

**SUPPORT CARE NEEDS AMONG PATIENTS WITH  
CANCER ATTENDING PALLIATIVE CARE CLINIC IN  
MERU LEVEL5 HOSPITAL, MERU COUNTY, KENYA**

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**DECLARATION**

This thesis is my original work and has not been presented for a degree in any other university.

Signature.....Date.....

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This thesis has been presented for examination with our approval as the university supervisors.

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## **DEDICATION**

This study is dedicated to my wife (carol), my son (Ryan), my parents (Mr and Mrs. Gitonga), my brothers (James and Eugene) and my sisters (Agrippina and Stella).

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## **ABBREVIATION AND ACRONYMS**

<b>AHS</b>	Albert Health Services.
<b>CCAS CCR</b>	Cancer Control Alberta’s Supportive Care Council Report.
<b>CCA</b>	Cancer Control Alberta.
<b>CPAC</b>	Canadian Partnership against Cancer.
<b>CC S</b>	Canadian cancer society.
<b>FGD</b>	Focused group discussion.
<b>JKUAT</b>	Jomo Kenyatta University of Agriculture and Technology.
<b>KEMU</b>	Kenya Methodist University
<b>KIIS</b>	Key informants
<b>IOM</b>	International organization for immigration.
<b>IARC</b>	International Agency for Research on Cancer
<b>NACOSTI</b>	National Council for Science, Technology and Innovation.
<b>NGCM</b>	National Guidelines for Cancer Management Kenya,
<b>NHIF</b>	National Hospital Insurance Fund.
<b>WHO</b>	World Health Organization.

## OPERATIONAL DEFINITION OF TERMS

- Data saturation** This refers to the point of data collection where no new information is discovered with subsequent data collection and the data collected is enough to achieve the objective of the study.
- Information needs** Information required by the patients and the families to empower them with necessary knowledge regarding cancer care and treatment through the trajectory of cancer.
- Navigation** Entails the entire process of guidance of the patients and families to negotiate through all the process of cancer treatment and care.
- Psychological needs** This addresses psychological, social, emotional and spiritual needs of patients with cancer.
- Palliative care** Care of any patients whose disease is not responsive to curative treatment.
- Supportive care needs** These are all necessities that patient with cancer experience and need to be addressed.
- Socio-economic needs** These are needs pertaining transportation, finances, long distances to access service, accommodation/infrastructure and social support group.
- Trajectory** This refers to the spectrum of experience of diseases throughout the cancer journey from pre-diagnosis, diagnosis, referrals, treatment, rehabilitation, relapse, palliation to bereavement.

**Thematic analysis** A technique of analyzing qualitative data in which the researcher identifies meaningful categories or themes in written text, conversations or discussions

## ABSTRACT

Patients with cancer experience numerous negative impacts due to the nature of the disease. This leads to poor quality of life and need for support care. The aim of this study was to establish the supportive care needs among patients with cancer attending palliative care clinic in Meru level 5 Hospital. The study used descriptive cross-sectional design that adopted qualitative approach in data collection. Purposive sampling method was used to select the respondents. A total of twenty-four respondents participated in the study, twenty-one of the respondents were patients with cancer while were key informants working in palliative clinic. A focus group discussion guide was used to modulate focused group discussions while interview schedule was used for individualized interview. Two sets of individualized interviews were conducted, one for the three key informants and another one for the patients. Individualized interviews were done till when no new information was forthcoming from subsequent interviews and when further coding was not feasible hence redundancy. Two focused group discussions were conducted, (one for male patients and another one for female patients). All interviews were recorded and transcribed. The study employed thematic qualitative data analysis where processing and analysis of the data was done manually. Descriptive analysis was computed to analyze quantitative data on the respondents' socio-demographic characteristics and presented in form of tables. Qualitative results were presented in narrative with selected compelling exemplar quotes from the interview. The study revealed support care needs are felt in a wide spectrum which includes socio-economic needs such as high cost of treatment, NHIF challenges, long distances to the facility, poor road networks, accommodation challenges, stock out of medication and inadequate infrastructure. Psychological needs are stigma, anxiety, fear, anger, low self-esteem, hopelessness and depression. Informational care needs on diagnosis, treatment, side effects and prognosis. All participants had financial constraints throughout the cancer trajectory due to out-of-pocket expenses. In conclusion it was evident from the findings that cancer patients have a range of supportive care needs in various domains which include financial, psychological, informational and social domains. Therefore, to address the supportive care needs mobilization of resources and formulation of policies will be of paramount importance.



## **CHAPTER ONE**

### **INTRODUCTION**

#### **1.1 Background of Study**

Globally life expectancy for patients with cancer is coupled with poor quality of life has increased sharply, with more than 70% of these patients being unable to afford treatment and quality supportive care (Williams, 2010). The World health organization [WHO] report (2017) projected that by 2035 there will be about 24 million new cases cancer of translating to 14.5 million annual cancer related deaths. A study by International Agency for Research on Cancer (IARC, 2012) on the incidence, prevalence and mortality in the world indicated that there were 850,000 newly diagnosed cancer cases in Africa and predicted that by 2020 there will be 1.056 million new cases. The impact of cancer is far beyond the physical effects of the disease since more adverse consequences are felt in psychological, social and economic domains. Campbell et al (2014) pointed out that globally 61 % of the patients with cancer are believed to suffer from physical, psychological, grief and pain while about 80% of the patients suffer from depressive related symptoms, pain and shortness of breath in their terminal phase of the illness. Land (2012) noted that across the globe cancer has got adverse consequences on physiological, social, spiritual and economical domains of the patients thus the need for support care services. He further argued that globally there are numerous overwhelming challenges for patients with cancer and their families.

Supportive care needs are non-medical needs of cancer patients (Fitch, 2008). Support care gives patients with terminal illness an opportunity to comprehensive palliative services. These services are offered in various settings to include hospital, hospice, palliative centers and homes. Due to lack of support for care needs, people with cancer in United Kingdom experience negative impact (Madams, 2012). To halt this negative impact, support care model will be important because it is holistic focusing not only in clinical but also on other supportive needs. A study in Denmark by Hansen et al (2013) revealed that it is vital to identify support care needs to

enhance quality care of patients with cancer since unmet needs affect their quality of life.

A study conducted in rural Uganda, Kenya, and Malawi by Grant et al (2011) noted that incurable diseases coupled with poverty and pain is common in sub-Saharan Africa where minimal resources and shortage of qualified workforce are common and the major focus is in preventive and curative. Stjernsward (2007) also noted that an approximate of 5.7 million patients in Africa are diagnosed with cancer illness that requires palliative care.

In Kenya, cancer is one of the major causes of mortality. It is estimated that 40,000 Kenyans are diagnosed with cancer annually while more than 27,000 Kenyans die from cancer within the first two years post-diagnosis (Malloy et-al., 2017). According to WHO, over 18,000 Kenyans die annually with up to 60% mortality occurring among people who are in the most productive years of their life (WHO, 2010). The Kenya Health Policy framework (2012-2030) aims at halting the burden of cancer and suffering experienced by patients with cancer through effective cancer management by enhancing supportive care. The National cancer control strategy [NCCS] (2011-2016) report indicated that there are few consultants on oncology and the few available are concentrated in Nairobi thus majority of the patients who require cancer care are left unattended exposing them to more needs related to cancer care. Likewise, the infrastructure for cancer treatment is inadequate leading to unavailability of some cancer treatment options necessitating sourcing for cancer treatment abroad. This delays early treatment of curable cancer, hence advancement of the disease to late stages which are incurable and thus requiring supportive palliation care. The NCCS report further noted that in Kenya there is scarcity of specialists in the public sector. The report further cited lack of awareness, lack of facilities, high cost of treatment and high poverty index as other factors that lead to more needs for patients with cancer, hence the need for supportive care.

A study done in Malawi, Kenya, and Rwanda by Grant et al., (2011) indicated that due to adverse effects of cancer, quality of life of the patients is negatively affected and despite these adverse effects, major focus of cancer care is only in preventive and curative services

## **1.2 Statement of the Problem**

In United Kingdom (UK) very high numbers of unmet supportive care needs are common in patients with cancer; this is due to numerous overwhelming challenges experienced throughout the cancer trajectory (Knowles et al., 2013). In Canada 70 % of the patients with cancer are unable to afford treatment and support care (Williams, 2010). Maddams et al., (2012) stated that 22% of people with cancer in United Kingdom experience negative impacts of the disease due to lack of support care. In Africa approximately 5.7 million patients with cancer require support through palliative care (Stjernsward2007).

A study in Australia by Sanson (2009) on the assessment of quality of life and satisfaction indicated that there was dissatisfaction among cancer patients with the support care given.

Despite the dissatisfaction and an increase in need of support care, there are very few documented studies in sub-Saharan Africa related to support care needs among cancer patients and no such study documented in Kenya. This has led to over-reliance of study findings done in other parts of the world.

Meru hospice serves patients with cancer from four other counties and has got a high prevalence of cancer with a total of 2,418 cases in 2019 (Meru level five hospital Ministry of health [MOH] 746 register). Despite this high prevalence there are no studies documented on support care needs among patients with cancer in Meru County. Therefore, this study explored the support care needs among patients with cancer in hospice in Meru level five hospital, Kenya.

## **1.3 Justification of the Study**

The study area was of importance focus due to high prevalence of cancer cases in the region with a total of 2,418 cases in 2019 (Meru level five hospital, MOH746 register). Despite this high prevalence there are no studies documented on support care needs among patients with cancer in the study area (Meru County). The study

respondents were of keen interest because they are either consumers or providers of the cancer services.

The study findings will be of great importance to management of hospital who are the policy implementers, palliative department as well as academicians. To the management of hospitals, the study findings will be of great importance as it will provide more information on the needs of the patients with cancer hence proper cancer care and quality clinical palliative support care. As a result, this will facilitate reduction of unnecessary suffering of the patients thus fulfilling patients' right as stipulated under international human rights. To academicians, the study will add literature to the existing body of knowledge thus forming a basis for further researches.

#### **1.4 Research Questions**

This study aimed at answering the following questions:

- i. What are the psychological care needs experienced by patients with cancer attending palliative Clinic at Meru level 5 Hospital?
- ii. What are the information care needs experienced by patients with cancer attending palliative Clinic at Meru level 5 Hospital?
- iii. What are the socio-economic care needs among patients with cancer attending palliative Clinic at Meru level 5 Hospital?
- iv. How can support care needs of the patients with cancer attending palliative Clinic at Meru level 5 Hospital be addressed?

## **1.5 Broad objective**

To establish the supportive care needs among patients with cancer attending palliative care clinic at Meru level 5 Hospital.

### **1.5.1 Specific objectives**

This study aimed at achieving the following specific objectives:

- i. To explore the psychological care needs among patients with cancer attending palliative Clinic at Meru level 5 Hospital.
- ii. To determine the information care needs among patients with cancer attending palliative Clinic at Meru level 5 Hospital.
- iii. To establish the socio- economic care needs among patients with cancer attending palliative Clinic at Meru level 5 Hospital.
- iv. To establish measures that may be implemented to address the supportive care needs of patients with cancer attending palliative Clinic at Meru level 5 Hospital.

## **1.6 Scope of the study**

The study was carried out in Meru Level 5 Hospital in the palliative Clinic. The study investigated psychological, information, socio- economic care needs and possible mitigating measures of the same for patients attending Meru palliative Clinic at Meru level 5 Hospital. The findings of this study can be generalized to other setting because it meets naturalistic generalizability. According to Lewis etal.2014, naturalistic generalizability occurs on the basis of recognition of similarities and differences to the results with which the reader is familiar with. It also happens when the research resonates with the reader's personal engagement in life's affairs, experiences, settings they move in, events they have observed, read or heard about and from the people they have talked to. Further the study is line with similar studies carried out in different settings in the globe.

### **1.7 Limitation of the study**

Due to the privacy for cancer patients, some patients were reluctant to give the information about their needs avoiding the possibility of stigmatization by the community. There was a problem with recall of information among the respondents. However, the researcher rephrased the questions to enable the participants recall the information and assured them that the study was only meant for academic purposes and that the information will be treated with confidentiality.

### **1.8 Assumptions of the Study**

In this study it was assumed that the information gathered was only related to experienced care needs for patients with cancer. It was also assumed that the cancer patients gave out the required information for this study.

## CHAPTER TWO

### LITERATURE REVIEW

#### 2.1 Introduction

This chapter covers the literature review related to supportive care needs for cancer patients. The chapter shows both theoretical and empirical literature relating to the variables under study.

#### 2.2 Cancer Trends and Prevalence

Globally life expectancy for cancer patients has been faced by poor quality of life. More cases of cancer are reported every day across the globe with projections of WHO estimating that 24 million will suffer from cancer by the year 2035. WHO further noted that annual cancer related deaths would surpass 14.5 million (WHO, 2017). A study in Canada by Williams (2010) noted that 70% of cancer patients are unable to afford treatment and quality supportive care since the major focus of cancer care targets mostly preventive and curative service with little attention on supportive palliative care. In Kenya, Rwanda and Uganda the impact of cancer is far beyond physical effect of disease, more adverse consequences are felt in psychological, social and economic domains (Grant et al 2011). Twenty two percent of cancer patients in United Kingdom experience negative impact due to lack of support for their care needs (Madams, 2012). Campbell et al (2014) pointed out that globally 61% of the cancer patients are believed to suffer from physical and psychological related symptoms. Further he estimated that 80% of cancer patients suffer from depressive related symptoms, pain and shortness of breath in their terminal phase of illness. WHO (2010) noted that 13% of the deaths globally are related to cancer. This was supported by the WHO (2017) report, which recorded that cancer kills more patients in the world than other diseases. Likewise, Land (2012) argued that globally there are numerous overwhelming challenges for cancer patients and their families. In concurrence with Land (2012), the National Cancer Control and Strategy [NCCS] (2015) further estimates 35 million patients worldwide suffer from cancer.

In the developing world, survival rate of cancer patients is very low than in developed countries. For example, a study by IARC (2012) on incidence, prevalence and mortality in the world indicated that there were 850,000 newly diagnosed cancer cases in developing economies especially in Africa and predicted that by 2020 there would be 1.056 million new cases. Cancer illness especially in developing economies has adverse consequences on physiological, social, spiritual and economical aspects of the patients thus need for support care services (Land, 2012). A study by Grant et al (2011) observed that in Sub-Saharan Africa, incurable diseases coupled with poverty and pain is common where minimal resources and shortage of qualified work force are common and with major focus in preventive and curative service. Stjernsward (2007) noted that approximately 5 .7 million cancer patients in Africa require palliative care. In Kenya cancer is one of the major causes of adult related deaths. WHO (2010) estimated that annual cancer diagnosis in Kenya is around 40,000. Further the report estimates that over 27000 cancer patients die every year, with up to 60% of mortality occurring in the most productive years of life (WHO, 2010).

### **2.3 Cancer patients' needs**

People living with cancer experience numerous needs ranging from financial, psychosocial, and informational. This occurs in various phases of cancer trajectory (MacMillan cancer support, 2015). A study by Butow et al, (2012) in Lincolnshire London indicated that cancer patients from rural communities experience higher needs related to finances, transport and psychological problems. He further indicated that cancer patients often experience unmet needs which are never reported especially after they finish their treatment regimen. Another study in London highlighted that People living with cancer may experience unmet needs during the entire period of cancer trajectory (Boyes et al., 2012).

A study in Canada by Fitch (2008) on supportive care framework noted that cancer patients experience a wide range of needs ranging from psychological, lack of vital information, social economic needs among others. He further argued that there are several domains under support care frame work ranging from psychological,



spiritual, physical, informational, social, and emotional which need to be addressed. Physical domains comprise of nutritional and rehabilitation services while the emotion domain is made up of spiritual, practical, psychological and social domains. Informational domain encompasses cancer patients' navigation, patients and family education. A study in Canada by Land (2012) on co-morbidity and survival after early breast cancer indicated that cancer management focuses mostly on treatment and curative services only. He further urged that this is common in developing countries and is not adequately provided due to lack of expertise and vital resources.

A study by Morhason-Bello et al, (2013) on challenges and opportunities for cancer control in Africa, indicated that there is poor access to care and poor quality of data system in Africa. Similarly, a study by Kingham et al, (2013) on treatment of cancer in sub-Sahara Africa cited poor access to personals as a big obstacle to cancer care. The study further cited inadequate infrastructure and high cost of cancer care to be an obstacle.

A study in Uganda by Orem, & Wabinga, (2009) on the role of Cancer Research Institution in evolving comprehensive cancer control program in developing countries indicated that there is high burden of cancer in Uganda as well as other developing countries in Sub-Sahara Africa. The study further revealed that there is a high morbidity due to cancer which is attributed to late diagnoses and treatment.

Similarly, a study in Tanzania by Lyimo et al, (2020) revealed that like many other Sub Sahara Africa, there is late diagnoses of cancer when the disease has advanced such that cure is not possible; pain and symptoms management becomes the main needs. The study also stated that in Tanzania cancer treatment options covers only a small fraction of the actual need.

A study in Kenya, by Malloy et al, (2017) also revealed that there are numerous challenges affecting cancer care in Kenya; these challenges are further complicated by the Kenya's poverty hence needs for more support care to the patient with cancer.

### **2.3.1 Psychosocial needs**

A study in America by Ross et al (2010) observed that cancer patients in different stages and their caregivers face various psychological needs that affect their quality of life. She further argued that use of a navigator can ease the process of seeking care, hence reduction of psychological needs. Another study in Japan by Onkuyama (2011) indicated that highest unmet needs fall under the psychological domain. Similarly, a study by Lam et al (2011) in Germany and China found out that cancer patients are commonly affected by psychological issues post diagnosis. The Alberta report (2016) on cancer control indicates that distress in families and patients has been evident in relation to psychosocial needs affecting the cancer patients. The report further stated that screening for psychosocial needs is paramount but cancer patients are un-aware of where to assess the services. In Canada, transportation and financial constraint are the key contributors to psychological needs among cancer patients that require intervention (CCA report, 2016).

Andrew (2013) stated that anxiety and depression are other psychological needs that face cancer patients in all stages and that counseling and cognitive behavior therapy on cancer victims showed positive impact to patients and families with anxiety and depression. Another study in Japan by Akechi (2011) on patients' perceived needs noted that psychological issues like anxiety and depression related to cancer are well managed through psychotherapy. He further observed that psychological needs are associated greatly with psychological stress and poor quality of life which can be improved if psychological and informational needs are addressed. On the same aspect, Alberta health service report (2013) indicated that spiritual suffering causes psychological suffering to patients and their families. Cancer patients also need to be guided and comforted spiritually to avoid psychological suffering as experience of connection with Supreme Being acts as a therapy to comfort the patients and family (CCA report, 2016).

A Study in America by Ross et al (2010) on psychosocial adjustment of family caregivers of head and neck cancer survivors, established that there was need for availability of spiritual health practitioners when breaking difficult news to family and patients. This is critical especially where there is no further treatment that can

halt transition to end of life. Distress, depression and anxiety are significantly reduced by spiritual care. In sub-Saharan Africa, family, religious groups can be able to meet some of the psychological, social and spiritual needs and especially at the end of life, (Brem & Kumar, 2011).

A study in South Africa by Rayne, (2017) revealed that 65.4 %of the patients scheduled to undergo chemotherapy treatment have fears to start treatment due to the associated side effects. A study in Tanzania by Swai, (2011) revealed that patients with cancer suffer psychological stress more often than those in general population. Similarly, a study in Kenya by Bosire et al (2020) on psychological effects of chemotherapy indicated that patient with cancer undergoes psychological symptoms related to side effects of the chemotherapy treatment. A study by Ndetei et al (2012) in Kenyatta national hospital on psychological and social profile among patients with cancer revealed that 44% and 66.2% of the patient with cancer suffered from depression and anxiety respectively.

### **2.3.2 Informational needs among cancer patients**

Patients' education is part of informational domain. The latter includes all the information given to patients and the families to empower them with necessary knowledge regarding cancer care and treatment through the trajectory of cancer care to survivorship and end of life. Cancer education enables patients and families to be equipped with information that enables them to be partners in the care, (Cancer Care Nova Scotia, 2016).

A study in Iran by Valizadeh et al., (2012) established that in Iran, Patient with cancer don't get enough information about their illness hence end up obtaining unreliable information from other sources such as relatives and other patients thus higher unmet informational needs. Similarly, a study in Iran by Zamanzadeh et al., (2013) indicated that a cancer patient does not have valid and adequate information about their prognosis thus less understanding of the magnitude of their disease.

A study by Fiszer, et al (2011) on Prevalence, intensity, and predictors of the supportive care needs of women diagnosed with breast cancer showed that informational domain entails navigation and education of the patients and the

families. A study by Canadian Partnership Against Cancer [CPAC] (2012) on guide to implementing and screening for distress stated that navigation entails the entire process of guidance of the patients and family to negotiate through all the process of cancer treatment and care. A study in America by Ross et al (2010) further argued that navigation enables patients to have less barriers when seeking for cancer related services, from the time of diagnosis throughout the trajectory of cancer illness, patients and family experience a lot of anxiety and uncertainty about the expectation, treatment, where to get services and the prognosis thus having a navigator makes this process easier hence reduction of anxiety, distress and uncertainty.

Cancer Journey Portfolio (2012) noted that newly diagnosed cancer patients especially from rural communities experience a lot of difficulties seeking for information on cancer services intended for them. Ross et al (2010) also noted that patients' education is part of informational domain which includes all the information given to patients and their families to empower them with necessary knowledge regarding cancer care and treatment through the trajectory of cancer care to survivorship and end of life. Cancer education enables patients and families to be equipped with information that enables them to be partners in the care (CCA Report, 2016). Imparting patients and families with knowledge of cancer leads to reduction of anxiety, improve decision making on care thus promoting effective coping and adherence during cancer care. A study in Japan revealed that Patient's education needs to be patient centered, evidence based through research and clinical expertise (Akechi, 2011). More information should be availed in different languages and formats. This way it will lead to knowledge sharing, empowerment of patients and the families thus patients' participation to care (CCA Report, 2016).

A study in Kenya by Malloy et al (2017) on palliative care for cancer patients in Kenya indicated that about 80% of the cancer cases in Kenya are diagnosed late due to lack of cancer awareness on signs and symptoms and diagnostic and referral systems. Lack of cancer related education in Kenya, leads to late diagnosis and untimely treatment. He further argued that in Kenya, there are various myths which hinder cancer control and care.

### **2.3.3 Socio-economic care needs among cancer patients**

A study in Lincolnshire by Butow et al, (2012) indicated that cancer patients from rural areas endure much suffering on socio-economic domain especially where they have to travel long distances to access services leading to practical, emotional and financial challenges. Patients who come from rural and isolated urban centers have got additional challenge of navigating through the cancer program, such patients commute long distances in order to access cancer services, thus navigation and informational service would offer them less struggle and distress.

A study in Asia by Lam et al (2011) indicated that there was high unmet support care needs in Asian cancer patients than in western breast cancer patients which showed that culture and health care systems shaped the type of support care needs. Another study by Afaf et al (2013) on physical, psychosocial, relationship, and economic burden of caring for people with cancer stated that access to primary care is critical for early diagnosis since it enables timely diagnosis for cancer. Socio-economic needs faced by cancer patients and caregivers range from and are related to financial constraints, transportation obstacles, poverty and inflexible working conditions, non-availability of services, socio-cultural and gender-related factors among others. In this regard, Ayash et al, (2018) investigated unmet socio-economic needs among Arab-Americans and established that a significant percentage (52%) of patients who receive cancer diagnosis do not initiate or complete treatment due to inability to afford care or fear of financial catastrophe which results to non-attendance to diagnosis, delay and abandonment of treatment among patients with early cancer symptoms.

Afaf et al (2013) further argued that in some settings, as much as 50% of cancer patients forego treatment due to their inability to pay for care. Indirectly, out-of-pocket costs and the time required to seek and navigate care can be burdensome and function as disincentives to accessing timely and affordable treatment. Similarly, a study by Maccimilan Cancer Support Center (2015) indicated that cancer patients experience needs across various domains to include physical, socio-economic, informational and emotional needs.

Those patients who travel from rural areas may incur huge amount of money in transport, accommodation and food which can exceed treatment cost (Canadian cancer society [CCS], 2013).

World Health Organization (2017) report on guide to early cancer diagnosis in Geneva indicated that patients from lower socio-economic groups, those with lower-level of education, people with disabilities, indigenous populations or other socially excluded groups are less likely to be able to access primary care services. As a result, these groups present with emergency symptoms when cancer has already grown and often spread. This is in line with a study by Malloy et al., (2017) on palliative care for cancer patients in Kenya which indicated that 50% of Kenyans live below poverty line thus cost of diagnosis and treatment prohibit most patients with cancer in Kenya from accessing treatment. Malloy et al, (2017) further stated that in Kenya, those who live in remote areas travel hundreds of kilometers to seek medical service. Further, a study by Grant et al (2011) on good death in rural Kenya indicated that rural communities in Kenya have got capacity to care for their patients at home but they lack resources.

In concurrence, another case study in Kenya, by Yonga (2013) highlighted that most of the cancer centers in Kenya, are concentrated in the capital city of Nairobi and patients with from rural areas end up travelling over 600kms to seek for cancer treatment in the city.

Cancer patients are also known to face a lot of stigma which is a sense of devaluation by individuals or communities related to cancer patients. Sometimes patients are embarrassed about the symptoms or fear the financial or personal impact of receiving care for cancer.

#### **2.3.4 Measures to mitigate experienced cancer care needs among patients**

Ayash et-al (2018) recommended that facilities providing comprehensive cancer services should be increased to ensure timely access to diagnosis and treatment and establish a think tank composed of experts from all areas of cancer services to identify major areas of cancer services which require attention. Afaf et-al (2013) noted that improvement of human resources for cancer treatment and palliative care

such as oncology nursing, oncology pharmacy, surgical oncology, and pediatric oncology among others are critical to meeting needs faced by cancer patients and caregivers. Further, WHO (2017) advocated expansion of cancer specialist outreach programmes in medical oncology/chemotherapy at all levels of health care. WHO further noted that there is need to improve the capacity for cancer treatment and palliative services by providing infrastructure, equipment and commodities in order meet the needs of the cancer patients and their care givers.

To fight cancer globally, Akechi (2011) and Fitch et al. (2015) advocated for an increase in overall cancer screening and treatment facilities. Butow et al (2012) and Ayash et al (2018) recommended spiritual and family support care as means of providing support to the cancer patients and affected family members. A study in Kenya, by Malloy et al (2017) and another study in America by Ross et al (2010) recommended that governments should provide means of providing information related to cancers through relevant agencies to ensure that cancer patients and other care givers have a full access to information to fight cancer in a timely manner. Malloy (2017) further stated that governments should establish and improve cancer treatment centers, mobilize financial resources for cancer diagnosis and treatment through advocacy for increased budgetary allocation, supply of up-to-date essential drug lists by integrating it into the national essential drug list, provision of supportive counseling and people centered care and establishment of an institutional framework to coordinate national cancer control activities.

## **2.4 Theoretical Framework**

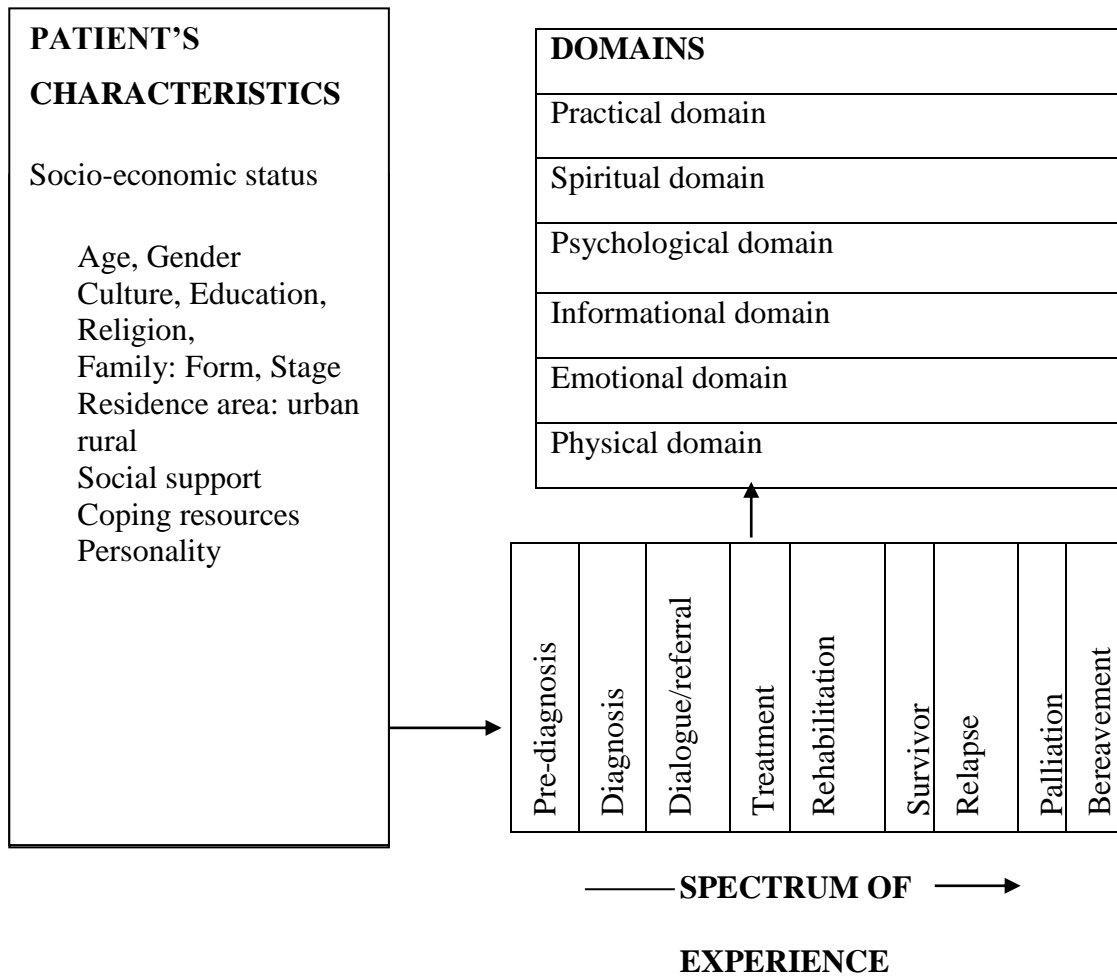
In modern health care, nursing theories assist nurses by offering a number of different strategies and approaches to providing patients with optimal care. This study was guided by two theories namely the need theory and support care theory

### **2.4.1 Supportive care model**

The supportive care model was developed by Margaret Fitch in 1994. It was a tool for cancer care providers to conceptualize on the care needs for cancer patients. The Model tries to explain and understand patients' perspective in the context of family

and individual patients need throughout the trajectory of cancer illness (Fitch, 1994). It draws the construct of human needs, coping and adaptation, how human beings experience and deal with cancer. Family and individual patient experience needs which should be screened and assessed. These needs are beyond physical aspect. They are categorized in various domains that cancer patients perceive they need help with thus easier intervention. The cancer control Alberta's supportive care council report (2016) noted that supportive care frame work model tries to define supportive care in cancer patients and families in order to facilitate good understanding among health care workers which will lead to better care for cancer patients and their families. The framework also represents support care needs and synthesizes the evidence that informs the care provision. The strength of this approach is that it will allow assessment and understanding of patients' needs as perceived by the patients, this will enable delivery of care based on needs raised by the patients themselves. The concept will also serve as guide for making decision about the range of service that should be made available for cancer patients. It will also be useful in guiding research and education programs.





**Figure 2.1: Theoretical frame work for supportive care (Fitch 1994)**

## 2.5 Summary of literature review

Despite the fact that there are extensive studies related to cancer care, most of the studies are based in Europe, America, Asia and Australia. There are very few studies based in Africa particularly in sub-Sahara Africa. There is no documented study in Kenya, particularly in Meru County (the study area) on support care needs among cancer patients. This has led to over- reliance on findings from other part of the world.

## **CHAPTER THREE**

### **RESEARCH METHODOLOGY**

#### **3.1 Introduction**

This chapter outlines the research design and methodology that was applied in conducting this study. It covers research design, target population, sample size and sampling design. The chapter also covers data collection methods, measurement of variables and model specification and data analysis.

#### **3.2 Research Design**

The study employed descriptive cross-sectional design that adopted qualitative approach in data collection. This design enabled collection of data as it was hence describing the phenomena without influencing it. While cross section helped in collecting data at that one specific point in time. Qualitative method was relevant in providing in-depth, detailed information based on an individual's experience, to identify unexpected outcome, to document interaction and responses.

#### **3.2 Study area**

The study was carried out in Meru level five hospital-palliative clinic. Meru level five hospital is a referral and training hospital that offers promotive, curative, palliative and hospice care. It is situated in Meru County about 280 kilometers from Nairobi, Meru County covers 6,936 square kilometers. It borders Isiolo, Tharaka Nithi and Garissa counties. Meru Hospice/palliative clinic serves patients from three counties which include Meru, Tharaka Nithi and Isiolo Counties. The unit offers chemotherapy service, palliative and hospice care to patients.

#### **3.3 Study Population**

A population is defined as an entire group of individuals or objects having common observable characteristic. It refers to the entire group of people, items or things of interest that the researcher wishes to investigate and from which the sample is drawn

and studied (Bowerman, 2012). The study targeted 44 respondents comprising 40 patients diagnosed with cancer attending Meru Palliative Clinic in a month and all 4 medical staff who were working in palliative clinic. They include one oncologist, two nurses and one pharmacist.

### **3.3.1 Inclusion criteria**

The study included patients with cancer over 18 years of age and health care worker (nurses, oncologist and pharmacist) working in palliative clinic.

### **3.3.2 Exclusion criteria**

The study excluded patients with cancer who were severely ill and unable to give information needed.

The study excluded health care workers working in palliative clinic who were not available during the period of the study.

### **3.3.3 Sampling Procedure and Sample Size**

The study employed purposive sampling technique to select the cancer patient respondents for both individualized interview and for the focus group discussions (FGD) while Census was used to select key informants. Census was used to select the all four medical staff. This method was appropriate due to the small sample size of the key informants.

Recruitment of the patients was done with assistance of the nurses and oncologist who work in palliative clinic because of their prior knowledge about them. They identified and referred patients whom they knew could provide the needed and credible information regarding the study. More so they gave contacts of the identified patients to the researcher. Two focused group discussions were enough due to high similarity of the characteristics of the study population which led to results consistent from the two groups. A sample of six participants was selected for each focus group discussion. The size of the group was ideal so that the group is small enough to enable all members to share their thought and yet large enough to create a diverse

group (Lasch et al, 2010). First FGD was composed of male participants only while the second group was composed of female participants only for purpose of homogeneity.

### **3.4. Data Collection Instruments**

The study employed researcher designed focus group discussion guide to collect data during focused group discussion and two different in-depth interview schedules to obtain information from the two sets of respondents (the key informants and the patients). The two mode of data collection enhanced optimal data collection which gave a chance to compensate for the weakness of an individual mode hence improving the quality of data. All data collection tools were designed to gather in-depth information on experienced psychological, informational, socio economic needs for cancer patients and ways to mitigate those needs.

#### **3.4.1 Interview schedule**

Interview schedule was used to collect data from the key informants and from the individual interview with the cancer patients. Questions were mainly open-ended question on various support care needs which included, psychological care needs, informational care needs, socio-economic care needs and ways to mitigate those needs. Open ended questions allowed participants to express their thoughts and feelings. Few closed ended questions on socio-demographic characteristics were included. The content of the tool remained static throughout the interview since most of the probes and responses were encountered in the open-ended questions.

#### **3.4.2 Focus group discussion guide**

This tool was used to collect data during focused group discussion for cancer patients. The tool contained four ground rules to govern participants during discussion and four major areas of discussion which were based on three domains of supportive care needs which included psychological care needs, informational and socio-economic care needs. The fourth part contained discussion guidelines on ways to mitigate those support care needs.

### **3.5 Pretesting**

Pretesting of the data collecting tools was done to cancer survivors attending palliative clinic in Chuka level four hospital. Pretesting sample comprised of five participants (one palliative nurse and four cancer patients). Pretesting helped to check whether the data collecting tools were clear, specific and aligned to the study objectives. This helped to identify errors and refining of the instruments. Results of pretesting enabled the researcher to make corrections, clarification and check for any omission. This helped in validating and ensuring reliability of the data collecting tools. This helped to collect appropriate data and capture the required materials relevant in this study.

#### **3.5.1 Validity of the Instruments**

Validity is the degree to which a research instruments measures what it is supposed to measure. To enhance validity of the data collecting tools, content of the interviews schedule and focus group discussion guide was reviewed with the help of the experts (Doctor specialist working at palliative clinic in Kenyatta hospital) on its relevance to the study. Their suggestions and recommendations were used to improve on the instruments with a view to make it more valid.

#### **3.5.2 Reliability of the instruments**

According to Kasomo (2006) it is vital to test reliability of instruments in order to ensure dependability. He further stated that testing for reliability is important as it refers to the consistency across the parts of a measuring instrument. According to Casey and Murphy (2009) Verifying participants' answers, response uniformity, and within method triangulation provide a construct to test instrument reliability related to the interview questions. Stevenson and Mahmut (2013) asserted that similarity in responses among the participants throughout the interview corroborates the research. In this study, the researcher ensured consistency a cross the measuring tool by comparing and verifying participant's response for uniformity and within method triangulation.

### **3.6 Data Collection Procedure.**

The research started with recruitment and training of two research assistants who were diploma holder nurses working in outpatient department in Meru level five Hospital. Training entailed importance of accurate data, ethical issues to be observed during the study, data collection and participant selection criteria. With the help of the research assistants, the researcher obtained the patients contact addresses and telephone numbers from the hospital palliative care records and scheduled a meeting with each of them at their appropriate time. A common meeting was scheduled for those participants who took part in focus group discussion. Before data collection started, the participants were informed the aim of the study, what was expected from them; ethical issues and issued with participant consent form to read. After understanding the contents of the consent, all participants signed consent form indicating that they are willing to participate in an interview. Those patients who consented for individualized interview made arrangement with the research team on the convenient time for the interview. A common date was set for those who participated in focused group discussion. Local language (Kimeru) was used to conduct the interview. Interview modulation was done by the researcher while the assistance took notes of the interview. The research started by doing individualized interviews to nine study respondents; each interview lasted between 25 and 35 minutes. Individualized interviews were done until saturation of information was achieved. Saturation was achieved when no new information was coming from subsequent interviews and when further coding was not feasible. Further individualized interviews were conducted to all the three key informants who were available at the time of the study. To enhance triangulation of information the research further conducted two focused group discussions to different respondents from those who participated in the individualized interview. The threshold of the two focused group discussion was determined after data saturation was achieved at the end of the second focused discussion. Data from individualized interview enabled the researcher to further probe for more information and validate responses during focused group. Each focused group discussion lasting for approximately one hour. During data collection, ethical issues were adhered to my ensuring privacy and confidentiality through individualized interview and carrying out interview in a

private room. During focused group discussion, ground rules were adhered to and participants were advised that they were under no obligation to answer any questions which they may not have felt comfortable with. The information from both interview and focus group discussions was recorded using a voice recorder and short hand written notes taken by the research assistant.

### **3.7 Data Analysis**

The study employed manual thematic data analysis approach which followed the six steps as outlined by Braun and Clarke (2006). These included; familiarization, coding, collating codes into themes, reviewing of themes, defining themes and producing the report. Familiarization with the data was done which involved manual intelligent verbatim transcription of qualitative audio recorded data, followed by reading through the transcript severally in order to get familiar with the data. Generating of initial codes was done by coding each segment of data set that captured important information about research questions. Codes of similar aspect were collated into a broader theme which was deduced in line with the objectives of the study. Reviewing of themes by research team was done to find out whether they worked in harmony to the coded extracts. This was followed by defining and naming of themes to refine each theme and the overall analysis, generating clear definition of theme names. In the final phase, report production was carried out by interpreting and explaining the data followed by descriptive narrative presentation of the results from both FGD and individualized interview. Quantitative data was analyzed using descriptive statistics and presented in tables.

### **3.8 Dissemination of Results**

Timely dissemination of the study findings will be done to JKUAT University, school of nursing and then to Meru Level 5 Hospital palliative. The researcher disseminated the findings through preparation of manuscripts that will be published in relevant refereed journals and scientific conferences.

### **3.9 Ethical Issues**

Prior to this study, the researcher obtained approval from Jomo Kenyatta University of agriculture and technology (JKUAT) school of nursing. Ethical Review Committee clearance was obtained from Kenya Methodist University (KEMU), Meru level five Teaching and Referral hospital management and from the in charge, palliative Meru level five hospital. Research permit was also obtained from National Council for Science, Technology and Innovation (NACOSTI). Respondents were allowed to participate freely without coercion. Information sheet containing the purpose and content of the study was availed to the participants in order to make an informed consent. Anonymity was upheld by making sure that no identification details of the participants appeared on the transcript instead unique codes were used. The researcher also ensured confidentiality of the information was maintained by ensuring all digital transcriptions are stored in a computer with private a password and printed version stored under locked cabinet till one year after conferment of the degree.



## CHAPTER FOUR

### RESEARCH FINDINGS

#### 4.1 Introduction.

The study used qualitative data collected from Meru level 5 hospital palliative clinic for the period starting December 2019 to January 2020. Results are organized according to the study objectives.

#### 4.2 Socio-demographic characteristics of the participants.

The sample consisted of a total of 24 participants (seven female and two males) who participated in in-depth interview, three key informants, six females and six males who participated in focus group discussions. Majority of the respondents were from rural areas. The age of the respondents ranged between 41 to 79 years. See Table 1 and 2 below for further details of the sample.

**Table 4.1: Key informants characteristics (N=3)**

Characteristic	Frequency	%	Years of exp
Profession			
Pharmacist	1	33%	3
Oncologist	1	33%	2
Nurse	1	33%	10
Gender			
Male	0		
Female	3	100%	

**Table 4.2: Patients' socio-demographic characteristics (N=21)**

<b>Age</b>	<b>Living area</b>	<b>Marital status</b>	<b>Employment status</b>	<b>Diagnosis</b>	<b>Period since diagnosis</b>
<b>Participant for individualized interview</b>					
59	Urban	Married	Business	ca ovarian	< 1 year
61	Rural	Married	Farmer	ca breast	8 years
57	Urban	Single	Business	ca colon	1 year
51	Rural	Married	office work	ca breast	7 years
70	Rural	Married	Retired	ca endometrial	19 months
68	Urban	Married	Business	ca esophagus	2 years
50	Urban	Separated	Business	ca breast	3 years
59	rural	Married	retired	Melanoma	1 year
68	Rural	Married	Farmer	Hodgkin lymphoma	2 years
<b>Participants for female focused group discussion</b>					
52	Rural	Married	Farmer	ca breast	1 year
38	Rural	Married	Business	ca cervix	5 months
49	Rural	Married	office work	ca breast	1 year
69	Rural	Married	Retired	ca breast	2 years
56	Rural	Married	Farmer	ca colon	9 months
54	Rural	Married	Farmer	ca breast	Years
<b>Participant for male focused group discussion</b>					
76	Rural	Married	Retired	Ca prostate	1 years
79	Rural	Widowed	Farmer	Ca prostate	5 months
41	Rural	Married	Farmer	Hodgkin lymphoma	7 months
64	Rural	Married	Farmer	Ca esophagus	1 years
72	Rural	Married	Farmer	Ca prostate	1 year
62	Rural	Married	Farmer	Ca esophagus	7 months

**Table 4.3: Codes and subthemes leading to the outlined results.**

Data extracts from the transcripts	Source	Codes	Sub-theme	Themes
"... people were saying that I am also dying".	Participant 5	Stigma	Stigmatization	Psychological needs
"...Some associate cancer with curses."	KI 1	Stigma		
".. I wonder when this illness will end...".	Participant 4	Worry		
Though am also worried the doctor has told me that this colostomy might not be closed".	Participant 7	Worry	Fear	
"Definitely patients fear chemotherapy related side effects".	KI 2	Fear		
"...Sometimes you fear for your life because you are just taking medication without certainty of the life you are living".	FGD1	Fear	Hopelessness	
Somehow I thought that I am also dying".	Participant 5			
"Patient have very many psychological challenges like anxiety, fear, Hopelessness, ..	KI3	Hopeless, uncertainty, anxiety		
"What really disturb me most is this colostomy bag...".	Participant 7	low esteem/ rejection	low self-esteem and anger	
"My appearance after removal of the breast is a big concern."	Participant 5	low esteem		
"You even feel angered towards people.... ...you think they are coming to see you to find something to talk about".	Participant 9	Anger		
"... in 2018 a biopsy was taken and the hospital administration promised to call me when histology report is out.....but they gave result one year later ( i .e 2019)"	Participant 7	late diagnosis	Diagnosis	informational needs
"I was sick for the last around two years but I was not told which condition am suffering from....".	Participant 3	Delayed information		
".. some may not be aware of their diagnosis."	KI3	Information gap		
"There is lack of enough time because of high work load and shortage of personnel....	KII	Inadequate time	Need for more contact time	informational needs
"We might not have enough time to inform the patients about all the side effect..."	KI2	Inadequate time	Lack of prior-preparation on diagnosis and treatment	
"I did not know what was to be done in theater".	Participant 7	Un informed		
"When patients come here, they have very little or no information about their disease because primary doctors don't break the news"	KI1	Lack of formation		

### **4.3 Psychosocial needs among the participants**

The study sought to establish the psychological needs among the cancer patients attending Meru level 5 hospital oncology clinic. Qualitative data collected indicated cancer patients experience several psychological challenges ranging from anxiety, fear, stigma, uncertainty, hopelessness, depression and insomnia among others. These findings are elaborated in sections 4.3.1 to 4.3.4.

#### **4.3.1 Stigma**

Stigma was one of the major psychological stressors that was experienced by most of the patients as evidenced by the statements below.

*“Stigma is all over ...only that I got used to it but at the beginning it was difficult...even children in the village normally check to see the one who is suffering from cancer...you hear that so and so is suffering from cancer .... her breast was removed (Participant9).*

Another one lamented

*“People thought you are dying. It was a big issue even my friends were nowhere. I had lost my close relatives before hence people thought it was a curse ... people were saying that I am also dying” (Participant 5).*

*“Actually, HIV patients are laughing at cancer patients saying that we will die and live them surviving and laughing” (Participant2).*

The fear of stigmatization (as narrated by the participant 2) could be the reason why another participant stated;

*“I refused to tell people of my condition because they discourage you...like my real brother said to me that you know cancer is killing more than HIV” (Participant 7).*

Another participant said;

*“My big problem is my husband ...he insults me always saying that am about to die... but others encouraged me.... I sometimes think of leaving that family” (Participant 6).*

Stigma was echoed by several of the key informants with one of them stating;

*“Stigma is real for cancer patients; there is a lot of self-stigmatizations... There are patients who think that there is something they did or maybe they did not do.... like they did not pay dowry for their wife and something among other issues. Other form of stigma is from the society regarding dying when a patient is diagnosed with cancer the society believe that you are going to die soon and tend to ignore or neglect you” (Key informant 3).*

In relation to stigmatization for cancer patients, another key informant said;

*“They undergo psychological challenges.... starting with stigma.... cancer is highly stigmatized from this community.... they associate cancer with death. Some relatives don't see any need to bring patients to the hospital because they think the patient will eventually die. They are hopeless...Some associate it with curses and witchcraft or they don't have certainty about their future” (Key informant 1).*

#### **4.3.2 Fear and worries**

Majority of the patients expressed worries after news on cancer diagnosis was communicated to them and also throughout the trajectory as evidenced by the statements below. One of the participants said;

*“I was told of my cancer in 2007 but I stayed at home until 2015 without going to the hospital due to fear, I was shocked and worried that I will die and leave my young children” (Participant 9).*

In relation to worries and fears among the cancer patients, one of them lamented;

*“I am surprised where this condition is coming from....I am not sure about tomorrow... I wonder when this illness will end.... I am worried about my*

*children. I have fear about my life. I am unable to do anything.... It is my daughter who assist me” (Participant 4).*

During focused group discussion, one of the participants had the following to say about cancer related worries and fears;

*“When I received the result, I was told that I have cancer, I felt very bad, cried, I had not been counseled though we only talked this.... we shared a little and felt like I will die. Will this body tolerate these medications, I had a lot of thought. I thought I will die considering my age” (Participant 2).*

The same participant also said;

*“My mind thought of where am going to get money from. This is because I have seen many patients diagnosed with cancer struggle to get money through fundraising and selling their properties” (participant2).*

On the same aspect another participant stated;

*“Though am also worried the doctor has told me that this colostomy might not be closed” (Participant 7).*

One of the key informants echoed about fear among cancer patients by stating;

*“Definitely patients fear chemotherapy related side effects.... Even nurses fear chemotherapy.... Patients are very skeptical on side effects especially when starting chemotherapy” (Key informant 2).*

Similarly, another participant in focused group stated

*“You get worried when you are not aware of the outcome of the treatment...Sometimes you fear for your life because you are just taking medication without certainty of the life you are living.... You are also very worried when you think on where to get money from...even now am worried for many reasons. One is money because am not sure if I will get money for treatment” (FGD 1).*

### 4.3.3 Hopelessness

Several participants in the study said that they experienced hopelessness and lacked certainty in life as evidenced by the utterance by one of them that;

*“Somehow I thought that I am also dying ...I was depressed...I opted to stay at home to wait for my death”* (Participant 5).

### 4.3.4 Low self -esteem and anger

Few of the participants experience low self- esteem and anger. In this case, one of them stated,

*“What really disturb me most is this colostomy bag...I carry it everywhere.... I feel uncomfortable and embarrassed. I feel as if some of my sisters hate me...I feel unwanted and rejected.... but I am hopeful that I will get well”* (Participant 7)

Likewise, one of the participants said;

*“After my breast was removed, I feel uncomfortable especially when wearing cloth like this .one side of my chest is flat....it is embarrassing”* (Participant 6).

Similarly, another participant indicated;

*“My appearance after removal of the breast is a big concern ...I put something there but it is sometimes not comfortable and I fear it will fall off (laughing)”*. (Participant 5)

While another stated;

*“You even feel angered towards people.... You don't want people to come to your home ...you think they are coming to see you to find something to talk about”* (Participant 9).

## 4.4 Informational needs

The study sought to establish the information needs among the patients with cancer attending Meru level 5 hospital palliative clinic. Majority of them felt that information is important throughout the cancer trajectory. That is, during pre-diagnosis, at the diagnosis stage and at the start of the treatment. The findings on different themes under informational needs are presented in sections 4.4.1 to 4.4.3.

### 4.4.1. Diagnosis

Delayed information on diagnosis and staging was evident from the patients and the key informants as evidenced by one of them who stated;

*“It started like a hard skin around five years ago (i.e., in 2015) which was treated.... after two years the problem reoccurred ...in 2018 a biopsy taken and the hospital administration promised to call me when histology report is out.....but they gave result one year later (i. e 2019)”* (Participant 7).

On the same aspect, another one stated

*“I was sick for the last around two years but I was not told which condition am suffering from.... the entire glands on the body were swollen. I have stayed for long without being informed my problem ...I now want to immediately be told which condition am suffering from”* (Participant 3).

Yet another stated that,

*I knew of my diagnosis in August this year after almost one year of being in and out of the hospital with complain of abdominal sounds/ discomfort and blood-stained stool...I was treated for Helicobacter pylori and amoebiasis. In august my condition worsened, with swollen abdomen ... a scan was done which revealed accumulation of gas... (Participant 9)*



Another participant exclaimed;

*“My cancer is in stage four.... I have known it today...actually it is my fellow patient who has seen it written on this paper.... I don’t know what stage four means”* (Participant 4).

Some of the key informants also supported the complaints by patients with cancer in relation to delayed information. One of them said;

*“I will say majority of the cancer patients have little knowledge in terms of staging for various reasons.... some may not be aware of their diagnosis.... Some of the patients come blindly without any information which is a shame.... they are given result and told.... go there, but others are aware of their diagnosis but not too much information about the disease. We are the one who break bad news to them. If it is curable, I tell them but if it palliative I tell them that we are controlling the disease but I don’t tell them about death and dying”* (Key informant3).

#### **4.4.2 Lack of prior- preparation of patients on diagnostic and treatment modalities**

Several participants reported lack of preparation of the patients by the health care workers on cancer diagnosis, treatment modalities and their side effects. This contributed to information gap as stated by one of the participants;

*“I did not know what was to be done in theater I thought they are going to relieve the gas from the abdomen .... From theatre I was shocked to find that this colostomy has been done...actually did not know what the stoma was. Biopsy was sent to KNH.... the result came but they did not tell me what the real problem was ....one day I heard them saying I need chemotherapy.... that is when I started suspecting I had cancer.... I heard one of the doctors telling the other in English “is it not good to tell her?” .... Nevertheless, they did not tell me the diagnosis”* (Participant7).

On the same issue another participant lamented;

*“I blame the doctors because they did not prepare me...that was a big mistake that no counseling was done yet cancer is a killer....I was not very well informed on the side effect of the drug .....Like my entire lower and upper limbs had peeled off.... a thing I did not expect”* (Participant 7).

Likewise, another participant said

*“I was not prepared at all when results came....I was told it is cancer....I felt badly....I cried a lot ‘(FGD1).*

Another participant in FGD stated;

*“I also need to know the cause of dizziness and lack of appetite that am experiencing”.* (FGD2).

These complaints by the participants in the FGD were supported by one of the key informants who stated;

*“When patients come here, they have very little or no information about their disease because primary doctors don’t break the news. When a doctor meets a patient and realizes that the patient has tumor or a growth, they just give false hope that this is a small thing that will go away ...When they come here, they are not aware .... they don’t even know why they are coming to this clinic. We break the news here* (Key informant 1).

#### **4.4.3 Needs for more contact time with health care workers.**

Participants reported that they don’t have enough time with the health care workers. This was attributed to shortage of staffs. One of the key informants stated,

*“There is lack of enough time because of high work load and shortage of personnel...we have one doctor...and two palliative nurses ...We don’t have an oncology nurse.... We only have one general psychologist who is not enough to address patients’ care holistically”* (Key informant 1).

On the same aspect, another key informant said;

*“They also don’t know the prognosis... the doctor tries to explain to them but they don’t understand fully due to lack of enough contact time because of high work load and shortage of personnel. Patients may not have enough contact time with health care workers to disclose their problem due to high work load and shortage of personnel”* (Key informant 1).

She further stated

*“We don’t have patients’ navigator and we need one ...this is because patients don’t know where to get services for example you send a patient to NHIF office.... they like take two hours to get to the office”* (Key informant 1)

Another key informant stated;

*“We might not have enough time to inform the patients about all the therapy side effect... we advise them to report any side effects. We are relying on palliative care nurses to help the patients psychologically but they are also not enough.... because they have numerous duties”* (Key informant 2).

#### **4.5 Socio-economic needs among the participants**

The study sought to establish the socio-economic needs among the patients with cancer attending oncology clinic at Meru level 5 hospital. The findings on different themes that emerged from the findings are presented in sections 4.5.1 to 4.5.7.

##### **4.5.1 Cost of treatment**

All the participants reported that the high-cost medication is overwhelming and sometimes unbearable. One of the participant lamented how all her income was depleted due to the bank loan he acquired to finance her treatments

*“I struggled to raise money...My income was depleted by this illness... no money... I took bank loan seven years ago which I have never fully paid...”* (Participant1).

On the same aspect another participant reported how he was unable to raise money for chemotherapy in one of the private health facility.

*“After a scan I was told that there is fluid in my chest thus need to start more session of chemotherapy at a cost of 57,000 per session which I was to pay in cash. .... I was unable to rise that money...I went home. This is because I had exhausted my NHIF cover” (Participant 4).*

Yet another lamented:

*“The cost of treatment is high...like I take tomoxefn which I buy at ksh 150 per a tablet” (Participant 2)*

On the same issue, another participant lamented;

*“I have spent a lot of money because my NHIF card is not working, everything I pay in cash...like now am not sure what I will be told because am hearing it is a lot of money” (Participant 3).*

On the same issue a participant in FGD said;

*“There is this medication which I take every 3 months which cost me ksh 19000.every month I need ksh 9000 to buy medication” (FGD2).*

These complaints by the participants were supported by one of the key informants who stated;

*“Medication is a bit costly like some of the patients (especially for breast cancer) require a tablet that cost around ksh 190 per tablet that is 84 tablets in month and should be continuous.... We are sticking to first line therapy only...Second line is too expensive for patients” (Key informant 2).*

She further explained the cost of treatment as follows:

*“Some patients are unable to pay for drugs in private chemists when there is stock out in our facility. These leads to missing out of medication actually some miss medication for months because they cannot afford to buy in private chemist. Others patients will go home and keep calling you to ask if there is medication....I had a prostate cancer patient who stayed for months without drug hence disease progression” (Key informant 2).*

#### 4.5.2 National Health Insurance Fund challenges

Majority had an insurance cover (NHIF) which catered for some of their medical expenses; however, all the participants raised challenges related to NHIF which leads to delayed treatment. Majority of the participants raised challenges related to NHIF which leads to delayed treatment. The same sentiments were echoed by the key informants and again during focused group discussion. This is evident below.

*“Several scans were requested.... but NHIF officer refused to approve the two scan but instead they approved only one” (Participant 2).*

On the same issue, participants explained how they were unable to get treatment because they had exhausted their NHIF cover.

*“Sometimes you are told that you have exhausted your NHIF thus you need to spend money ...like I had exhausted mine in February....I spend a lot of money from then till June ...I spent a lot of money ...I almost gave up” (Participant 8).*

Another participant said that they sometimes miss treatment because of the delayed NHIF approval.

*“Sometimes you miss your chemotherapy administration due to delay in authorization of NHIF ... I was told to do MRI scan but is not yet done because NHIF did not approve it...I don't know why it is not approved even now...This long waiting for approval is leading to much suffering” (Participant 6).*

Another participant made suggestion on NHIF cover services.

*“On NHIF cover, there should be no waiting time for card to mature, you should be allowed to use it immediately you register and apply for the NHIF card. Choosing of the hospital should not apply to the cancer patients, they should be allowed to be treated to any outpatient services. Abolishing of pre authorization of all cancer related services because this leads to delaying treatment and it is time consuming for the patients” (Participant 1).*

### 4.5.3 Transport and accommodation expenses

High transport cost also contributed to social-economic support care needs for patients with cancer. One of the participants stated;

*“Transport to Kenyatta and back is high, (in case you are referred) remember you can’t go alone you incur transport expense for two persons every time you go to the hospital. If a patient is very ill, there is problem with transport like now see we are waiting for tax to come”* (Participant 4).

Yet another participant lamented

*“Coming for treatment is a problem due to lack of bus fare that is around ksh1200 per trip”* (Participant 5).

During the focused group discussion, one of the participants had the following to say about transport cost;

*“Transport and accommodation is a problem because I come from far.... I come from (name of the place) ...I spend ksh 400 per day this is too much for me”* (FGD 1).

On the same issue, one of the key informants stated,

*“We attend to patients from very far distance.... remember some patients can’t come alone because of the illness, they are escorted by their relatives ...this is double cost of transport to the family”* (Key informant1).

Accommodation and frequency of hospital visits was validated by the key informants. One of them said;

*“Accommodation is another challenge because patients are forced to be here for 3 days before everything is done. These patients are sometimes told to come biweekly or monthly which is very costly. Due to high cost some patients are unable to return back for treatment.... For example, when patients are sent to Nairobi, they end up not going because they have never been there.... they don’t have anybody in Nairobi to accommodate them.*

*...they refuse to go saying they don't know Nairobi this leads to loss of follow up...They do fund raising to raise fund for treatment” (Key informant 1).*

On the same aspect, another key informant also stated,

*“Sometimes they may come on Tuesday to do lab work and again on Wednesday for review then come again on Thursday for chemotherapy administration. This leads to a big accommodation issue. Sometimes we have patients who sleeps in the hospital awaiting treatment...Some sleep at the waiting bay others in the MCH clinic which is a bit sheltered (laughing), but otherwise we have patients who sleeps at the corridor awaiting treatment (Key informant 3).*

#### **4.5.4 Cost of outsourcing of services and supplies unavailable at the facility**

Participants reported to have been told to buy some of the medical resources and outsource service due to the lack of the same in the facility. This has contributed to support care needs. One of the participants explains how he bought biopsy kit which was not available in the hospital. She stated

*“Biopsy kit was not available I had to buy it at 7000 from Meru town and biopsy cost 4000k which I did not have. I got it as a debt from my friends” (Participant6).*

On the same aspect, one of the key informants stated

*“There are services that are not available in the hospital.... Such services are like endoscope services, specialized surgical procedures, specialized blood test, imaging text and radiotherapy” (Key informant3).*

On the same issue another key informant said;

*“Patients are referred to Kenyatta hospital for radiotherapy because we can only offer chemotherapy and surgical services...The machine needs to be of high quality.... like we have an MRI machine that cannot do pelvic scanning among others” (Key informant 1).*

Yet another key informant stated;

*“The main challenge is stock out... We tell them to buy drug outside but it is only one chemist that stock chemotherapy drugs in Meru.... if not in Meru they can only get it from Nairobi... like we are sticking to first line therapy only. This is because second line is too expensive for patients”* (Key informant 2).

#### **4.5.5 Inadequate infrastructure in the palliative clinic**

This entailed lack of good layout of the palliative clinic and physical structures. Inadequate infrastructure in the clinic leads to suffering of patients. This contributes to support care need for cancer patients. One of the key informants summarized inadequate infrastructure by the statement below.

*“There is only funding for drugs that are available... We have a waiting bay that was donated but there are no enough seats for patients... You find like during chemotherapy day.... the place is very congested.... We need to have unit where we have good patients’ flow.... like patients are moved around because services are not under one roof.... Like no ablution block for this unit, they go to casualty or those which are down there. ...there are a bit far because like when we are administering chemotherapy, they keep going to the washrooms due to hydration”* (Key informant1).

On the same aspect, another key informant said;

*“Infrastructure is a very big challenge.... like now I am actually supposed to be talking to the patients but there is no room for me to attend client in”* (Key informants2).

Similarly, one Participant stated,

*“We stay in the queue for so long and there nowhere to sit on. Enough seats are required in various places like at the pay point and lab”* (FGD2).

Yet another participant in FGD said;



*“Sometimes there are no seats on the queue thus you have got nowhere to seat” (Participant 3).*

On the same aspect of infrastructure, another participant said;

*“No toilets around... Urine start dripping before you gets to the toilet. We need all under one roof, medication, and laboratory” (Participant 4).*

#### **4.5.6 Long distance covered by the patients and poor road network to the facility**

Another challenge was the long distance covered to access services. This was evident from the statement made by all the categories of the participants. One of the key informants stated

*“They come from within the county and outside the county but many a times there are coming from the village, 150 km from here.... you find that if it has rained heavily patients may show up late or may not be able to show up at all because the boda boda (motorbike) they use to get to the main road may not be able to get to their homestead thus patients may not be able to walk” (Key informant3).*

Similarly, another key informant said;

*“We to attend cancer patients from very far distances...Meru teaching and referral hospital is the only hospital around offering cancer treatment. Considering the distance of sometimes more than 500kms” (Key informant 1).*

On the same aspect, one of the participants stated;

*“I comes from far (name of the area) ... I sometime come for three days... I spend ksh 500 each time income here .... per week is ksh 1500.” (Participant4)*

## **4.6 Measures to address the support care needs of cancer patients**

The study sought to explore the measures that may be implemented to address the supportive care needs of cancer patients attending palliative Clinic at Meru level 5 Hospital. Various measures were proposed by the respondents. They included those related to easing of NHIF services, availing services nearer to the consumer, free medication, improvement of infrastructure, formation of support groups and increase in work force in the health care facility. The supportive measures that were highlighted by the cancer patients are further presented in sections 4.6.1 to 4.6.5.

### **4.6.1. Measures to address challenges on NHIF utilization among cancer patients.**

Majority of the patients expressed challenges in utilization of NHIF and therefore they had their various recommendations. One participant said;

*There should be no exhaustion of NHIF card, no approval request as far as your card is functional and no selection of the hospital. Cancer patients can access any hospital, and get free treatment and without choosing the hospital” (Participant 1.)*

Similarly, another participant in FGD stated.

*“NHIF cover for cancer patients should not be getting exhausted and no selection of the hospital” (FGD1).*

Yet another participant said;

*“NHIF should cater for everything and not partial” (Participant 9).*

### **4.6.2 Supportive measures to address accessibility of the services among cancer patients**

Majority recommended availability of the service nearer to their home health care facility. They felt that this will ease the cost of transport. One of the participants said,

*“I pray they bring service to the nearby facilities... like radiotherapy.... instead of being told to go to Nairobi they bring it here (Participant 3).*

Similarly, another participant said;

*“Let the clinic be decentralized this will ease burden of coming here.... like last month I was unable to come due to transport money” (Participant 5).*

#### **4.6.3 Supportive Measures to address the high cost of cancer treatment.**

The cost of treatment was evidently overwhelming thus participants in the study had different recommendations. Such recommendations were free treatment, provision of funds for cancer patients and sponsorship for their children due to lose of livelihoods. One participant in the focused group discussion said;

*“I would request the hospital to provide free cancer treatment ...If HIV patient are getting treatment for free why not cancer patients” (FGD 1).*

Similarly, another participant said;

*We fought for this country thus we need free cancer treatment for the elderly”. (Participant4).*

On the same aspect one of the participants stated;

*“Government should consider cancer patients and provide fund like that of the elderly because we are unable to do our daily work” (Participant 9).*

Another participant felt that the government should consider giving them some monetary assistance. She sated;

*“Our families are poor ... government can be giving us something to feed on ...even our children at home are dropping out of school...If they can get sponsored things would be better” (Participant 7).*

#### **4.6.4 Measures to address information gap and psychological needs among cancer patients.**

Key informants and patients expressed need for more information which included early diagnosis, adequate work force in order to have enough contact time with patients. Transparency of information from the health workers to the patients was also recommended. One of the participants stated,

*“If we can have more doctors that will be very good .... this will be good for us ...that is good”* (Participant 2).

Another participant recommended constant counseling. She stated;

*“Constant counseling is important...even when patients are seated like this; someone should be talking to them and educates them. There should be no approval time for cancer patients”* (Participant 8).

Similarly, another participant said;

*“I would recommend doctors to be open and do counseling to the cancer patients”*. (Participant9).

The participant further recommended formation of support group for cancer patients;

*“I would like this hospital to organize a support group so that we can come and give encouragement to other cancer patients”* (Participant 9).

On the same issue, focused group discussion agreed that there is need for a support group. Participants unanimously stated;

*“There is need to form support group for the cancer patients”* (FGD1).

Hiring of more personnel was also suggested by one of the key informants. The key informant said;

*“Additional support services, hiring of palliative nurses, social workers, and psychologist and having program that these patients can enroll to improve their quality of life” (Key informant 3).*

The key informant further suggested establishment of palliative in various hospitals and to appeal to the NHIF to recognize palliative care as an important component.

The key informant stated;

*“We need to have palliative care practitioner based on various hospitals within the country, to ensure that the NHIF recognizes palliative care and in UHC Palliative is put as an important component” (Key informant3).*

On the same aspect, another key informant stated;

*“The government should strengthen palliative care services in this hospital and the entire country.... all the energy is put only in treatment and leave very little for palliative..., the government should put more resource” (Key informant2).*

#### **4.6.5 Supportive Measures to address unavailability of medical supplies and medication among cancer patients.**

Several measures were suggested by the participants. Such suggestion included offering services under one roof, provision of more furniture, ensuring that there is no stock out of medication, ensuring that cancer treatment services are available, and providing accommodations for patients who are coming from far. In respect to the layout of the hospice unit, participants in the focused group stated;

*“If all the services can be done here it would avoid going around the hospital to service .... It can be of great help.... Sometimes you are unable to walk around (FGD1).*

Another participant from the same focused group said;

*“We need enough and good seats...Like now you see some patients are standing outside due to lack of seat” (FGD1).*

Another participant felt that government should provide prosthesis to the cancer patients who required them.

*Government should avail breast prosthetic device to the cancer patients who underwent mastectomy” (Participant2).*

On the issue of stock out of drugs, one of the key informants said;

*“Government should assist by ensuring that there is no stock out of essential drugs especially analgesic drugs and opioid, because I think the whole last year there was stock out in the most of the facilities in the country” (Key informant 3).*

The same key informant made a suggestion on accommodation of the patients. She said;

*It can have a great relieve to the cancer patients if accommodation arrangement can be done for them” (Key informant 3).*

On the same aspect of accommodation another participant said;

*“We need a separate ward for cancer patients...Like when I was operated, I was put together with the patients who had accident. Everyone was wondering why my breast was removed” (Participant 4).*

## **CHAPTER FIVE**

### **DISCUSSION, CONCLUSION AND RECOMMENDATIONS**

#### **5.1 Discussion of the results**

The discussion was organized based on the results analyzed. It was arranged in order of the objectives of the study.

#### **5.2 Summary of research findings**

This section provides a summary of the findings of the study objective which sort to establish the supportive care needs among patients with cancer. Support care needs include; psychological care needs, information care needs, socio- economic care needs and to explore the measures that may be implemented to address the supportive care needs of cancer patients. The study revealed higher support care needs in various domains which included financial, psychological, informational and social domains.

##### **5.2.1 Socio- demographic characteristics**

A total of twenty-four respondents participated in the study. The twenty-four respondents were divided into four categories. One category of nine patients suffering from cancer (seven female and two males) participated in individualized interview, while the second category was made up of six female patients with cancer who participated in first focused group discussion. The third group was made up of six male patients with cancer who participated in the second focused group discussion. The fourth group was made up of three key informants. Majority of the respondents were from rural areas with only four of them who lived in urban areas. This might have exposed them to social economic needs especially on huge amount incurred on transport and accommodation. This is line with the study in Kenya by Malloy et al (2017) on provision of palliative care of patients with cancer revealed that those living in remote areas suffer most because cancer services are commonly found in big cities where cancer patients in the rural areas are forced to travel

hundreds of kilometers to access these services. The age of the respondents ranged between 41 to 79 years with one of them having separated from the spouse while another one single. Majority (Seventeen) of the study participants were married hence possibility of better family support system. Eight of the cancer patients who participated in the study were farmers, followed by those who ran small business (five). Those who were retired were four while the other two had employment. This is an indicator that their financial capability is limited. Financial related factors play a key role in support achieving support needs for cancer patients. Three of the key informants (pharmacologist, one oncologist doctor and one palliative nurse) participated in the study. They were able to give in-depth information regarding the care needs of the cancer patients. However, the unit lacked other essential professionals like psychologist who could have given more information on psychological care needs.

### **5.2.2 Psychological care needs among the study participants**

The study showed that all of the participants were psychologically disturbed and traumatized after they received the news on cancer diagnosis, and also throughout the cancer trajectory. The study also revealed that some patients with cancer experienced anxiety while waiting the results. This exposed them to more needs on psychological aspects consequently negatively affecting the quality of care for patients with cancer. These findings are in line with a study by Lam et al (2011) in Germany and China which established that cancer patients were commonly affected by psychological issues post diagnosis. This was also similar to the findings of a study in Japan by Okayama (2011) where cancer patients in different stages were faced by many psychological needs that affected their quality of life. Pre-diagnosis health information is essential to alleviate anxiety while waiting for the diagnostic results.

The study showed that the highest unmet needs among the participants are under psychological domain. Worries and anxiety were associated with fear on where to get money, prognosis and outcome of the treatment. This exposes patient to poor quality of life hence more care needs. This was in line with a report in Canada which showed that, transportation and financial constraints were the key contributors



to psychological needs among cancer patients and hence they required intervention (CCA report, 2016). Taking care to the peripheral facilities would otherwise reduce the psychological care needs which are as a result of high cost of navigating the health care system.

The study found out that stigma was associated with some of the beliefs of the society that includes, failure to pay dowry, curses and beliefs that cancer is a death sentence. these beliefs led to hindrances in care seeking behavior of the patients thus more psychological suffering hence more care needs. This is in line with the findings of a study in Kenya, by Malloy et al (2017) on palliative care for cancer patients in Kenya, which indicated that there are various myths which hinder cancer control and care. Continuous public sensitization by the health workers to enlighten the public on cancer to demystify myths on cancer is essential.

### **5.2.3 Informational care needs among patients with cancer.**

It is evident from the study findings that there is need for more information by the patients. Information is needed while waiting investigation result, after diagnosis and throughout the trajectory. It was evident that majorities were from the rural areas and this could have contributed to lack of adequate information regarding cancer. This similar to the report on cancer Journey Portfolio (2012) that noted that newly diagnosed cancer patients especially from rural communities experience a lot of difficulties seeking for information on cancer services intended for them.

The study found out that diagnoses were done after several years of symptoms treatment hence delayed diagnosis. This delay in diagnosis is attributed to lack of information on signs and symptoms of cancer thus detecting of cancer at an advanced stages hence exposing patient to more care needs. This is similar to the finding of a study in Kenya, by Malloy et al (2017) on palliative care for patients with cancer, which indicated that about 80% of the cancer cases in Kenya are diagnosed late due to lack of cancer awareness on signs and symptoms and diagnostic and referral systems. Public sensitization on early signs and symptoms of cancer can be

beneficial to the public hence easier for the public to identify sign and symptoms in order to seek health services before the disease get to the advanced stages. The study also found out that information was important right before diagnosis, awaiting result in order to prepare patients psychologically on the expectation throughout the cancer trajectory. This is attributed to patients' lack of vital information on staging and prognosis of the diseases. This is similar to study in Iran by Valizadeh et al., (2012) which reviewed that Iran patients with cancer don't get enough information about their illness hence ends up obtaining unreliable information from other sources such as relative and other patients thus higher unmet informational needs. Similarly, a study in Iran by Zamanzadeh et al., (2013) indicated that patients with cancer do not have valid and adequate information about their prognosis thus less understanding of the magnitude of their disease. More information is very essential around diagnosis. The study also found out that there is shortage of health care workers thus limited contact time with the patients' hence limited time to convey information. The study found out that lack of patients' navigator was also one of the obstacles in passing of information to the cancer patients. These findings corresponds to a study by Grant et al (2011) on patients' perceived needs in rural Uganda which noted that patient with cancer experiences psychological related issues like anxiety and depression due to challenges in navigating health care system and shortage of qualified work force. Use of patient health care navigators and ensuring enough work force may improve contact time between the patients and health care workers hence enough time to convey information the patients.

#### **5.2.4 Socio-economic needs among patients with cancer.**

The findings of the study showed that the cost of high treatment is overwhelming and sometimes unbearable. The high cost of treatment is attributed to high cost of medication especially when there is stock out, investigations, frequent visits to the hospital, transport, meals and accommodation and long distance to the facility. Due to this high cost of treatment, patient are unable to afford various health services to include diagnosis and treatment consequently some patients are unable to initiate or have delayed commencement of treatment and sometimes unable to complete care and treatment. This exposes them to more suffering and poor quality of life hence

need for supportive care. This is in line with the national research carried out in London by (MacMillan cancer support, 2015) which indicated that patients with cancer have got higher financial needs. The study further showed that some patients were unable to afford treatment due to lack of money attributed to the high cost of treatment. Similarly, it is in line with a study by Ayash et al (2018) on unmet social economic needs among Arabs-American that indicated a significant percentage (52%) of the cancer patients who receive cancer diagnosis do not initiate or complete treatment due to inability to afford care or fear of financial catastrophe which results to non-attendance to diagnosis, delay and abandonment of treatment among patients. Individual causes of high cost of treatment need to be evaluated and addressed.

The study revealed that distance covered by the patients to access services is challenging with some patients covering a distance of around 300kms. Long distance to the facility was attributed by the fact that majority of the patients live in rural areas and some patients travels from far distances of around 300km. This led to high transport cost expenses hence more suffering thus needs for support care. This is in line with a study done in Kenya by Yonga (2013) that highlighted that most of the cancer centers in Kenya are concentrated in the capital city Nairobi thus cancer patients from rural areas ends up travelling over 600kms to seek for cancer treatment in the city. Similarly, a study in Kenya by Malloy et al. (2017) further stated that in Kenya, those who lives in remote areas travel a hundred of kilometers to seek medical service. Another studying Lincolnshire by Butow et al, (2012) indicated that patients from rural areas endures much suffering on social economic domain especially where patients have to travel long distances to access services leading to practical, emotional and financial challenges. Taking cancer related services to the peripheral facility nearer to residential area of the patients can ease the burden of traveling long distances.

The study revealed that majority of the respondents had NHIF related support needs which included, delayed approval, partial approval of the request or partial payment of the hospital bills, getting services from the NHIF selected facilities only and exhaustion of the NHIF cover before the year ends. It was evident from the study that sometimes patients missed chemotherapy administration due to delay in

authorization of NHIF pre-authorization request. This is necessitating an out-of-pocket expense that is not always affordable. consequently, leading to high cost of treatment, psychological stress and delayed treatment. However, some of the patients benefit from waiver system that is introduced by the hospital after the management realized some of the patients were missing treatment. The researcher was unable to find any study done on NHIF insurance challenges thus further challenges need to be explored and addressed.

The study also revealed that palliative clinic had inadequate infrastructure and resources. The unavailability of inadequate infrastructure and other resources in the hospital forces patients to outsource services from the private chemists and others referred to hospitals outside the county for specialized care and treatment hence further suffering due to difficulties in navigating health care system and the high cost attached to it. This study corresponds to the study in United Kingdom by Madams (2009) which showed that cancer patients experience negative impact in their cancer trajectory due to lack of essential resources patients. Similarly, a study in Kenya, Malawi and Uganda by Grant (2011) observed that in sub-Saharan Africa, incurable diseases coupled with minimal resources and shortage of qualified work force are common. Availing more resources may be of beneficial to the patients hence reduction in most of the patient's support care needs

It also revealed that the layout of the hospice clinic is not ideal with some amenities such as toilets, billing office among others are not within the hospice clinic forcing patients to go at a far distance to access these services. These infrastructures related items were reported to affect service delivery to the patients consequently exposes patients to further stress and suffering in navigating the health care system.

#### **5.2.5 Supportive care measures to address the challenges faced by patients with cancer.**

The study revealed various suggestions made suggested by different categories of the respondents. They included those related to easing of NHIF services, availing services nearer to the consumer, free medication, improvement of infrastructure, formation of support group, and increase in work force.

The participants suggested free cancer treatment similar to that offered to the HIV/AIDS patients. They further suggested some fund to be set aside like that provided to the elderly. Sponsorship to their children especially in school fees was suggested by some of the participants. This is because they feel that they are unable to work like for or they have lost their livelihood. More so they incur a lot of out-of-pocket expenses. This in line with the recommendations in a study done in Kenya by Malloy (2017) who recommended that governments should establish and improve cancer treatment centers, mobilize financial resources for cancer diagnosis and treatment through advocacy for increased budgetary allocation, supply of up-to-date essential drug and provision of supportive counseling and people centered care.

The study also revealed needs for more information to the patients especially on the expectation awaiting test results. Cancer awareness and early diagnosis was also suggested. Participants also suggested that counselors and doctors should practice openness when giving out information. They also suggested constant counseling. Further the participants advocated for formation of support group in the hospital so that patients with cancer can come together and give encouragement to each other.

In this study it was evident that there was inadequate contact time between the patients and the health workers due to high work load and shortage of staffs. In this study, participants suggested more staffs to enhance adequate contact time. This is similar to the suggestion made in a study in Australia by Afaf et-al (2013) noted that improvement of human resources for cancer treatment and palliative care such as oncology nursing, oncology pharmacy, surgical oncology, and pediatric oncology among other are critical to meeting needs faced by cancer patients and caregivers. Participant further suggested strengthening of palliative service services in this hospital and the entire country through allocation of more resources to enhance optimal care. This is because all the energy is put only in treatment and leave very little for palliative. Participants also suggested that there should be outreach programs to enable access of the service and low the cost of treatment. The study revealed that participants suggested additional support services, hiring of palliative nurses, social workers, and psychologist various hospitals within the country and having program that these patients can enroll to improve their quality of life. They

further suggested that the government should put more resource to improve palliative service. This is similar to the recommendation made by WHO (2017) for expansion of cancer specialist outreach programs in medical oncology/chemotherapy at all levels of health care. WHO further noted that improvement of capacity for cancer treatment and palliative services by providing infrastructure, equipment and commodities can help meet the cancer patients and care givers. In this study, participants suggested that the government should ensure that the NHIF recognizes palliative care and in UHC palliative is put as an important component. Participants also suggested that waiting time for NHIF card to mature should be abolished. Furthermore the study showed that cancer patients were able to get services from their NHIF hospital of choice a thing that patients felt that should not apply to the cancer patients. Participants suggested that cancer patients should be allowed to visit any hospital and get services because they have numerous medical related challenges.

Need for infrastructure was also evident in this study and various recommendations to address the issue of infrastructure were suggested by the participants. They recommended the improvement of the layout of the oncology unit to ensure all cancer related services are offered under one roof. They further suggested provision of enough furniture especially in the waiting bay, laboratory and at the pay point and construction of a separate ward for the cancer patients to avoid admitting cancer patients together with other patients. An accommodations arrangement for the cancer patients who comes from far distances was also suggested to ensure that they are not spending night in the cold. The study also revealed that there is need for continuous supply of essential drugs and other medical supplies moreover the study revealed that some cancer patients how had undergone surgery required prosthesis.

### **5.3 Conclusions**

It was concluded that patients with cancer experiences supportive care needs in all domains right from the diagnosis, and throughout the cancer trajectory.

The study results showed that the psychological care needs experienced by patients with cancer included stigmatization from the community, anxiety, fear and worries,

uncertainty, hopelessness, depression, rejection, low self-esteem, anger and insomnia.

In addition, the study results revealed that the informational care needs experienced by the patients with cancer included scanty information on cancer diagnosis, treatment, side effects of medication and prognosis; however, they have prior knowledge on high cost of treatment.

The study results further showed that the socio-economic supportive care needs experienced by the patients with cancer range from high cost of treatment, NHIF challenges, financial constraints, long distances to access cancer related services, poor road network, lack of accommodation, stock out of essential medication and inadequate infrastructures.

#### **5.4 Recommendations**

Based on the finding and conclusions of this study, the following recommendations were made.

1. The hospital management should ensure psychological support care needs among cancer patients are addressed through counseling and to put in place measures that minimizes stress to the patients during cancer trajectory. Such measure includes provision of infrastructure, equipment commodities and human resource (Such as palliative care nurses, social workers, patient's navigator, psychologists, and counselors among other to meeting needs faced by cancer patients).
2. The hospital cancer coordination team should ensure socio-economic challenges related to the distance covered by the patients are addressed by expansion of cancer specialist outreach programs for medical oncology/chemotherapy at all levels of health care and to ensure palliative care practitioner are based on various hospitals within the country.

3. Health care workers should provide cancer related information and free screening to raise cancer awareness among patients and the community in every level of health care.
4. The hospital management to introduce waiver system to patients with cancer who may be having challenges with NHIF cover to ensure no patient will miss cancer related services.
5. The hospital management should address socio-economic challenges related adequate infrastructure, equipment commodities, medications/ chemotherapy drugs stock out and ensure services are offered under one roof.

### **5.5 Suggestions for further studies**

A comparative study is suggested between different economies classified by the World Bank i.e., low-, middle- and high-income economies to find out the differences in cancer supportive care needs.



## REFERENCES

- Akechi, T., Okuyama, T., Endo, C., Sagawa, R., Uchida, M., Nakaguchi, T., Furukawa, T. (2011). Patient's perceived need and psychological distress and/or quality of life in ambulatory breast cancer patients in Japan. *Psycho-Oncology* 20, 497–505.
- Andrews, L. (2013) Systematic Review Summary: Psychological interventions to improve quality of life and emotional well-being for recently diagnosed cancer patients. *Singapore Nursing Journal*, 40 (3), 47-49
- Ayash, C., Costas-Muñiz, R., Badreddine, D. *et al.* An Investigation of Unmet Socio-Economic Needs Among Arab American Breast Cancer Patients Compared with Other Immigrant and Migrant Patients. *J Community Health*. 43, 89–95 (2018).
- Bosire A, Mageto I, & Kimani S. (2020) Psychological effects of chemotherapy experienced by patients diagnosed with breast and cervical cancer attending Kenyatta national hospital cancer treatment center *Int J Health Sci Res*. 2020; 10(1):166-174.
- Bowerman, M., Murray, M., Boyer, J., Anderson, C., Kothary, R., Fasudil (2012). Improves survival and promotes skeletal muscle development in a mouse model of spinal muscular atrophy. *BMC Medicine* 2012; 7(10):24
- Boyes, A., Girgis, A., D'Este, C. *et al* (2012). Prevalence and correlates of cancer survivors' supportive care needs 6 months after diagnosis: a population-based cross-sectional study. *BMC Cancer* 12, 150 (2012).
- Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101.
- Brem, S., & Kumar, N.B. (2011). Management of treatment related symptoms in patients with breast cancer. *Clinical journal of Oncology Nursing*, 15(1), 63-71.

- Butow,p., Phillips, F., Schweder, J. et al.(2012). *Psychosocial well-being and supportive care needs of cancer patients living in urban and rural/regional areas: a systematic review*. *Support Care Cancer*, 20, 1–22 (2012).
- Campbell, H., Hotchkiss, R., Bradford, N., & Porteous, M. (2014). Integrated care pathways. *British Medical Journal*, 316, 133–137.
- Canadian Cancer Society. (2013). *Financial hardship of cancer in Canada: A call for action*. Retrieved from <http://www.cancer.ca/~media/cancer.ca/MB/get%20involved/take%20action/financial%20hardship%20of%20cancer%20in%20canada/financialhardshipofcancer-MB-EN.pdf>
- Canadian Partnership Against Cancer & Cancer Journey Action Group, .(2012).*Guide to implementing screening for distress, the 6th Vital Sign. Moving towards person-centered care*. Retrieved from <http://www.cancerview.ca>
- Cancer control Alberta (2016). *Supportive Care Framework Report*. Alberta, Canada: Alberta Health Services. Retrieved from <http://www.alberta.ca › info › cancer>.
- Cancer Journey Portfolio. (2012). *Navigation: A guide to implementing best practices in person-centred care*. Toronto, Ontario: Canadian Partnership against Cancer. 24.
- Cancer Care Nova Scotia. (2016). *Patients' families*. Retrieved from <http://www.cancercare.ns.ca/en/home/ patients and families/default.aspx>
- Casey, D., &Murphy,K. (2009). Issues in using methodological triangulation in research. *Nurse researcher*, 16(4), 40–55
- Cheng, K., Darshini, R., Wong, W., &Koh, C. (2013). Perceived symptoms and the supportive care needs of breast cancer survivors six months to five years post-treatment period. *European Journal of Oncology Nursing*. 2014; 18(1), 3–9.

- da Silva, R. C. F. (2017). Guide to Cancer Early Diagnosis. *Revista Brasileira de Cancerologia*, 63(1), 41-42.
- Fischer, S., Dolbeault, S., Sultan, and A. Brédart, (2014). Prevalence, intensity, and predictors of the supportive care needs of women diagnosed with breast cancer: a systematic review,” *Psycho- Oncology*, vol. 23, no. 4, pp. 361–374
- Fitch M, Zomer S,&Lockwood G, (2015). Experiences of adult cancer survivors in transitions. *Support Care Cancer*. 2019, 27(8):2977-2986.
- Fitch MI (1994). *Providing supportive care for individuals living with cancer*. Ontario Cancer Treatment and Research Foundation, Toronto 3938.
- Fitch,M.(2008).Supportive care framework. *Canadian Oncology Nursing Journal*, 18(1),
- Girgis, A., Lambert, S., Johnson, C., Waller, A., & Currow, D. (2013). Physical, psychosocial, relationship, and economic burden of caring for people with cancer: a review. *Journal of oncology practice*, 9(4), 197-202.
- Grant, L., Brown, J., Leng, M. *et al.* (2011). Palliative care making a difference in rural Uganda, Kenya and Malawi: three rapid evaluation field studies. *BMC Palliative Care* 10, 8(2011).
- Hansen, D., Larsen P., Holm L., Rottmann N, Bergholdt S., Sondergaard J. (2013). Association between Unmet needs and quality of life of cancer patients: a population-based study. *Acta Oncol*. 52(2), 391-9.
- IARC. (2013). *Cancer Mortality Worldwide: Base No. 11*. Lyon, France, International Agency for Research on Cancer. Retrieved from <http://globocan.iarc.fr>
- Kasomo, D. (2006). *Research Methods in Humanities and Education Statistics, Measurement, Evaluation and Testing*.
- Kingham, T., Alatisse, O., Vanderpuye, V., Casper, C., Abantanga, F., Kamara, T., Denny, L. (2013). Treatment of cancer in sub-Saharan Africa. *The Lancet. Oncology*, 14(4), e158–e167.

- Knowles, G., Haigh, R., McLean, C., Phillips, H. A., Dunlop, M. G., & Din, F. V. (2013). Long term effect of surgery and radiotherapy for colorectal cancer on defecatory function and quality of life. *European Journal of Oncology Nursing*, 17(5), 570-577.
- Lam, W. W., Au, A. H., Wong, J. H., Lehmann, C., Koch, U., Fielding, R., & Mehnert, A. (2011). Unmet supportive care needs: a cross-cultural comparison between Hong Kong Chinese and German Caucasian women with breast cancer. *Breast cancer research and treatment*, 130(2), 531-541.
- Land, L. H., Dalton, S. O., Jørgensen, T. L., & Ewertz, M. (2012). Comorbidity and survival after early breast cancer. A review. *Critical reviews in oncology/hematology*, 81(2), 196-205.
- Lasch, K. E., Marquis, P., Vigneux, M., Abetz, L., Arnould, B., Bayliss, M., & Rosa, K. (2010). PRO development: rigorous qualitative research as the crucial foundation. *Quality of life research*, 19(8), 1087-1096.
- Lyimo, E. P., Rumisha, S. F., Mremi, I. R., Mangu, C. D., Kishamawe, C., Chiduo, M. G., & Mboera, L. E. (2020). Cancer Mortality Patterns in Tanzania: A Retrospective Hospital-Based Study, 2006-2015. *JCO global oncology*, 6, 224-232.
- Macmillan Cancer Support (2015). *'Hidden at Home: The social care needs of people with cancer*. London: Macmillan Cancer Support.
- Maddams, J., Brewster, D., & Gavin, A. (2009). Cancer prevalence in the United Kingdom: estimates for 2008. *Br J Cancer*, 101, 541-547.
- Malloy P, Boit J, Tarus A, Marete J, Ferrell B., & Ali Z. (2017). Providing palliative care to patients with cancer: Addressing the needs in Kenya. *Asia Pac J Oncol Nurs*; 4, 45-9.
- Meru level five hospital register (ministry of health [MOH 746]2019).

Morhason-Bello, I. O., Odedina, F., Rebbeck, T. R., Harford, J., Dangou, J. M., Denny, L., & Adewole, I. F. (2013). Challenges and opportunities in cancer control in Africa: a perspective from the African Organisation for Research and Training in Cancer. *The Lancet. Oncology*, 14(4), e142–e151.

National Cancer Control strategy. (2015). *Kenya National Cancer Prevention and Control*. Act <http://www.ipcrc.net/pdfs/Kenya>, 1 Dec 2016.

Ndetei, D., Musibi, M., Mathai, M., Nato, J., Khasakhala, L., Mutiso, V....Kitetu, W. (2011). *The psychological and social profiles of cancer patients seen at Kenyatta National Hospital*. A monograph of Africa mental health foundation.

Nikoletseas, M. (2014). *Statistics: Concepts and Examples*.

Okuyama, T., Akechi, T., & Yamashita, H. (2011). Oncologists' recognition of supportive care needs and symptoms of their patients in a breast outpatient consultation. *Jpn J Clin Oncol*, 41, 1251-8.

Orem, J., Wabinga, H. (2009). The Roles of National Cancer Research Institutions in Evolving a Comprehensive Cancer Control Program in a Developing Country: Experience from Uganda. *Oncology* 2009;77, 272-280.

Orodho A. J (2009). *Elements of education and social science research methods: Maseno-Kenya: Kanezja publishers. ISBN: 978 – 9966 – 7350 – 1 – 1.*

Rayness, S. (2017) fear of treatment surpasses demographic and social economic factors in affecting patient with breast cancer in rural area of south, *Africa journal of global oncology*, 3(2), pp:125-134

Ross, S., Mosher, C. E., Ronis-Tobin, V., Hermele, S., & Ostroff, J. S. (2010). Psychosocial adjustment of family caregivers of head and neck cancer survivors. *Supportive care in cancer: official journal of the Multinational Association of Supportive Care in Cancer*, 18(2), 171–178.

- Sanson-fisher, R.W., A Girgis, A. & Boyes. (2009). The unmet supportive care needs of patients with Cancer, 88: 226– 237, 2009.
- Stevenson, R., &Mahmut, M. K. (2013). Using response consistency to probe olfactory knowledge. *Chemical Senses*, 38, 237–249.
- Stjernswärd, J. (2007). Palliative Care: The Public Health Strategy. *Journal of Public Health Policy*; 28, 42-55.
- Swai, P. (2011). *Psychiatric Morbidity among Adult Cancer Patients Admitted at Ocean Road, Cancer Institute, DareSalaam, Tanzania*.
- Valizadeh, L., Zamanzadeh,V.,& Rahmani, A., (2012). Cancer disclosure: Experiences of Iranian cancer patients. *NursHealth Sci*, 14,250-56.
- Williams, A., Crooks, V., & Whitfiel, K (2010), Tracking the evolution of hospice care in Canada: A comparative case study analysis of seven provinces.*BMC health Services Research*, 10(147).
- World Health Organization, (2010). *Palliative care for older people: Better practices*. Denmark: Regional Office for Europe.
- Yonga,G.(2012).*Case Kenya Study: NCD Situation*. Retrieved from <http://iom.edu/~media/Files/Activity%20File/GlobalcontrolChronicDiseases/Session2Sp2Yonga.pdf>;
- Zamanzadeh, V., Rahmani, A., &Valizadeh, L., (2013). The taboo of cancer: the experiences of cancer disclosure by Iranian patients, their family members and physicians. *Psychooncology*, 22, 396-402.

## APPENDICES

### **Appendix I: Participant invitation**

#### **Supportive care needs for cancer patient in Meru level 5 hospices /palliative unit**

Dear,

Am a student from school of health science at the Jomo Kenyatta university of agriculture and technology Kenya carrying out a study on support care needs for people affected by cancer thus am inviting you to take part in a research study.

The study aims at gaining in-depth insight into the needs of the cancer patient and how those needs can be addressed.

It is the hope of the researcher that the information from this study will enhance service provision and assist in mitigating the challenges encountered by the cancer patient.

The researcher is inviting people who are going through the cancer trajectory to take part in this study. You have been identified as potential participant from an existing case load of cancer patients attending Meru hospice /palliative clinic.

With your consent, we would like to interview you at your convenient time and place. Interview will take approximately 20-30 minutes.

You are free to contact the researcher for more information, advice or any clarification on taking part in the research study through the details provided.

Contact. Mr. Gitonga: +254724710386

DR, Drusilla Makworo, PHD +254721262355

JKUAT-KENYA

Thank you

Yours sincerely

Josphat Gitonga

## **Appendix II: Participant invitation in Meru version**

**Ubataru bwa utungata kiri aajie ba ndwari ya nyiimba ndene ya cibitari ya Meru level 5 gicunci gia utungata bwa mwanya.**

Riitwa riakwa ni Josphat Gitonga, na ndi muritwa wa digrii ya ijiri nkithithagia degree ya master ya science kiri Nursing ndene ya Jomo Kenyatta University of Agriculture and Technology. ndithithia Utwiria buu buriirigiira kuumbura mathiina ja wejani utethio bwa umenyeeri kiri aajie ba murimo jwa nyiimba, kwongu nigukugwata ugeni kithomoni gwia utwiria bubu.

Utwiria buu buriirigiira kuumbura mathiina ja wejani utethio bwa umenyeeri kiri aajie ba murimo jwa nyiimba, na gucoa njira iria ciumba gutethia maubatu jau. Mpumi igatumika kwagirithia mautungata ja utethio kiri aajie jaria jari o na kwou kwagirithia utungata na utethio bwa aajie ba nyiimba. Muchukuni ni akugwata ugeni aajie ba muriimojwa nyiimba kiithomome gikii.

Uri muuthure ta mueejani wa ntento kuuma kiri ibuku ria riri an mariitwa ma aajie ba nyiimba baria bagwataga utungata nyiimba klinikine ya meru.

Waejana rutha (wetikiiria) na gwiikira rwano kiri fomu ya witikira iria uei ukaurua mbiuria ukarite oaria ukegua wiganiirite. Biuria bukajukia kagiita ka ndakinga 20-30.

**Contact details:** Wenda kumenya nteto nkuruki, ncoa na namba ijji cia thimu:

Mr. Gitonga: +254724710386.

DR, Drusilla Makworo, PHD +254721262355

JKUAT-KENYA



## **Appendix III: Participant informed consent form.**

### **PART 1. Participant information**

#### **Introduction.**

My name is Josphat Gitonga, a post graduate student pursuing Master of Science in nursing degree at Jomo Kenyatta University of Agriculture and Technology as one of my requirements of this course am required to carry out a study on supportive care needs for cancer patient in Meru level 5 hospital hospices-palliative unit.

#### **Research Objective**

To establish the supportive care needs among cancer patients attending hospice/palliative care clinic in Meru level 5 Hospital.

#### **Purpose of the study**

The study tries to seek support care needs/challenges for cancer patient and possible ways to mitigate those needs and challenges. Results will be used to redesign the existing support care services and dress support care needs hence significant improvement of support care of cancer patient.

#### **Expectations from the participant**

This study invites health care workers working at hospice clinic and patient attending the same clinic. You are hereby requested to participate in this study voluntarily after reading and understanding the information sheet. You are further requested to consent by ticking consent form provided. Interview will be conducted at a private location of your choice and at your convenient time. With your permission the interview will be audio recorded and typed later. You are under no obligation to participate in this study.

### **Confidentiality**

Any information obtained will be treated with utmost confidentiality, your name will not be recorded anywhere. One of the information will be linked to you and it will be used for the intended purpose only.

### **Compensation**

There will be no payment to the participant

### **Right to withdraw from the study**

Your participation is voluntary and you are free to decline to participate from in the study or withdraw at any stage. Refusal to participate will not in any way deny you rights to services.

**Contact details:** For more information, contact the following numbers:

Researcher: Mr. Josphat k. Gitonga P.O BOX 8 CHUKA +254724710386 .  
[josphatgitnga01@yahoo.com](mailto:josphatgitnga01@yahoo.com)

Supervisors:

Dr, Drusilla Makworo, P.O BOX 62000-00200 Nairobi +254721262355, JKUAT-KENYA,

Dr, Bernard Mbithi P.O BOX 62000-00200 Nairobi Tel 0722321945. JKUAT-KENYA,

Director KEMU-ERC: DR Alex Wamachi P. O BOX 267-60202 Meru

Email:Info@kemu.ac.ke

Thank you.

Yours Sincerely

Josphat Gitonga.

## **Appendix IV: Participant information sheet in Meru version**

### **KIAMBIRIRIA**

Riitwa riakwa ni Josphat Gitonga, na ndi muritwa wa digrii ya ijiri nkithithagia degree ya master ya science kiri Nursing ndene ya Jomo Kenyatta University of Agriculture and Technology. Ya bumwe bwa mantu jaria nkwendekana kuthithiakiri mathomo jaja imbatere gucunkuna ubataru bwa utungata kiri aajie ba ndwari ya nyiimba ndene ya cibitari ya Meru level 5 gicunci gia utungata bwa mwanya.

### **Mworooto jwa Utwiria**

Kumenya maubatu ja umenyeeri kiri aajie ba nyiimba baria bacoaga utungata bwa mwanya cibitari ya Meru.

### **Gitumi gia Utwiria**

Utwiria buu buriirigiira kuumbura mathiina ja wejani utethio bwa umenyeeri kiri aajie ba murimo jwa nyiimba, na gucoa njira iria ciumba gutethia na maubatu jau. Mpumi igatumika kwagirithia mautungata ja utethio kiri aajie jaria jari o na kwou kwagirithia utungata na utethio bwa aajie ba nyiimba.

### **Wirigiuro Kuuma Kiri Mwejani Nteto**

Utungata buu buriita ariti ngugi ba ugima bwa mwiri baria baritaga ngugi cibitari cia utungata bwa mwanya na aajie baria beetaga cibitari iu. Kwou nukuurua wirite gutetheeria kiri utwiria buu nyuma ya kuthomana kwerewa biuria. Nkuruki nukuurua witikire na njira ya wikira rwano rwa kiri fomu ya witikira iria uei. Biuria bikaurirua withone antu aria we ukeenda na kagiita karia we wengwa ukeenda. Niukuurua witigire macookio jaku jajukue sauti na nyumene rwandikwe.

**Witho**

Nteto iria ikeethiranua igeekwa withone, riitwa riaku ritijukia no ariku. Guti nteto ciaku ikaringithanua nawe na igatumirwa kiri ngugi iria ibateere aki.

**Marii**

Guti marii ma mbecha kir acokia ba biuria

**uuge Bwa Kwirita Utwiriene Buu**

Gutetheeria gwaku ni gwa kwirita na uri na ruutha rwa kurega gutetheeria kana kurekana na gucookkia biuria itagariene o rionthe ria utwiria buu. Kurega gwaku gutetheeria gutittima uatwa utungata.

**Contact details:** Wenda kumenya nteto nkuruki, rigira namba iiji cia thimu:

**Muthuthuria:**

Mr. Josphat k. Gitonga P.O Box 8 Chuka +254724710386 .

[josphatgitonga01@yahoo.com](mailto:josphatgitonga01@yahoo.com)

**Murugamiri:**

Dr, Drusilla Makworo, P.O BOX 62000-00200 Nairobi+254721262355.JKUAT-KENYA,

Dr, Bernard Mbithi P.O Box 62000-00200 Nairobi ,Tel 0722321945.JKUAT-KENYA,

**Mwrekeria:** KEMU-ERC DR Alex Wamachi P. O BOX 267-60202 Meru

: Email:Info@kemu.ac.ke

Niwega muno

Nini waku,

Josphat Gitonga.

**Appendix V: Acceptance by the participant.**

I declare that;

**Please Tick**

1. I have read and understood information sheet in this study and allowed to ask questions which were answered and I was satisfied with the response.

2. I understand well that am taking part in this study voluntarily and I can withdraw from the study any time I wish.

3. I understand that there will be STRICT CONFIDENTIALITY.

4. I understand and agree that interview/discussion will be tape recorded and transcribed.

5. I understand that if I may be requested to participate in a group discussion

6. I agree to participate in the study.

Signature (participant)..... Date.....

Signature (researcher)..... Date.....

**Appendix VI: Acceptance by the participant in Meru version**

- Inthomete na ndaciukirwa ni nteto cia utwiria buu na ndaewa kaanya ga kuuria biuria biria bicookeetue na ndang'anirwa ni macokio.
- Ninkumenya bubwega ati nini ncienderete gutetheeria kiri uchunkuuni buu na nombutiganirie kagiita konthe karia nkeenda.
- Ninkumenya nikubatiirie kwithirwa kuri na witho bwa nteto.
- Ninkumenya na ngaitikiiria ati rwaria rukajukua mbica kana kaju na rwanikwe.
- Nikumenya no mbirwe gatanire na babagi rwariene rwa gikundi.
- Ati ningwitikiira guthetheeria kiri utwiria buu.

Kirore (Uria Acoketie Biuria).....

Ntariki.....

Kirore (Muchunkuni).....

Ntariki.....

**Appendix: Interview schedule for key informants.**

Date of interview.....venue.....

Time interview start .....Time interview ends.....

**Section 1: Socio-demographic**

1. What's your gender?

a. Male

b. Female

2. How long have worked at the hospice and palliative clinic.

a. <1 year

b. 1-5 years

c. 6-10 years

d. >10 years

3. What is your Cadre ?

a. Doctor

b. Clinical officer

c. Nurse

d. Pharmacist

## **SECTION 2 GUIDING QUESTIONS.**

1. What are the challenges faced by cancer patients and their impact under the domains below?

- Social economic issues (distance to the facility, finances, accommodation, infrastructures, food, and transport, availability of services.
- Informational challenges on
  - i. Cancer diagnosis and staging,
  - ii. Modalities of treatment and prognosis?
  - iii. Side effects of treatment?
  - iv. Where to get various services and support?
  - v. Cost of treatment?

### **Psychological challenges**

2. What are the psychological needs experienced by the cancer patient. PROBES (Stigma, fear, anxiety, hopelessness, feeling sad, uncertain about the future).

- i. In your own opinion how do these needs affect the patient?
- ii. How do you manage these needs?
- iii. Do you have the capacity to manage psychological needs affecting cancer patient? PROBES (number of psychologist/counselor and their qualification)

3. What would you say about psychological preparedness for cancer patient?

4. What are your suggestions on how to mitigate against psychological needs experienced by cancer patient?



### **Socio-economic needs**

5. What are socio-economic needs experienced by the cancer patient?

PROBES (distance to the facility, finances, accommodation, infrastructures, food, and transport, availability of services. support system.

6. In your own opinion what is impact of these needs to the cancer patient?

7. What are your suggestions on how to address experienced socio-economic needs among cancer patient? By who?.

Thank you.

## Appendix VIII: Interview guide for cancer patients

Date of interview.....venue.....

Time interview start .....Time interview ends.....

Introduction: study, anonymity, confidentiality.

Outline of interview structure.

Retaliate that respondent may chose not to answer and can withdraw from interview at any time.

1. How old are you?.....years.

2. What's your gender?

Male  female

3. Where do you reside?

Rural  Urban.

4. Marital status. Married  single  widowed  divorced

5. What is your occupation?  office work business casual  
worker farmer

6. How long have you been living with cancer?

Less than 1 year ago  1- 2 year ago  3-4 years  
 above 5 years ago.

7. Stage of diagnosis.  early stage  advanced  don't know  
(confirm from medical report)

8. What phase of treatment are you in? (Navigation  treatment,   
follow  Palliation.  (confirm also from the register)

**Exploring psychological, information, social economic needs and possible mitigation of the needs.**

**Psychological care needs**

1. What was your psychological preparedness regarding cancer on?

- Cancer screening, diagnosis and staging?
- Modalities of treatment and prognosis?
- Side effects of treatment?
- Where to get various services and support?
- Cost of treatment?

2. Tell me what are the psychological needs you have experienced during your cancer trajectory? PROBES (Stigma, fear, anxiety, hopelessness, feeling sad, uncertain about the future).

- i. In your own opinion how does these needs affect you?.
- ii. What were your solutions to these needs?
- iii. Tell me how your psychological needs were addressed?
- iv. Probes; by the family, hospital, government, health care provider, clergy, others.
- v. What measures/support would you suggest to enable you meet psychological needs? Probes; by who?

### **Informational care needs**

3. What information did you have on cancer before diagnosis? .
4. Tell me what your experienced informational needs were after diagnosis and throughout the trajectory. Probes on information on?
  - Cancer screening, diagnosis and staging?
  - Modalities of treatment and prognosis?
  - Side effects of treatment?
  - Where to get various services and support?
  - Cost of treatment?
    - i. How did these needs affect you?
    - ii. How were these informational needs addressed and by who? Probes; family, hospital management, health care provider, government, others.
    - iii. What measures/support would you suggest to enable you meet psychological needs?

### **Social economic issues**

5. What social economic needs did you experience?

PROBES (distance to the facility, finances, accommodation, infrastructures, food, and transport, availability of services. support system.

  - i. How these social economic does needs affect you?
  - ii. What was your solution to these needs?
  - iii. How were these social economic needs addressed and by who?

Probes; family, hospital management, government others.
  - iv. What measures/support would you suggest to enable meet your needs (social, economic).
6. Is there anything we have not discussed you want to add?

Thank you.

**Appendix IX: Interview guide for cancer patients in Meru version.**

Tariki ya rwaria.....kuu.....

Thaa jia rwaria kambiria .....Thaa jia rwaria kuthira.....

**Kiambiriria:** kithomo, witha bwa riiwa, witho bwa nteto.

Mukarii jwa muthingatano jwa biuria.

Kinyiiria ati uria agucookia biuria no abicokie na no acirire kiri rwaria ruu kagiita konthe.

**Ukuru Bwaku**

Uri na ukuru bung'ana atia? Miaka.....

- Uri Muka kana Ntomurume?

Ntomurume  Muka

- Utwire naa?

Ntuura  Mucii Munene.

- Uri na Nja? yii  ari  ninkwiririte  nitwatiganire

- Uritaga ngugi iriku?  ya ubici  biacara  kibarua  urimi

- Ukariite na nyiimba kagiita kan'ana atia?

Ruungu rwa mwaka jumwe mwaka 1- 2  miaka 3-4   
nkuruki ya miaka 5

- Yaakuriite atia ikimenyekana? mwambiirione  yaari igukura   
ntimenya

- Ukinyiite naa kiri kurigitwa? ( ucunkuni  urigiti,   
kuthingatiira  Kwewa uumiiria

**Gutegeera maubatu ma kimathugania, kiumenyo na ja kimutuurire na iria maubatu jaja jobikana kuthiirwa.**

**Ubatwi bwa mathugania**

1. Niatia wabangabagitwe inguru ria nyiimba utigasubuke mathuganio?
  - Kuthima nyiimba na kwathura iwango?
  - Moatagaaria ja urigiti na rugendo rwa urigiti?
  - Utungata na umenyeeri bwonekanaga naa?
  - Ngarama ya urigiti?
2. Mbira ni ubatwiii buriku bwa mathugaania wanaitukira rugendone rwaku rwa nyiimba. (uguaa, kumaka, anxiety kuregwa, muthuuro, ioru, na kurega kumenya mwerekera kagiita ga gutuura na nyiimba)?
  - i. Mbira uriito buria ubwatwii bwa mathuganio buretaga kirigwe.?
  - ii. Mbira uria ubatwii bwa ntumiiri bwa ntugatirwe . Uria nkuruki; ni mucii jwaku,, thibitari, thirikari, aritiba gungi ba thirikari, auujia ba kanitha,
  - iii. Ukienda matagaaria/utethio buriku buria ukwendekithia gukuumbithia gukinyaniria maubatu ja kimathugania.

**Umenyeri bwa ubwatwi bwa ntumiiri**

3. Wari na ntumiiri iriku inguru ria nyiimba mbeere umenyeka uria na nyiimba.?
4. Mbiira ni ubwatwii buriku ba ntumiiri ya nyiimba walinabu kuuma wamenyithiwa ulina nyiima mwaka thaa iji..

Probes (uria nkuruki kiri).

- Kuthima nyiimba na kwathura iwango?
  - Moatagaaria ja urigiti na rugendo rwa urigiti?
  - Utungata na umenyeeri bwonekanaga naa?
  - Ngarama ya urigiti?
- i. Mbira uoni bwaku inguru ria urito bwa ubatwii bwa ntumiiri kiriigwe.?
  - ii. Thiina ya ubatwii bwa ntumiiri bwatugatirwe atiana niu? Uria nkuruki, ni mucii jwaku,, thibitari, thirikari, aritiba gungi ba thirikari.

- iii. Ukienda matagaaria/utethio buriku buria ukwendekithia gukuumbithia gukinyaniria maubatu ja kimathugania.

**Gichuchi gia matu ja mbesa na waraniria.**

5. Ni ubwatwi buriiku bwa mbesa na waraniiria uonaga.

PROBES(uria nkuruki kiri).

(rugendo guita thibitari,, mbesa, gwa kulala, miako,irio, garama ya rugendo, kuonekana ga utugata,kugwata mbaru..

- i. ubatwii bubu bwa mbesa na waraniria burin a urito buriku kirigwe.
  - ii. Niatia waruthire gucheria kionia gia ubatwii buu.
  - iii. Thiina ya ubatwii bwa mbesa an waraniria ya thithirwe atiana niu?  
Uria nkuruki, ni mucii jwaku,, thibitari, thirikari, aritiba gungi ba thirikari.
  - iv. Ukienda matagaaria/utethio buriku buria ukwendekithia gukuumbithia gukinyaniria maubatu ja kimathugania.
6. Kuri bu tutiratiga ukwenda kwongeera?

Nibubwega.

## Appendix X: Focused group discussion guide.

Target group.....

Date of FGD.....Venue.....

Time FGD commenced .....Time FGD ended.....

Number of participants invited.....Number attended FGD.....

### Introduction

This discussion seeks to gather information regarding support care needs for cancer patient. This will be factored in improvement of care for cancer patient.

### Focused group participant demographic data.

1. How old are you?.....years.
2. What's your gender? Male  female
3. Where do you reside? Rural  Urban.
4. Marital status. Married  single  widowed  divorced
5. What is your occupation?  office work business casual worker farmer
6. How long have you been living with cancer?  
Less than 1 year ago  1- 2 year ago  3-4 years   
above 5 years ago.
7. Stage of diagnosis.  early stage  advanced  don't know
8. What phase of treatment are you in? Navigation treatment  follow   
Palliation.

### Facilitator's welcome, introduction and instructions to participant

**Welcome** to this gathering and thank you for volunteering to participate in this group discussion. You have been asked to participate because your views are important. I appreciate your time out of your busy schedule



**Introduction:** This focused group discussion aims at gathering your views on support care needs for cancer patient and what can be done to alleviate challenges encountered during cancer journey. Discussion will take approximately one hour and it will be tape recorded. I retaliante that despite being taped, the discussion and participant will remain anonymous.

### **Ground rules**

- Only one person to speak at a time.
- Everyone is urged to actively participate because it is important to get views of each of you.
- Information from this discussion should confidential
- You do not have to agree on views of other people in the group.

**Does anyone have a question before we start?**

### **Introductory question**

Am going to give you a few minutes to think of the challenges /needs encountered during your cancer journey. Is anyone happy to her experience?

### **Guiding questions.**

**Exploring psychological, information, social economic needs and possible mitigation of the needs.**

### **Psychological care needs**

1. What was your psychological preparedness regarding cancer on?

- Cancer screening, diagnosis and staging?
- Modalities of treatment and prognosis?
- Side effects of treatment?
- Where to get various services and support?
- Cost of treatment?

2. Tell me what are the psychological needs have you experienced during your cancer trajectory? PROBES (Stigma, fear, anxiety, hopelessness, feeling sad, uncertain about the future).

- i. In your own opinion how does these needs affect you?
- ii. What were your solutions to these needs?
- iii. Tell me how your psychological needs were addressed?.Probes; by the family, hospital, government, health care provider, clergy, others.
- iv. What measures/support would you suggest to enable you meet psychological needs? Probes; by who?

### **Informational care needs**

3. What information did you have on cancer before diagnosis?

8. Tell me what your experienced informational needs were after diagnosis and throughout the trajectory. Probes information on?

- Cancer screening, diagnosis and staging?
- Modalities of treatment and prognosis?
- Side effects of treatment?
- Where to get various services and support?
- Cost of treatment?

- i. How did these needs affect you?
- ii. How were these informational needs addressed and by who? Probes; family, hospital management, health care provider, government, others.

9. What measures/support would you suggest to enable you meet psychological needs?

### **Social economic issues**

10. What social economic needs have you experience? PROBES (distance to the facility, finances, accommodation, infrastructures, food, and transport, availability of services. support system.

- i. How do the social economic needs affect you?
- ii. How have you addressed these needs?

- iii. How were these social economic needs addressed and by who?  
Probes; family, hospital management, government others.
- iv. What measures/support would you suggest to enable meet your needs  
(social, economic).

11. Is there anything we have not discussed you want to add?

### **Conclusion**

Thank you very much for coming and sharing you thought and opinion. It has been a successful discussion.

**Appendix XI: Focused group discussion guide meru version.**

Gikungi kiriku.....

Tariki ya ya rwaria.....kuu.....

Nthaa jia kwambiria .....Tithaa jia kuthiria.....

Namba ya agwate ungeni rwariene.....Namba ya baria bekinyitie

rwariene.....

**Kiambiriria:**

**Mworooto jwa** Rwaria ruru ni rwa kugwata ntumiri ya Ubataru bwa utungata kiri aajie ba ndwari ya nyiimba ndene ya cibitari ya Meru level 5 gicunci gia utungata bwa mwanya.

**Ukuru bwa aejani ntento cia ngikundi .**

Uri na ukuru bung'ana atia? Miaka.....

1. Uri Muka kana Ntomurume?

Ntomurume  Muka

2. Utwire naa?

Ntuura  Mucii Munene.

3. Uri na Nja? yii  ari  ninkwiririte  nitwatiganire

4. Uritaga ngugi iriku?  ya ubici  biacara  kibarua  urimi

5. Ukariite na nyiimba kagiita kan'ana atia?

Ruungu rwa mwaka jumwe mwaka 1- 2  miaka 3-4

nkuruki ya miaka 5

6. Yaakuriite atia ikimenyekana? mwambiirione  yaari igukura   
ntimenya

7. Ukinyiite naa kiri kurigitwa? ( ucunkuni  urigiti,   
kuthingatiira  Kwewa uumiiria

**8. Kugwata uengeni, kiambirira na ntumiiri ya munchunkui wa ntento kiri  
aejani ntento.**

**Ni nkubugwata uengeni** kiri gikaro ngiki na ni wenga muno niutnu bwa kwirutira kuruta maoni menu ngurubuni inji.muthuritwe ta aaejani ntento niuntu mathuganio na ntento iji cienu ni ciambata muno. Ni buega ningutiga mibago yenu an niutnu bwa thaa jienyu.

**Kiambirira:**Mworooto jwaRwaria ruru ni rwa ginkundi kugwata ntumiri ya Ubataru bwa utungata kiri aajie ba ndwari ya nyiimba. Rwaria ruru rukajukia kagita taka ithaa rimwe .rwaria ruru rukajukua sauti na video na nyumeene rwandukwe. Nteto iria ikeethiranua igeekwa withone, riiwa riaku ritijukia no ariku. Guti nteto ciaku ikaringithanua nagwe na igatumirwa kiri ngugi iria ibateere aki.

**Mawatho makuthigatira rwariene.**

- Omuntu akaragia kagata kae.
- Omuntu niakuurua aenjane ntento niuntu niwega kwigwa maoni ma muntu wothe.
- Ntento iria tukaria ni ja wiitho.
- Nto mwanka witikire maoni ma muntu uria ungi.

**Kwina mtu ari nakiuria mbere twambirira?**

**Kiuria gwa kwambirira.**

Nikubunikera ndakiga nini mbwichire mathina/na ubataru bwenu rugendone ruru rwa nyiimba. Kuriwe akeneerete nteto iria etukiirite?.

**Mbiuuria bia gutwerekeria.**

**Gutegeera maubatu ma kimathugania, kiumenyo na ja kimutuurire na iria maubatu jaja jobikana kuthiirwa.**

**Ubatwi bwa mathugania**

1. Niatia wabangabagitwe inguru ria nyiimba utigasubuke mathuganio?

Kuthima nyiimba na kwathura iwango?

- Moatagaaria ja urigiti na rugendo rwa urigiti?
- Utungata na umenyeeri bwonekanaga naa?
- Ngarama ya urigiti?

2. Mbira ni ubatwiii buriku bwa mathugaania wanaitukira rugendone rwaku rwa nyiimba. (uguaa, kumaka, anxiety kuregwa, muthuuro, ioru, na kurega kumenya mwerekera kagiita ga gutuura na nyiimba)?

- i. Mbira uriito buria ubwatwii bwa mathuganio buretaga kirigwe.?
- ii. Mbira uria ubatwii bwa ntumiiri bwa ntugatirwe . Uria nkuruki; ni mucii jwaku,, thibitari, thirikari, aritiba gungi ba thirikari, auujia ba kanitha,
- iii. Ukienda matagaaria/utethio buriku buria ukwendekithia gukuumbithia gukinyaniria maubatu ja kimathugania.

**Umenyeri bwa ubwatwi bwa ntumiiri**

3. Wari na ntumiiri iriku inguru ria nyiimba mbeere umenyeka uria na nyiimba.?

4. Mbiira ni ubwatwii buriku bwa ntumiiri ya nyiimba walinabu kuuma wamenyithiwa ulina nyiima mwaka thaa iyi..

5. Probes (uria nkuruki kiri).

- Kuthima nyiimba na kwathura iwango?
  - Moatagaaria ja urigiti na rugendo rwa urigiti?
  - Utungata na umenyeeri bwonekanaga naa?
  - Ngarama ya urigiti?
- i. Mbira uoni bwaku inguru ria urito bwa ubatwii bwa ntumiiri kiriigwe.?
  - ii. Thiina ya ubatwii bwa ntumiiri bwatugatirwe atiana niu? Uria nkuruki, ni mucii jwaku,, thibitari, thirikari, aritiba gungi ba thirikari.
  - iii. Ukienda matagaaria/utethio buriku buria ukwendekithia gukuumbithia gukinyaniria maubatu ja kimathugania.

#### **Gichuchi gia matu ja mbesa na waraniria.**

6. Ni ubwatwi buriiku bwa mbesa na waraniiria uonaga.PROBES(uria nkuruki kiri).

(rugendo guita thibitari,, mbesa, gwa kulala, miako,irio, garama ya rugendo, kuonekana ga utugata,kugwata mbaru..

- i. ubatwii bubu bwa mbesa na waraniria burin a urito buriku kirigwe.
- ii. Niatia waruthire gucheria kionia gia ubatwii buu.
- iii. Thiina ya ubatwii bwa mbesa an waraniria ya thithirwe atiana niu? Uria nkuruki, ni mucii jwaku,, thibitari, thirikari, aritiba gungi ba thirikari.

iv. Ukienda matagaaria/utethio buriku buria ukwendekithia gukuumbithia  
gukinyaniria maubatu ja kimathugania.

7. Kuri bu tutiratiga ukwenda kwongera?

Ni wenga muno niuntu bwa kwija na kugaana meshiria na maoni jenu.no  
rwaria rurari na mpumi injega.



**Appendix XII: Permission letter**

Josphat Kariuki Gitonga

Jomo Kenyatta University of agriculture and technology

College of Health Sciences,

School of Nursing,

9/11/2019.

Medical superintendent

Meru Level Five Hospital

P.O Box 8-60200

Meru.

Dear Sir/Madam

**REF: PERMISSION TO COLLECT DATA IN MERU LEVEL FIVE  
HOSPITAL**

I am a student at Jomo Kenyatta University of agriculture and technology studying masters of Science in Nursing. I am carrying out a research project on support care needs for cancer patient attending hospice/palliative clinic in Meru Level Five Hospital. I hereby request for your permission to proceed. Thank you in advance.

Yours faithfully,

Josphat Gitonga

### Appendix XIII: Ethics and review committee approval



KENYA METHODIST UNIVERSITY

P. O. BOX 267 MERU - 60200, KENYA  
TEL: 254-064-30301/31229/30367/31171

FAX: 254-64-30162  
EMAIL: [INFO@KEMU.AC.KE](mailto:INFO@KEMU.AC.KE)

7<sup>th</sup> November 2019

KeMU/SERC/HSN/80 /2019

Josphat Kariuki Gitonga  
HSN311-5076/16  
Jomo Kenyatta University of Agriculture and Technology

Dear Josphat,

**SUBJECT: SUPPORT CARE NEEDS AMONG CANCER PATIENTS ATTENDING HOSPICE/PALLIATIVE CARE CLINIC IN MERU LEVEL 5 HOSPITAL**

This is to inform you that Kenya Methodist University Scientific Ethics and Review Committee has reviewed and approved your above research proposal. Your application approval number is KeMU/SERC/HSN/80/2019. The approval period is 7<sup>th</sup> November 2019 – 7<sup>th</sup> November 2020.

This approval is subject to compliance with the following requirements:

- i. Only approved documents including (informed consents, study instruments, MTA) will be used.
- ii. All changes including (amendments, deviations, and violations) are submitted for review and approval by Kenya Methodist University Scientific Ethics and Review committee.
- iii. Death and life-threatening problems and serious adverse events or unexpected adverse events whether related or unrelated to the study must be reported to KeMU SERC within 72 hours of notification.

- IV. Any changes, anticipated or otherwise that may increase the risks or affected safety or welfare of study participants and others or affect the integrity of the research must be reported to KeMU SERC within 72 hours.
- V. Clearance for export of biological specimens must be obtained from relevant institutions.
- VI. Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. Attach a comprehensive progress report to support the renewal.
- VII. Submission of an executive summary report within 90 days upon completion of the study to KeMU SERC.

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

  
Yours faithfully,  
07 NOV 2019  
Dr. A. Mwachachi  
Chair, SERC

Cc: Director, Postgraduate Studies

## Appendix XIV: Approval from Meru level five hospital

**COUNTY GOVERNMENT OF MERU  
DEPARTMENT OF HEALTH**

Telegrams: "MEDICAL" Meru  
Telephone: Meru 064-32370/1  
Fax: 31242  
Email: [hospitalmeru@gmail.com](mailto:hospitalmeru@gmail.com)  
When replying should be to:  
Chief Executive Officer



MERU TEACHING & REFERRAL HOSPITAL  
P. O. BOX 8 - 00200  
MERU

**Ref: MRU/MED/GEN/R.12** **DATE: 12<sup>th</sup> November, 2019**

---

Josphat Kariuki Gitonga  
Jomo Kenyatta University of Agriculture & Technology  
**College Of Health Sciences**

**RE: APPROVAL TO COLLECT YOUR RESEARCH DATA**

This is to inform you that your request to collect data for your Research on  
" ( Support care needs for cancer patient attending hospice/palliative clinic in  
**Meru Level 5 Hospital)** has been approved.

As per the research ethic approval you are required to ensure you safeguard  
the identity of persons from whom data will be collected.

You will stick to the approved timelines and incase of any extension beyond the  
stipulated 12 months period must be pre-authorized.

You are required to share your findings with this office upon completion.

  
Dr. James Kirmi  
Chief Executive Officer & Maxillofacial Surgeon  
Meru Teaching and Referral Hospital



CHIEF EXECUTIVE OFFICER  
MERU TEACHING AND REFERRAL HOSPITAL  
P. O. BOX 8-00200 MERU

---

Mr. Mtsheck Mutuma M'Muyuri  
CECM- HEALTH  
COUNTY GOVERNMENT OF MERU  
Email: [mtsheck.mutuma@meru.go.ke](mailto:mtsheck.mutuma@meru.go.ke)

Dr. Victoria Kanana Kimonye  
Chief Officer of Health  
COUNTY GOVERNMENT OF MERU  
Email: [kananakimonye@gmail.com](mailto:kananakimonye@gmail.com)



REPUBLIC OF KENYA



NATIONAL COMMISSION FOR SCIENCE, TECHNOLOGY & INNOVATION

Ref No: 819183

Date of Issue: 25/May/2020

RESEARCH LICENSE



This is to Certify that Mr., Josphat Kariuki Gitonga of Jomo Kenyatta University of Agriculture and Technology, has been licensed to conduct research in Meru on the topic: SUPPORT CARE NEEDS AMONG CANCER PATIENTS ATTENDING HOSPICE/PALLIATIVE CARE CLINIC IN MERU LEVEL5 HOSPITAL for the period ending : 25/May/2021.

License No: NACOSTI/P/20/5064

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NATIONAL COMMISSION FOR  
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