Any Type Of Advance Directive For End-Of-Life Care. Health Affairs. 2017 Jul;36(7).

19. Detering KM, Buck K, Ruseckaite R, et al. Prevalence and correlates of advance care directives among older Australians accessing health and residential aged care services: multicentre audit study. BMJ Open. 2019 Jan;9(1).

20. Evans N, Bausewein C, MenacaA, et al. A critical review of advance directives in Germany: attitudes, use and healthcare professionals' compliance. Patient Education Counselling. 2012 Jun;87(3).

21. Van WijmenMps, Rurup Ml, Pasman Hrw, Kaspers Pj, Onwuteaka-Philipsen Bd. Advance Directives in the Netherlands: An Empirical Contribution To The Exploration Of A Cross-Cultural Perspective On Advance Directives. Bioethics. 2010 Mar;24(3).

22. Chan CWH, Wong MMH, Choi KC, et al. Prevalence, Perception, and Predictors of Advance Directives among Hong Kong Chinese: A Population-based Survey. International Journal of Environmental Research and Public Health. 2019 Feb 1;16(3)

23. Narang AK, Wright AA, Nicholas LH. Trends in advance care planning in patients with cancer: Results from a national longitudinal survey. JAMA Oncology. 2015Aug;1(5).

24. Kubi B, Istl AC, Lee KT, Conca-Cheng A, Johnston FM. Advance Care Planning in Cancer: Patient Preferences for Personnel and Timing. JCO Oncology Practice. 2020;16(9).

25. Berkowitz CM, Wolf SP, Troy J, Kamal AH. Characteristics of Advance Care Planning in Patients With Cancer Referred to Palliative Care. JCO Oncology Practice. 2021;17:94-100.

26. Omondi S, Weru J, Shaikh AJ, Yonga G. Factors that influence advance directives completion amongst terminally ill patients at a tertiary hospital in Kenya. BMC Palliat Care. 2017 Jan;16(1)

27. Barakat A, Barnes SA, Casanova MA, Stone MJ, Shuey KM, Miller AM. Advance Care Planning Knowledge and Documentation in a Hospitalized Cancer Population. Baylor University Medical Centre Proceedings. 2013 Oct 11;26(4)

28. Sittisombut S, Maxwell C, Love EJ, Sitthi-Amorn C. Effectiveness of advance directives for the care of terminally ill patients in Chiang Mai University Hospital, Thailand. Nursing Health Sciences. 2008 Mar;10(1).

29. Toguri JT, Grant-Nunn L, Urquhart R. Views of advanced cancer patients, families, and oncologists on initiating and engaging in advance care planning: a qualitative study. BMC Palliative Care. 2020 Oct;19(1).

30. Silveira MJ, Wiitala W, Piette J. Advance Directive Completion by Elderly Americans: A Decade of Change. Journal of the American Geriatric Society. 2014 April;62(4).

31. Ministry Of Health Republic Of Kenya National Palliative Care Guidelines National Palliative Care Guidelines 2013 National Palliative Care Guidelines-2013 National Palliative Care Guidelines (Internet). (Cited 2021 Nov 4). Available from http://Guidelines .Health.GoKe/#/Category/7/14/Meta

32. Ali Z. Kenya Hospices and Palliative Care Association: Integrating palliative care in public hospitals in Kenya. Ecancermedicalscience. 2016 Jul 7;10.

33. https://www.who.int/news-room/fact-sheets/detail/palliative-care.

34. Downing J, Gomes B, Gikaara N, et al. Public preferences and priorities for end-of-life care in Kenya: a population-based street survey. BMC Palliative Care. 2014;13(1).

35. Stanford J, Sandberg DM, Gwyther L, Harding R. Conversations Worth Having: The Perceived Relevance of Advance Care Planning among Teachers, Hospice Staff, and Pastors in Knysna, South Africa. Journal of Palliative Medicine. 2013 Jul 1;16(7).

36. Cohen MG, Althouse AD, Arnold RM, et al. Is Advance Care Planning Associated With Decreased Hope in Advanced Cancer? JCO Oncology Practice. 2021;17(2).

37. Cochran, WG (1977). Sampling Techniques (3rd edition). New York: John Wiley & Sons.

38. Flo E, Husebo BS, Bruusgaard P, et al. A review of the implementation and research strategies of advance care planning in nursing homes. BMC Geriatric. 2016;16(1).

APPENDICES

Appendix 1: Study Proforma

Please indicate your Answers in the Spaces Provided Below		
SECTION A: GENERAL INFORMATION		
1.	Age (in years)	
2.	Gender	1. Male 2. Female
3.	Religion	1. Christian 2. Muslim 3. Traditional 4. Areligious 5. Others
4.	Marital Status	1. Single 2. Married 3. Divorced 4. Widowed
5.	Education Level	1. Primary 2. Secondary 3. Tertiary 4. None
6.	Employment Status	1. Employed a.) Formal b.)Informal 2. Unemployed 3. Self-employed 4. Others
7.	Residence	1. Urban 2. Rural
8.	Estimated Monthly Income	1. <5000 2. 5000-≤ 10000 3. 10001-≤25000 4. 25001-≤50000 5. >50000
SECTION B		
9.	Diagnosis	1. Breast Cancer 2. Stomach Cancer 3. Cervical Cancer 4. Prostate Cancer

		5. Lymphoma 6. Colorectal Cancer 7. Oesophageal Cancer 8. Kaposi's Sarcoma 9. Leukaemia 10. I don't know 11. Other (Please specify) -----
10.	Year of diagnosis Stage at diagnosis	
11.	Performance Status (ECOG)	
12.	How well do you understand your cancer	not at all 0 5 (very well) 1 2 3 4 (Put a mark along the line above where appropriate)

Appendix 2: Questionnaire in English

SECTION C: Planning for future medical care

Occasionally, people may become too sick to make decisions about what type of care they want (or don't want) at the end of life. For example, if they are unconscious or confused. These next series of items ask about your preferences and experiences in making decisions about future medical care. These questions have nothing to do with your current state of health.

If you are willing to participate in this section of the survey, please answer the following questions. If you prefer not to complete this section, please tick the box below and skip to the next section.

☐ **I choose to skip this section of the survey *(this completes the survey)***

1.	**How would you rate your overall health during the past week?**	**1**	**2**	**3**	**4**	**5**	**6**	**7**
	Please circle one number	Very poor						Excellent

People can communicate their preferences for end-of-life care by:

1) Telling the doctors and/or their families what they want.
2) Completing a written document that describes what they want (i.e. an "advance directive").
3) Choosing someone that can make decisions on their behalf (i.e. a "surrogate decision maker").

Please circle the one number on each line that best corresponds to your answer to each statement.

In case you are unable to make decisions later, do you think it is important that you:	**Strongly agree**	**Somewhat agree**	**Somewhat disagree**	**Strongly disagree**
2. Talk to your family about the type of end-of-life care you would want to receive.	1	2	3	4
3. Talk to yourdoctor about the type of end-of-life care you would want to receive.	1	2	3	4
4. Record the type of care you would want to receive in a written document (i.e. an advance directive).	1	2	3	4
5. Formally choose someone to make decisions about your care on your behalf (i.e. a surrogate decision maker).	1	2	3	4

If you were given the opportunity in the next month, would you choose to:	**Yes**	**No**	**Unsure**
6. Discuss your preferences for end-of-life care with your family.	1	2	3
7. Discuss your preferences for end-of-life care with your doctor	1	2	3
8. Record the type of care you would want to receive in a written document (i.e. complete an advance directive).	1	2	3
9. Formally choose someone to make decisions on your behalf (your surrogate decision maker).	1	2	3
10. Discuss how cancer may affect the length of your life (your life expectancy) with your doctor	1	2	3

Have you already:	**Yes**	**No**	**Unsure**

11. Talked with your <u>family</u> about the type of end-of-life care you would want to receive?	1	2	3
12. Talked with <u>your doctor</u> about the type of end-of-life care you would want to receive?	1	2	3
13. Recorded the type of care you would want to receive in a written document (i.e. advance directive)?	1	2	3
14. Formally chosen someone to make decisions about your care on your behalf (i.e. a surrogate decision maker)?	1	2	3
15. Discussed how cancer may affect the length of your life (your life expectancy) with your doctor?	1	2	3

Please tell us <u>who</u> you think should be responsible for starting discussions about planning for end-of-life care. Please circle one number on each line that best corresponds to how much you agree or disagree with each statement.

Discussions about end-of-lifecare should be started by the…	**Strongly <u>agree</u>**	**Somewhat <u>agree</u>**	**Somewhat <u>disagree</u>**	**Strongly <u>disagree</u>**
16. Patient	1	2	3	4
17. Family	1	2	3	4
18. Doctor	1	2	3	4
19. Other (please specify)________________	1	2	3	4

Appendix 3: Questionnaire in Kiswahili

<u>SEHEMU C: Kupanga kwa ajili ya matibabu ya baadaye</u>

Mara kwa mara, watu wanaweza kuwa wagonjwa sana kufanya maamuzi kuhusu aina gani ya huduma wanayotaka (au hawataki) mwishoni mwa maisha. Kwa mfano, ikiwa hawana fahamu au wamechanganyikiwa. Mfululizo huu unaofuata wa vitu unauliza kuhusu mapendeleo na uzoefu wako katika kufanya maamuzi kuhusu huduma ya matibabu ya siku zijazo. Maswali haya hayana uhusiano wowote na hali yako ya sasa ya afya.

Ikiwa uko tayari kushiriki katika sehemu hii ya utafiti, tafadhali jibu maswali yafuatayo. Ikiwa ungependa kutokamilisha sehemu hii, tafadhali weka alama kwenye kisanduku kilicho hapa chini na uruke hadi sehemu inayofuata.

☐ Ninachagua kuruka sehemu hii ya utafiti (hii inakamilisha utafiti)

1.	**Je, unaweza kukadiria vipi afya yako kwa ujumla katika wiki iliyopita?** *Tafadhali zungushia nambari moja*	**1** Mbaya sana	**2**	**3**	**4**	**5**	**6**	**7** Bora Zaidi

Watu wanaweza kuwasilisha mapendeleo yao ya utunzaji wa mwisho wa maisha kwa:
1) Kuwaambia madaktari na/au familia zao wanachotaka.
2) Kukamilisha hati iliyoandikwa ambayo inaelezea kile wanachotaka (yaani "maelekezo ya mapema").
3) Kuchagua mtu ambaye anaweza kufanya maamuzi kwa niaba yake (yaani "mtoa maamuzi mbadala").

Tafadhali zungushia nambari moja kwenye kila mstari ambayo inalingana vyema na jibu lako kwa kila kauli.

	Iwapo hutaweza kufanya maamuzi baadaye, unafikiri ni muhimu kwamba:	**Kukubaliana sana**	**Kukubaliana kwa kiasi fulani**	**Kutokubaliana kwa kiasi fulani**	**Kutokubaliana kabisa**
2	Zungumza na familia yako kuhusu aina ya huduma ya mwisho ya maisha ambayo ungetaka kupokea.	1	2	3	4
3	Zungumza na daktari wako kuhusu aina ya huduma ya mwisho ya maisha ambayo ungependa kupokea.	1	2	3	4
4	Rekodi aina ya utunzaji ambao ungetaka kupokea katika hati iliyoandikwa (yaani, maagizo ya mapema).	1	2	3	4
5	Chagua rasmi mtu wa kufanya maamuzi kuhusu utunzaji wako kwa niaba yako (yaani, mtoa maamuzi mbadala).	1	2	3	4

	Ikiwa utapewa fursa mwezi ujao, ungechagua:	**Ndio**	**Hapana**	**Sina uhakika**
6.	Jadili mapendeleo yako ya huduma ya mwisho ya maisha na familia yako?	1	2	3
7.	Jadili mapendeleo yako ya huduma ya mwisho ya maisha na daktari wako?	1	2	3
8.	Rekodi aina ya utunzaji ambao ungetaka kupokea katika hati iliyoandikwa (yaani. kamilisha maagizo ya mapema)?	1	2	3

9.	Je, uchague rasmi mtu wa kufanya maamuzi kwa niaba yako (mtoa maamuzi mbadala wako)?	1	2	3
10.	Jadili jinsi saratani inaweza kuathiri urefu wa maisha yako na daktari wako?	1	2	3

Je, tayari:	**Ndio**	**Hapana**	**Sina Uhakika**
Je, ulizungumza na familia yako kuhusu aina ya huduma ya mwisho ya maisha ambayo ungependa kupokea?	1	2	3
Je, ulizungumza na daktari wako kuhusu aina ya huduma ya mwisho ya maisha ambayo ungependa kupokea?	1	2	3
Umerekodi aina ya utunzaji ambao ungetaka kupokea katika hati iliyoandikwa (yaani maagizo ya mapema)?	1	2	3
Je, ulimchagua rasmi kufanya maamuzi kuhusu utunzaji wako kwa niaba yako (yaani, mtu anayefanya maamuzi mbadala)?	1	2	3
Je, ulijadili jinsi saratani inavyoweza kuathiri urefu wa maisha yako (umri wa kuishi) na daktari wako?	1	2	3

Tafadhali tueleze ni nani unadhani anastahili kuwajibika kwa ajili ya kuanzisha mijadala kuhusu kupanga maisha ya mwisho. Tafadhali zungushia nambari moja kwenye kila mstari ambayo inalingana vyema na ni kwa kiasi gani unakubali au hukubaliani na kila kauli.

Majadiliano kuhusu huduma ya mwisho wa Maisha inapaswa kuanzishwa na:	**Kukubaliana sana**	**Kukubaliana kwa kiasi fulani**	**Kutokubaliana kwa kiasi fulani**	**Kutokubaliana kabisa**
Mgonjwa	1	2	3	4
Familia	1	2	3	4
Daktari	1	2	3	4
Wengine (tafadhali taja)______________	1	2	3	4

Appendix 4: In-depth Interview Guide

Welcome and thank you for volunteering to take part in this IDI on ACP. You have been asked to participate as your point of view is important. We realize you are busy, and I appreciate your time.
Introduction: My name is ___________ and I am here to carry out an interview; this interview is designed to understand your thoughts and opinions on ACP. Your responses will be very useful in helping us to understand the gaps in adapting ACP in our cancer care settings and the best way to bridge those gaps.
This IDI will take no more than 60 minutes, and I will be taking notes on what we are discussing. The interview will be audio recorded.
Confidentiality: I would like to assure you that the discussion will be anonymous. The notes/recordings will contain no information that would link you to specific statements. Please answer as accurately and truthfully as possible. If there are any questions or discussions that you do not wish to answer or participate in, you do not have to do so; however please try to answer and be as involved as possible.

Ground Rules

- We need our phones to be on silent
- There are no right or wrong answers.
- If a question is unclear, feel free to ask me to repeat

Introduction:

1. Please tell me about the time you received your cancer diagnosis. How has the treatment journey been?

ACP Knowledge and perceptions

2. Have you heard of ACP?
    - Probes: from who? What were you told? Did you feel the information was adequate
    - Note: If they have **not heard** about ACP give a summary
3. If you had heard about ACP, have you participated? Why? Why not?
4. If you learned about ACP today, would you be interested in participating? Why? Why not?
5. In general, do you think ACP is relevant for you and others that have been diagnosed with cancer?
6. In your opinion, who would be the best person to guide you through the process?
    - Probes: What would their role be? Providing Information?
7. In your opinion when is the best time to initiate the ACP process for someone diagnosed with cancer?
8. Who else would you like to involve in the process
    - Spouse? Children? Other family members

ACP Experiences/ recommendations

9. For those that have been engaged in ACP – What did you like most about the process? What did you not like? What could be improved?
10. For those who have not been engaged in ACP – What are some of the things that would make you interested in the process? What might hinder you/others from participating in the process?

Appendix 5: Informed Consent for participants of the quantitative study(English)

STUDY TITLE: THE PRACTICE OF ADVANCE CARE PLANNING AMONG AMBULATORY CANCER PATIENTS RECEIVING TREATMENT AT KENYATTA NATIONAL HOSPITAL

Study number:

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Purpose

We wish to research patients attending the oncology outpatient clinic at Kenyatta National Hospital on the practice of advance care planning among cancer patients in the outpatient clinic. Occasionally, people may become too sick to make decisions about what type of care they want (or don't want) at the end of life. For example, if they are unconscious or confused. Although this has nothing to do with your current state of health, it will be of use in planning for the future in case of such eventualities. This study aims to identify the common practices, knowledge deficits, level of uptake, and preferences and aid in the improvement of patient education and engagement in advance care planning discussions. We will include patients aged 18 years and above. Participants shall be given information pamphlets on advance care planning following the completion of the interview.

Procedures

This study will be conducted through a questionnaire administered by a trained study assistant. We will document your age, gender, religion, marital status, level of education, income and relevant medical history regarding your cancer diagnosis. We will also ask questions regarding your uptake of advance directives and perceptions of advance care planning.

Benefits

Your participation in this study will help us determine the uptake of advance care planning as well as baseline information on perceptions, knowledge and preferred practices of advance care planning among patients with a diagnosis of cancer attending the oncology clinic. This will help improve our practice on advance care planning discussions and possibly aid in implementing policies to facilitate the inculcation of advance care planning as part of standard operating procedures.

Risks

There are no known risks to you as a person taking part in this study. The questionnaire may take about 20 minutes to complete but we will undertake all possible measures to aid in this process. If at any one point you feel that the questions are overwhelming, we will provide support and counselling services free of charge.

Participant's Rights

Your participation in this study is voluntary and if you decline to participate or withdraw at any point, you will not be denied any services that are normally available to you. If you have any questions about this research, you may call Dr. Lavender Otom at 0727097409

Confidentiality

We will make every effort to protect your identity. You will not be identified in any report or publication of this study or its results

The role of the Ethics Research Committee

The ethics and research committee (ERC) is a multidisciplinary, independent body charged with reviewing research involving human participants to ensure that rights, dignity and welfare of study participants are protected. This research work has been approved by the ERC and thus adheres to core principles of research.

Consent Certificate

Respondent Agreement

The study has been explained to me. I consent to participate. I have had a chance for my questions to be answered. I know that I may refuse to participate or stop the interview at any time without any loss of health care benefits that I am otherwise receiving. I understand that if I have questions about this study or my rights in taking it, I may contact Dr Lavender Otom on 0727097409. Further, I understand that the information recorded by the investigator will be confidential.

Respondent Signature______________________ Date________________________

Interviewer Signature______________________ Date________________________

Contacts of the investigator:

Dr. Lavender Otom
The University of Nairobi, P.O. Box 30197-00100
Email; lavenderotom@gmail.com, Phone: 0727097409

Lead Supervisor:

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University of Nairobi P.O. BOX 30197-0010

KNK-UON ERC: uonknh_erc@uonbi.ac.ke

Appendix 6: Informed Consent for participants of the quantitative study (Swahili)

KICHWA CHA KUJIFUNZA: TABIA YA UPANGAJI WA UTUNZAJI WA MAPEMA MIONGONI MWA WAGONJWA WA SARATANI YA AMBULATI WANAOPATA MATIBABU KATIKA HOSPITALI YA TAIFA YA KENYATTA.

Nambari ya masomo:

Mpelelezi Mkuu:

Dr. Lavender Otom (Rej. No: H58/38030/2020)
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Wasimamizi:

Prof. Elijah Ogola
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Chuo Kikuu cha Nairobi

Dr. Peter Oyiro
Idara ya Tiba ya Kliniki na Matibabu,
Chuo Kikuu cha Nairobi
Barua Pepe: peteroyiro@uonbi.ac.ke Simu:0700934072

Kusudi

Tunataka kufanya utafiti kuhusu wagonjwa wanaohudhuria kliniki ya wagonjwa wa nje ya saratani katika Hospitali ya Kitaifa ya Kenyatta kwa mazoezi ya kupanga huduma ya mapema miongoni mwa wagonjwa wa saratani katika kliniki ya wagonjwa wa nje. Mara kwa mara, watu wanaweza kuwa wagonjwa sana kufanya maamuzi kuhusu aina gani ya huduma wanayotaka (au hawataki) mwishoni mwa maisha. Kwa mfano, ikiwa hawana fahamu au wamechanganyikiwa. Ingawa hii haina uhusiano wowote na hali yako ya sasa ya afya lakini itakuwa ya matumizi katika kupanga kwa siku zijazo ikiwa kuna matukio kama haya.

Kusudi ni kutambua mazoea ya kawaida, upungufu wa maarifa, kiwango cha kuchukua, mapendeleo na usaidizi katika ubóreshaji wa elimu ya mgonjwa na ushiriki katika mijadala ya kupanga huduma mapema. Tuta jumuisha wagonjwa wenye umri wa miaka 18 na kuendelea. Washiriki watapewa vipeperusha vya habari juu ya upangaji wa utunzaji wa mapema baada ya kukamilika kwa mahojiano.

Taratibu

Utafiti huu utafanywa kupitia dodoso litakalo simamiwa na msaidizi wa utafiti aliyefunzwa. Tuta kuandikia umri, jinsia, dini, hali ya ndoa, kiwango cha elimu, mapato na historia husika ya matibabu kuhusu utambuzi wako wa saratani. Pia tutakuuliza maswali kuhusu uchukuaji wako wa maagizo na mitazamo ya mapema kuhusu upangaji wa huduma ya mapema.

Faida

Kushiriki kwako katika utafiti huu kutatusaidia kubainisha jinsi upangaji wa huduma ya mapema unavyofanyika pamoja na maelezo ya msingi kuhusu mitazamo, ujuzi na mbinu zinazopendekezwa za kupanga huduma ya mapema miongoni mwa wagonjwa walio na utambuzi wa saratani wanaohudhuria kliniki ya saratani. Hii itasaidia kuboresha utendaji wetu kuhusu kuendeleza mijadala ya kupanga utunzaji na ikiwezekana kusaidia katika kutekeleza sera ili kuwezesha kuingizwa kwa upangaji wa huduma ya mapema kama sehemu ya taratibu za kawaida za uendeshaji.

Hatari

Hakuna hatari zinazojulikana kwako kama mtu anayeshiriki katika utafiti huu. Hojaji inaweza kuchukua kama dakika 20 kukamilika lakini tutachukua hatua zote zinazowezekana kusaidia katika mchakato huu. Iwapo wakati wowote unahisi kuwa maswali ni mengi sana tutatoa huduma za usaidizi na ushauri bila malipo.

Haki za Mshiriki

Ushiriki wako katika utafiti huu ni wa hiari na ukikataa kushiriki au kujiondoa wakati wowote, hutanyimwa huduma zozote ambazo kwa kawaida zinapatikana kwako. Ikiwa una maswali yoyote kuhusu utafiti huu, unaweza kupiga simu kwa Dk. Lavender Otom 0727097409.

Usiri

Tutafanya kila juhudi kulinda utambulisho wako. Hutatambuliwa katika ripoti au uchapishaji wowote wa utafiti huu au matokeo yake.

Jukumu la Kamati ya Utafiti wa Maadili

Kamati ya maadili na utafiti (ERC) ni chombo chenye taaluma nyingi, kinachojitegemea chenye jukumu la kukagua utafiti unaohusisha washiriki wa kibinadamu ili kuhakikisha kuwa haki, utu na ustawi wa washiriki wa utafiti zinalindwa. Kazi hii ya utafiti imeidhinishwa na ERC na hivyo inazingatia kanuni za msingi za utafiti.

Cheti cha Idhini

Makubaliano ya Mjibu

Utafiti umefafanuliwa kwangu. Ninakubali kushiriki. Nimepata nafasi ya kujibiwa maswali yangu. Ninajua kwamba ninaweza kukataa kushiriki au kusitisha mahojiano wakati wowote bila hasara yoyote ya manufaa ya afya ambayo ninapokea vinginevyo. Ninaelewa kuwa ikiwa nina maswali kuhusu utafiti huu au haki yangu ya kuuchukua, ninaweza kuwasiliana na Dk. Lavender Otom kwa nambari 0727097409. Zaidi ya hayo, ninaelewa kuwa maelezo yaliyorekodiwa na mpelelezi yatakuwa ya siri.

Sahihi ya Mjibu ______________________ Tarehe________________________

Sahihi ya Mhojaji ______________________ Tarehe_________________________

Mawasiliano ya mpelelezi:

	Dk. Lavender Otom
	Barua pepe; lavenderotom@gmail.com, Simu: 0727097409
Msimamizi Kiongozi:	**Dk. Peter Oyiro**
	Email: peteroyiro@uonbi.ac.ke
	Simu: 0700934072
KNK-UON ERC:	uonknh_erc@uonbi.ac.ke

Appendix 7: Informed consent for participants of the qualitative study (English)

STUDY TITLE: THE PRACTICE OF ADVANCE CARE PLANNING AMONG AMBULATORY CANCER PATIENTS RECEIVING TREATMENT AT KENYATTA NATIONAL HOSPITAL

Study number:

Principal Investigator:

Dr. Lavender Otom (Reg. No: H58/38030/2020)
Registrar in Internal Medicine, the University of Nairobi
Phone: 0727097409, Email lavenderotom@gmail.com

Supervisors:

Prof. Elijah Ogola
Department of Clinical Medicine and Therapeutics
University of Nairobi

Dr. Peter Oyiro
Department of Clinical Medicine and Therapeutics,
University of Nairobi
Phone: 0700934072, Email peteroyiro@uonbi.ac.ke

Introduction

I wish to inform you about a medical research conducted by the above researchers. The purpose of having this discussion with you is to inform you of the aim of the study so that you can make an informed choice on whether to participate. Please feel free to ask any questions regarding any risks and benefits accorded to you for agreeing to participate in this research. I will clarify anything that you have not understood. I will ask you to sign the form below once you are content.

What is the research about?

Occasionally, people may become too sick to make decisions about what type of care they want (or don't want) at the end of life. For example, if they are unconscious or confused. Although this has nothing to do with your current state of health, it will be of use in planning for the future in case of such eventualities. The aim of this study is to identify the common practices, knowledge deficits, level of uptake, preferences and aid in the improvement of patient education and engagement in advance care planning discussions. We will include patients aged 18 years and above. Participants shall be given information pamphlets on advance care planning following completion of the interview.

Procedures

With your permission I will ask you questions on personal information and your view on planning for future healthcare provision. All the information obtained shall be handled in secrecy. This process will take around 30-45 minutes

Benefits

Your participation in this study will help us determine the perceptions, knowledge and preferred practices of advance care planning among patients with a diagnosis of cancer attending oncology clinic. This will help improve our practice with regards to advance care planning discussions and possibly aid in implementing policies to facilitate inculcation of advance care planning as part of standard operating procedures.

Risks

There will be no known risks to your health since we will not give any medication or perform any procedures; only questions will be asked. If at any one point you feel that the questions are overwhelming we will provide support and counselling services free of charge.

Participant's Rights

Your participation in this study is voluntary and if you decline to participate or withdraw at any point, you will not be denied any services that are normally available to you.

Assurance of confidentiality

We will make every effort to protect your identity. You will not be identified in any report or publication of this study or its results

The role of the Ethics Research Committee

The ethics and research committee (ERC) is a multidisciplinary, independent body charged with reviewing research involving human participants to ensure that rights, dignity and welfare of study participants are protected. This research work has been approved by the ERC and thus adheres to core principles of research

Consent Certificate

Respondent Agreement

The Study has been explained to me. I consent to participate. I have had a chance for my questions to be answered. I know that I may refuse to participate or to stop the interview at any time without any loss of health care benefits that I am otherwise receiving. I understand that if I have questions about this study or my rights in taking it, I may contact Dr Lavender Otom on 0727097409. Further, I understand that the information recorded by the investigator will be confidential

Respondent Signature______________________ Date________________________

Interviewer Signature______________________ Date________________________

Contacts of the investigator:

Dr. Lavender Otom
The University of Nairobi, P.O. Box 30197-00100
Email; lavenderotom@gmail.com Phone: 0727097409

Lead Supervisor:

Dr. Peter Oyiro
Email: peteroyiro@uonbi.ac.ke Phone:0700934072
University of Nairobi P.O. BOX 30197-0010

KNK-UON ERC: uonknh_erc@uonbi.ac.ke

Appendix 8: Informed consent for the participants of the qualitative study (Swahili)

KICHWA CHA KUJIFUNZA: TABIA YA UPANGAJI WA UTUNZAJI WA MAPEMA MIONGONI MWA WAGONJWA WA SARATANI YA AMBULATI WANAOPATA MATIBABU KATIKA HOSPITALI YA TAIFA YA KENYATTA.

Nambariyamasomo:

MpeleleziMkuu:

Dr. Lavender Otom (Rej. No: H58/38030/2020)
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Simu: 0727097409, Barua pepe lavenderotom@gmail.com

Wasimamizi:

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Idara ya Tiba yaKlinikinaMatibabu,
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Dr. Peter Oyiro
Idara ya Tiba yaKlinikinaMatibabu,
Chuo Kikuu cha Nairobi
Simu: 0700934072 Barua pepe: peteroyiro@uonbi.ac.ke

Utangulizi

Ningependa kukuarifu kuhusu utafiti wa kimatibabu uliofanywa na watafiti hao hapo juu. Madhumuni ya kuwa na mjadala huu na wewe ni kukufahamisha lengo la utafiti ili uweze kufanya uamuzi sahihi kuhusu kushiriki. Tafadhali jisikie huru kuuliza maswali yoyote kuhusu hatari na manufaa yoyote uliyopewa kwa kukubali kushiriki katika utafiti huu. Nitafafanua jambo lolote ambalo hujaelewa. Nitakuomba utie sahihi kwenye fomu iliyo hapa chini mara tu utakaporidhika.

Utafiti unahusu nini?

Mara kwa mara, watu wanaweza kuwa wagonjwa sana kufanya maamuzi kuhusu aina gani ya huduma wanayotaka (au hawataki) mwishoni mwa maisha. Kwa mfano, ikiwa hawana fahamu au wamechanganyikiwa. Ingawa hii haihusiani na hali yako ya sasa ya afya, itatumika katika kupanga siku zijazo endapo kutakuwa na matukio kama haya. Madhumuni ya utafiti huu ni kutambua mazoea ya kawaida, upungufu wa maarifa, kiwango cha matumizi, mapendeleo na usaidizi katika uboreshaji wa elimu ya mgonjwa na ushiriki katika mijadala ya kupanga huduma mapema. Tutajumuisha wagonjwa wenye umri wa miaka 18 na kuendelea. Washiriki watapewa vipeperushi vya habari juu ya upangaji wa utunzaji wa mapema baada ya kukamilika kwa mahojiano.

Taratibu

Kwa ruhusa yako nitakuuliza maswali kuhusu taarifa za kibinafsi na maoni yako kuhusu kupanga utoaji wa huduma za afya siku zijazo. Taarifa zote zilizopatikana zitashughulikiwa kwa usiri. Utaratibu huu utachukua kama dakika 30-45

Faida

Kushiriki kwako katika utafiti huu kutatusaidia kubainisha jinsi upangaji wa huduma ya mapema unavyofanyika pamoja na maelezo ya msingi kuhusu mitazamo, ujuzi na mbinu zinazopendekezwa za kupanga huduma ya mapema miongoni mwa wagonjwa walio na utambuzi wa saratani wanaohudhuria kliniki ya saratani. Hii itasaidia kuboresha utendaji wetu kuhusu kuendeleza mijadala ya kupanga utunzaji na ikiwezekana kusaidia katika kutekeleza sera ili kuwezesha kuingizwa kwa upangaji wa huduma ya mapema kama sehemu ya taratibu za kawaida za uendeshaji.

Hatari

Hakutakuwa na hatari zinazojulikana kwa afya yako kwani hatutatoa dawa yoyote au kufanya taratibu zozote; maswali pekee yataulizwa. Iwapo wakati wowote unahisi kuwa maswali ni mengi sana tutatoa huduma za usaidizi na ushauri bila malipo

Haki za Mshiriki

Ushirikiwakokatikautafitihuuniwahiarinaukikataakushiriki au kujiondoawakatiwowote, hutanyimwahudumazozoteambazokwakawaidazinapatikanakwako.

Ikiwaunamaswaliyoyotekuhusuutafitihuu, unawezakupigasimukwa Dk. Lavender Otom 0727097409.

Usiri

Tutafanyakilajuhudikulindautambulishowako. Hutatambuliwakatikaripoti au uchapishajiwowotewautafitihuu au matokeoyake.

Jukumu la Kamati ya Utafiti wa Maadili

Kamati ya maadili na utafiti (ERC) ni chombo chenye taaluma nyingi, kinachojitegemea chenye jukumu la kukagua utafiti unaohusisha washiriki wa kibinadamu ili kuhakikisha kuwa haki, utu na ustawi wa washiriki wa utafiti zinalindwa. Kazi hii ya utafiti imeidhinishwa na ERC na hivyo inazingatia kanuni za msingi za utafiti.

Cheti cha Idhini

MakubalianoyaMjibu

Utafitiumefafanuliwakwangu. Ninakubalikushiriki. Nimepatanafasiyakujibiwamaswaliyangu. Ninajuakwambaninawezakukataakushiriki au kusitishamahojianowakatiwowotebilahasarayoyoteyamanufaayaafyaambayoninapokeavinginevyo. Ninaelewakuwaikiwaninamaswalikuhusuutafitihuu au hakiyanguyakuuchukua, ninawezakuwasilianana Dk. Lavender Otom kwanambari 0727097409. Zaidi yahayo, ninaelewakuwamaelezoyaliyorekodiwanampeleleziyatakuwayasiri.

SahihiyaMjibu ______________________ Tarehe________________________

SahihiyaMhojaji ______________________ Tarehe_________________________

Mawasilianoyampelelezi:

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MsimamiziKiongozi: **Dk. Peter Oyiro**
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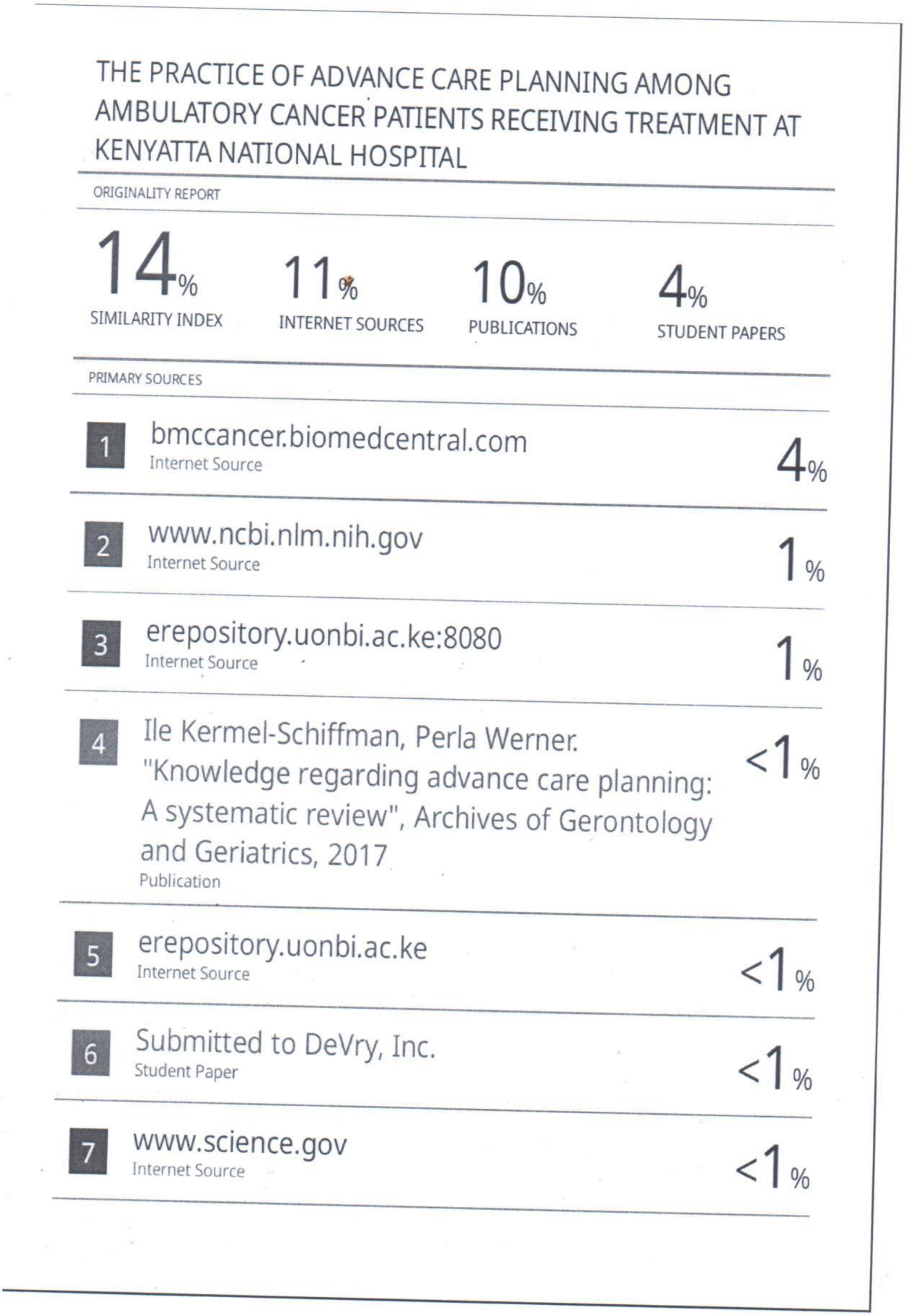

THE PRACTICE OF ADVANCE CARE PLANNING AMONG AMBULATORY CANCER PATIENTS RECEIVING TREATMENT AT KENYATTA NATIONAL HOSPITAL

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This dissertation has been submitted with the approval of my lead supervisor and Chairman of Department:

Prof. Elijah Ogola

Professor/ Cardiologist

Department of Clinical Medicine and Therapeutics

University of Nairobi

Signed: ………………………………………Date: 07/11/2023…………………

Prof. Erastus Amayo

Professor/Neurologist

Chairman of Department

University of Nairobi

Signed: ………………………………………Date: 07/11/2023…………………

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