

**CORONAVIRUS 2019 PREVENTIVE PROTOCOLS AND CANCER-CARE:  
EXPERIENCES AND PERSPECTIVES OF ADULT CANCER PATIENTS AT  
KENYATTA NATIONAL HOSPITAL CANCER TREATMENT CENTRE.**

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**H56/33590/2019**

**DISSERTATION SUBMITTED IN PARTIAL FULFILLMENT OF THE  
REQUIREMENTS FOR THE AWARD OF THE DEGREE OF MASTER OF  
SCIENCE IN NURSING (ONCOLOGY) OF THE UNIVERSITY OF NAIROBI**

**NOVEMBER 2021**

## DECLARATION

I, Fredrick Manyasi Sifuna, declare that this dissertation is my original work and has not been presented for any examination in any other institution.

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## **ACKNOWLEDGEMENT**

I thank God for his blessings and grace to enable me to write this dissertation. My gratitude goes to my supervisors, Dr. Lucy Kivuti-Bitok and Dr. Angeline C. Kirui for the guidance offered in accomplishing this work. I also thank my family for their support in ensuring the success of this work.

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## **ABBREVIATIONS AND ACRONYMS**

|                 |   |
|-----------------|---|
| ASCO.....       | American Society of Clinical Oncology           |
| COVID-19.....   | Coronavirus 2019 disease                        |
| CTC.....        | Cancer Treatment Centre                         |
| HCW.....        | Healthcare workers                              |
| KEMRI.....      | Kenya Medical Research Institute                |
| KESHO.....      | Kenya Society of Hematology and Oncology        |
| KNH.....        | Kenyatta National Hospital                      |
| NHIF.....       | National Hospital Insurance Fund                |
| QSR.....        | Quality Data Analysis Software                  |
| RAM.....        | Roy Adaptation Model                            |
| SARS-CoV-2..... | Severe acute respiratory syndrome coronavirus 2 |
| SPSS.....       | Statistical Package for Social Sciences         |
| WHO.....        | World Health Organization                       |

## **OPERATIONAL DEFINITIONS**

**Cancer** is a description for a malignant growth in any part of the body.

**Cancer-care** are the services afforded a patient with cancer. These services include treatment modalities, palliative care, psychosocial counseling, investigations like radiography, laboratory among others.

**Patient experience** encompasses the range of interactions that patients have with the health care system, including their care from health plans and from doctors, nurses, and staff in hospitals, physician practices, and other health care facilities. This includes several aspects of health care delivery that a patient values highly when they seek and receive care, such as getting timely appointments, easy access to information and good communication with health care providers.

**Perspectives** refers to two main components that can be highlighted as the views of the patient about their health conditions and views of patients about treatments and their expectations with regard to recovery or management as pertains to Coronavirus 2019 preventive protocols.

**Patient satisfaction** refers to the extent to which services gratify the desires of patients regarding structure, process and outcome dimensions and characteristics. A personal evaluation (or rating) of health care services and providers based on personal preferences and expectations.

**Coronavirus 2019** is a novel virus called severe acute respiratory syndrome coronavirus (SARS-CoV-2) that caused an outbreak of coronavirus disease 2019 (COVID-19) in December 2019. It leads to respiratory illness with symptoms like cough, fever and pneumonia.

**A protocol** is a set of predetermined criteria that define appropriate interventions that describe situations in which one makes judgments relative to a course of action for effective management of common patient care problems.

**Coronavirus 2019 preventive protocols** are predetermined criteria for controlling the spread of the COVID-19 to the population. For the case of COVID-19 or any epidemic countries whose population is at risk come up with protocols to help contain the effect of the epidemics.

**Quality of care** from the patient's perspective can be defined as the totality of features and characteristics of a health care product or services that bear on its ability to satisfy stated or implied needs of the consumers of these products or services.

**The cancer treatment Centre** is a unit which offers its service to patients with cancer that include review of new patients and referrals, chemotherapy admissions, review of patients with results, marking for radiotherapy, out-patient chemotherapy, nuclear patients review, follow-up of patients, joint radiotherapy and ear nose and throat clinic, emergency for radiotherapy.

**Coping mechanisms** are strategies employed by affected individuals in the face of a stressful event or process to help manage painful or difficult emotions.

## ABSTRACT

**Background:** This study was conducted in the month of September, 2021 to explore adult cancer patients' experiences and perspectives on cancer care during implementation of COVID-19 prevention protocols. The rationale was to fill the gap in knowledge on adult patient experiences and perspectives on cancer care, develop further understanding of the clinical situation, inform more integrated approaches to treatment of cancer patients during the COVID-19 pandemics and future pandemics.

**Methods:** The study was a cross sectional survey that employed a face- to- face in-depth interview method approach. The study targeted adult patients with cancer on follow-up or on active treatment attending clinics or had been/were admitted at CTC in KNH between March 2020 and May 2021 and understood English and/or Kiswahili language. The sample size (12) for the study was based on the data saturation; the point in data collection when new data no longer brings additional insights to the research questions. Purposive sampling was employed. Pretesting of the In-depth interview guide was carried out in two of the cancer units at KNH that did not take part in the main study (adult haemato-oncology clinic 23 and adult ward 8C). Approval to conduct this study was granted by Kenyatta National Hospital (KNH)- University of Nairobi Ethics and Research Committee reference number KNH-ERC/A/305 dated 06 September, 2021 (P353/05/2021). Approach to data analysis was by content analysis technique for qualitative data. Audio Recorded data was transcribed and entered into a computer through a word processing program. QSR International's NVivo 11 Software was employed while demographic data was checked for completeness and keyed into a computer program, statistical package for social scientist version 28.0 for analysis. Data was presented in frequency tables and emerging themes.

**Study Findings:** The respondents were of varied socio-demographic and clinical characteristics. Various themes emerged from the respondents' reports. Cancer services were accessed by adult patients at the study area though some respondents had difficulties in attending services. COVID-19 preventive protocols implementation effects on patients included financial hardship, psychological effects like fear of infection, social isolation and physical health deterioration. Generally, the respondents who received services were satisfied with cancer care services afforded to them. The study respondents employed various coping mechanisms like seeking divine intervention, seeking financial assistance, reduction in expenditures and adherence to preventive protocols.

**Conclusion:** The respondents continued receiving cancer care at study site of which most of the respondents were able to access. The study respondents experienced adverse economic effects, physical health deterioration, social and psychological effects during COVID-19 implementation period. The respondents were satisfied with the services provided and employed various coping mechanisms to contain the effects of the pandemic preventive protocols' implementation on their care.

**Recommendation:** The study recommends increase in clinic days to include weekends to cater for a large number of patients. An upgrade of the National Hospital Insurance Fund (NHIF) scheme to cover most if not all the cancer care services in line with universal health coverage goals is a necessity. The study also recommends that cancer centres should be decentralized to counties to make patients access cancer services with ease especially during pandemics.

**Key words:** COVID-19 pandemic, cancer care, patient experiences, patient perspectives, cancer, preventive protocols

## **CHAPTER ONE: INTRODUCTION**

### **1.1 Background Information**

Cancer makes up to 7 percent of all reported deaths in Kenya. Approximately 70–80% cancer cases are diagnosed in advanced stages. Healthcare workers are left to ponder on how to provide care to cancer patients and at the same time avoid exposure to Coronavirus 2019 (Kassaman et al., 2020). Cancer care are the services afforded a patient with cancer. These services include treatment modalities, palliative care, psychosocial counseling, investigations like radiography, laboratory among others. Cancer care has been disproportionately affected by Covid-19 (Rosenbaum, 2020). It is of necessity that patients attend clinics for various reviews, investigations and other interventions to assess the progress of their treatment.

ASCO, (2020) in Singapore found that 66% of patients, 72.8% of caregivers, and 41.6% of healthcare workers had a great level of fear from Coronavirus. Patients had 19.1%, caregivers had 22.5% while healthcare workers had 14% prevalence of anxiety (Ting et al., 2020). Coronavirus has disrupted cancer care world over. Sensitization among the public on Cancer awareness, screening and avoidance of the risk factors as well as follow up would be of public health interest. Whereas the developing countries in Africa, Kenya included, have been battling communicable diseases as their main public health priority, non-communicable diseases and mainly cancer are becoming a great public health concern. Access to care is a challenge and this has been complicated by the COVID-19 pandemic.

Adult patients may have had different experiences and perspectives in the wake of COVID-19 pandemic preventive protocols. This has also affected the way follow up clinics run in health institutions. Some clinics including cancer clinics have had to reschedule clinics to suit the situation at the same time provide the much-needed services to their clients. These services include investigations, medical and surgical reviews, disease process monitoring among others.

The Coronavirus 2019 disease is caused by Coronavirus type 2 (Liang et al., 2020) and has exhausted hospitals resources (Sohrabi et al., 2020). The virus originated from the town of Wuhan in China in December 2019 and coronavirus disease was declared a pandemic in March, 2020 (del Rio and Malani, 2020). COVID-19 disease curtailed care provision in healthcare facilities and therefore affected cancer care (Indini et al., 2020). Some of these impacts include rescheduling of clinics, missing out on various investigations and anxiety among patients and financial constraints. A number of ministries of health protocols have been developed to guide management of patients including cancer patients in various countries.

In Kenya, available cancer care institutions are in urban areas. Cancer patients travel to urban areas to seek cancer care. Many factors affect the delivery of cancer. Some of them are lack of finances, poor infrastructure, fewer wards for cancer patients and limited accommodation in towns hence denying cancer patients on time and appropriate health care and other services (Makau-Barasa et al., 2020). The stringent protocols instituted by the Kenya Government in April 2021 to restrict intercounty movement may have effects on cancer care among adult patients.

Kenyatta National hospital offers different health services which include medical and surgical outpatient services, in-patient services, various clinics which include comprehensive care clinics and cancer treatment centre clinics.

### **1.2 Study purpose**

The study explored adult cancer patients experiences and perspectives of COVID-19 preventive protocols on cancer-care at Kenyatta National Hospital Cancer Treatment Center. The aim was to draw on patients' experiences and perspectives and on how implementation of COVID-19 prevention protocols has influenced cancer care. This was to inform best design and review of the implementation approaches to ensure cancer care services are provided with minimal interruptions.

### **1.3 Statement of the problem**

Cancer makes up to 7 percent of all reported deaths in Kenya. Approximately 70–80% cancer patients are diagnosed in the advanced stage. Healthcare workers are left to ponder on how to provide care to cancer patients and at the same time avoid exposure to Coronavirus 2019 (Kassaman et al., 2020). Cancer patients require access to healthcare facilities more frequently and any obstacle to their care will lead to complications that can be fatal (Neal et al., 2015). Cancer patients have low immunity and coronavirus infection may complicate their condition (Liang et al., 2020). Consequently, cancer patients may forego treatment for fear of getting infected with coronavirus in the course of attending clinics and other services (Burki, 2020). Cancer patients are more likely to experience complications should they contract COVID-19. This is possible in case they are undergoing chemotherapy, radiation or after operation. This qualitative study intends to draw on patients' experiences and perspectives and identify needs and make recommendations on measures that will address cancer care.

De Joode et al found out that thirty percent of cancer patients had to shift from hospital visit to review through telephone and teleconference. The changes occurred in those patients receiving cancer drugs (30%) and immune therapies (32%). Among those who experienced a delay and whose therapy was halted, 55% and 63% of patients, respectively, were (very) concerned about these consequences of the Coronavirus disease (de Joode et al., 2020). The protocol of keeping social distance and quarantine brings loneliness among cancer patients. Cancer itself causes social and psychological turmoil among

those diagnosed and their families. There is need for support of these patients to enhance their wellbeing (Smith et al., 2011) since this offers protection against physical morbidity and mortality (Pinquart and Duberstein, 2010).

Many countries world over Kenya included came up with protocols to be observed during Covid-19 pandemic including social distancing, wearing of face masks, restricted movement, quarantine among others. Kenyan government continues to impose more stringent measures to contain the spread of the virus, the latest having been imposed in April 2021. Health institutions also came up with protocols to help respond to the pandemic. According to data records at KNH there was a decrease of 31% patients' attendance at outpatient CTC in 2020 compared to 2019. Cancer treatment centre attendance reduced by 21% while in-patient number reduced by 23% in 2020 compared to 2019 ("Statistics unit, KNH (unpublished)," 2021). According to the same data there was a reduction in number among the treatment modalities of those who received COBALT (20%), LINAC (23%) and chemotherapy (33%) services in 2020 compared with 2019 ("Statistics unit, KNH (unpublished)," 2021). There are limited qualitative studies on adult patients' experiences and perspectives of Coronavirus 2019 preventive protocols on cancer care more so in a national referral hospital in Africa. This qualitative study intends to draw on patients' experiences and perspectives and identify needs and make recommendations on measures that will address cancer care.

#### **1.4 Significance of the Study**

The study findings are useful and act as a reference to a number of healthcare institutions offering cancer care in Kenya. The study sought to elucidate information on patients experiences and perspectives of COVID-19 preventive protocols and cancer care. The findings will inform the design of patient centered measures based on qualitative data. It is hoped that the study findings will benefit the communities in terms of addressing needs of patients during Covid-19 pandemic. Strategies put forward will help alleviate patient harm in current and future pandemics. Researchers may use this research findings as a basis to replicate the study in other areas and for policy formulation. The study rationale was to fill the gap in knowledge of adult cancer patient experiences and perspectives on cancer care during implementation of COVID-19 pandemic protocols in a national referral hospital setting, develop further understanding of the clinical situation, inform more cost-effective approaches to treatment of cancer patients during the COVID-19 pandemics and future pandemics.

#### **1.5 Research Questions**

- i. What are the experiences of adult cancer patients on hospital cancer care at KNH CTC following implementation of COVID-19 preventive protocols?

- ii. What are the cancer patients' perspectives on cancer care at KNH CTC following implementation of COVID-19 preventive protocols?
- iii. What are the effects of implementation of COVID-19 preventive protocols on adult cancer patients on care at KNH CTC?
- iv. What are the coping mechanisms and support employed by adult cancer patients during cancer care following implementation of COVID-19 preventive protocols at KNH CTC?

### **1.6 Broad Objective**

To establish the adult patients' hospital experiences and perspectives of COVID-19 preventive protocols implementation on cancer-care at Kenyatta National Hospital Cancer Treatment Center.

### **1.7 Specific objectives**

- i. To establish the experiences of adult cancer patients on hospital cancer care at KNH CTC following implementation of COVID-19 preventive protocols
- ii. To explore perspectives of adult cancer patients on cancer care at KNH CTC following implementation
- iii. To assess effects of implementation of COVID-19 preventive protocols on cancer care of adult cancer patients at KNH CTC
- iv. To identify types of coping mechanisms and support employed by adult cancer patients during cancer care following implementation of COVID-19 preventive protocols at KNH CTC

## **CHAPTER 2: LITERATURE REVIEW**

### **2.1 Introduction**

This chapter included literature on the experiences of adult cancer patients, their perspectives of Coronavirus 2019 preventive protocols and cancer care, and the effects of Coronavirus 2019 pandemic preventive protocols on cancer care is reviewed. Other literature reviewed included cancer burdens, COVID-19 pandemic, preventive protocols, their effects on clinic attendance, treatment modalities and psychological effects on cancer care among patients and strategies employed during the COVID-19 pandemic.

### **2.2 The Cancer burden**

The cancer burden was at 18.1 million new cases and 9.6 million deaths in 2018 all over the world. More men than women worldwide are affected and die from cancer during their lifetime. A five-year survival rate is approximated to be 43.8 million all over the world (Bray et al., 2018). It is the second cause of death globally. Cancer patients appear to have approximately twice increased risk of contracting novel SARS-CoV-2 than the general population (Schade et al., 2020). There is a need to counter the effect of this disease on patients with cancer. The strategies may include availing resources and clinical assistance to patients.

Seven percent of deaths in Kenya are as a result of cancer making it the third cause of death (Bray et al, 2018; Kassaman, Kimani and Lusambili, 2020). There is a limited number of healthcare centres and qualified healthcare workers specialized to manage patients diagnosed with cancer in Kenya. Most of the cancer facilities are found in towns leaving the majority of cancer patients who live in rural areas with challenges of their care. Cancer patients travel to urban areas to seek cancer care. Lack of enough finances, poor infrastructure, fewer wards and limited accommodation affect cancer care provision (Makau-Barasa et al., 2020). This has been complicated by COVID-19 pandemic.

### **2.3 Coronavirus disease 2019**

The COVID-19 virus type two caused an epidemic of coronavirus disease 2019 in December 2019 in Wuhan, China. It leads to respiratory illness. Approximately 33% of patients with Coronavirus present with complications (Al-Quteimat and Amer, 2020). The coronavirus 2019 disease affected medical and surgical services across the world especially oncological services (Nnaji and Moodley, 2021). Currently, there are approved vaccines from pharmaceutical companies.

In Kenya Coronavirus disease 2019 was first confirmed on 13<sup>th</sup> March 2020. As of 27<sup>th</sup> April 2020, and 363 were confirmed with 114 recovered cases and 14 deaths. Since then, there were sustained transmissions spreading from urban centres to rural places (“The evolution of the COVID-19 pandemic in Kenya | RSTMH,” 2020).



According to the KEMRI report 2021 about one million people were to get coronavirus infection in Kenya before June 2021 and would result in about 289 new coronavirus related deaths. Two variants of the SRS-CoV-2 have been identified in Kenya — the B.1.1.7 from the UK and the South African variant (N501Y) that infects faster. Nairobi county and Mombasa County will have the highest attack rates. The government locked Nairobi, Mombasa, Kiambu, Nakuru and Kajiado in April 2021 due to the high numbers of cases. (“Bmutanu@ke.nationmedia.com.,” 2021). Cancer patients had different susceptibility to Coronavirus infection. This Coronavirus risk can help shape national social isolation policies (L. Y. W. Lee et al., 2020).

Coronavirus affected people's lives and disrupted cancer care (Veronesi, & Corso, 2020). Various healthcare facilities adapt to assure optimal care to the patients. Resources have been rerouted to manage emergency conditions and COVID-19 related illness. Mobility restrictions meant cancellation of meetings, conferences and training (Saini et al., 2020). Cancer care involving prompt diagnosis, surgeries and follow up have been affected during this period of the pandemic. A study by Li et al., (2020) found that patients with cancer did not receive necessary management. Surgical cases reduced from 16.4% in December 2019 to 2.6% in February 2020.

Jazieh et al 2020 found that most institutions (88.2%) reported facing challenges in delivering care during the pandemic. Although 55.34% reduced services as part of a preemptive strategy, other common reasons included an overwhelmed system (19.94%), lack of personal protective equipment (19.10%), staff shortage (17.98%), and restricted access to medications (9.83%). Institutions (46.31%) reported missing at least one cycle of therapy by 10% of patients.

#### **2.4 Covid-19 pandemic preventive protocols**

Coronavirus protocols were put in place by many countries worldwide to contain the spread of the pandemic. In the case of COVID-19 or any pandemic, all countries came up with protocols to help prevent spread of the disease. A multisectoral task force called National Emergency Response Committee (NERC) was formed to help come up with guidelines that could contain the spread of infection, guide management of cases and surveillance in Kenya. (“The evolution of the COVID-19 pandemic in Kenya | RSTMH,” 2020).

Corona virus 2019 pandemic preventive protocols were spelled out and enforced by various governments worldwide. The protocols put forth include social distancing, wearing of masks, testing to ascertain status in the wake of signs and symptoms defining coronavirus infections, testing of the contacts, testing of healthcare workers, hospital restrictions on consultations, admissions, travel restrictions, lockdowns of regions with high incidences of coronavirus disease among others. The

requirement to maintain social distance led to mental disorders, demotivation, and self-concept issues among cancer patients (Klaassen and Wallis, 2021).

In Kenya the ministry of health put protocols to contain the disease. Later on, the government put measures including lockdowns, curfews to help contain the situation. Measures that included a ban on movement from county centres to major towns where cancer services are domiciled. The Kenyan government instituted measures such as school closures, closure of clubs, restaurants, suspension of international flights, closure of international borders, suspension of in-person schooling and curfews. Other measures were a ban on social gatherings and limiting the number of passengers in public vehicles. Health protocols included hand washing, use of sanitisers, wearing of masks and social distancing. There were several challenges as reported by Dr Nanyingi in the evolution of Covid-19 in Kenya. These challenges included inadequate number of health workers, shortage of testing kits, and lack of enough ventilators. The COVID-19 containment strategies which failed to consider patients suffering from chronic conditions like cancer in the special needs of citizens may have affected the care provision to cancer patients.

Lack of clarity in messages shared from the Ministry of Health on ongoing chronic disease treatments, confused centres offering cancer services. Healthcare centres in developed countries came up with measures for patient consultation through telephone that mainly favored economically rich patients (Kassaman et al., 2020). Currently there are no international protocols to apply in the care of cancer patients in times of pandemics as a result of limited data (Al-Shamsi et al., 2020). This resulted in regions affected by pandemics to come up with protocols to help contain the situation and avoid spread of the infection and reduce human suffering. The Coronavirus disease has had effects on care of cancer patients around the globe due to logistical and psychosocial reasons (Ting et al., 2020). In the Philippines and for those working under similar circumstances various recommendations were proposed to guide in the management of cancer patients. They included prioritisation of cancer care and availing a safe working environment both for patients and health workers.

In a study in Canada, Healthcare workers in Alberta offered psychological support to cancer during Coronavirus pandemic via phones. Other ways of communication including use of social media were adopted to hold meetings, initiatives that patients were encouraged to explore (Klaassen and Wallis, 2021). As China opened its economy, return-to-work meant further preventive protocols to contain the spread of Coronavirus. (Pan *et al.*, 2020). The outbreak of Coronavirus epidemic 2019 prompted Wuhan to centralize quarantines at designated facilities for monitoring and managing infections and prevent further outbreaks. Quarantine was instituted nationwide to curb infections. Besides the preventive protocol, the number of daily confirmed new cases remained large (Pan *et al.*,

2020). Necessary protocols ought to be implemented to shield patients from harm as a result of the pandemic and enhance their care (Klaassen and Wallis, 2021). There are challenges for hospitals providing cancer services to continue providing appropriate therapy to clients. Strategies should be employed to optimize cancer care which include chemotherapy, radiotherapy, immunotherapy and surgery to improve patient outcome.

Recommended strategies from studies have helped in reorganization of hospital and other healthcare centres in cancer patient selection, management and plans which are patient centered (Belkacemi et al., 2020). A number of ministries of health protocols have been developed to guide management of patients including cancer adult patients in various countries. The ministry of health in Kenya came up with protocols to contain the covid-19 pandemic. Curfews were also introduced to restrict movement to certain times of the day and night (Jazieh et al., 2020). This in essence restricted patients, cancer patients included, from seeking care in already inadequate health care centres. Elective surgeries were put on hold to redirect energies and resources towards care of COVID-19 disease. (L. Y. W. Lee et al., 2020).

The Kenyan government-requirement for testing, tracking and facilitation of treatment in the cases. They instituted decentralization of targeted testing of high-risk populations who included healthcare employees, truck and public vehicle drivers (*The evolution of the COVID-19 pandemic in Kenya / RSTMH*, 2020). Daily updates on coronavirus 2019 were communicated via radio stations, televisions and social media. This was geared towards informing the public on the situation of the COVID-19 pandemic in the country and even emphasize the need for observing preventive protocols spelled out by the ministry of health and other agencies.

The Kenya Society of Hematology and Oncology recommended resumption of cancer surgery for both new and ongoing patients (Kassaman et al., 2020). This was a relief for patients who were in dire need of the services.

## **2.5 Effects of coronavirus preventive protocols on cancer care**

Hospital admissions fell dramatically due to the pandemic, most of them operating below their capacity (Cigna, 2020). Some medical conditions (for example, stroke, acute myocardial infarction, advanced cancer) require effective hospital treatment to avoid adverse outcomes of patient care. Birkmeyer et al. (2020) found that patients especially from minority or low-income neighborhoods may have experienced difficulties in access to healthcare during the pandemic in April,2020 resulting in higher mortality rates.

Studies conducted in China Wu and McGoogan, 2020 and the United Kingdom (L. Y. Lee et al., 2020) reported that patients with chronic conditions like cancer had a higher risk of being infected by Coronavirus.

Corona virus 2019 preventive protocols spelled out and enforced by various ministries of health of governments worldwide may have affected cancer care in various ways among patients. Hospital attendance is necessary though this can result in infection by SARS-CoV-2019 (de Joode et al., 2020). Due to the risk of infection the cancer patients may not have followed the appointments for consultant review and investigations needed for their monitoring and care. This may have had effects on the choice or adjustment of treatment modalities.

Karacin et al found that the number of patients in both clean and pandemic hospitals decreased significantly during the pandemic compared with the previous year recommending the need for local strategies during Coronavirus pandemic. (Karacin et al., 2021). Many patients experienced mental effects during the Coronavirus pandemic. Effects included depression and anxiety (Klaassen and Wallis, 2021). Factors that affected effects of the pandemic on cancer patients included the patient, cancer type, treatment modality and community factors (Hartman et al., 2020). Others were pre-existing health system and cancer management gaps in many countries within the low resource regions areas usually bedeviled with lack of adequate oncology resources, cancer specialists and other resources on top of COVID-19 preventive protocols (Nnaji and Moodley, 2021). This can affect the treatment modalities and other cancer care interventions among patients.

## **2.6 Cancer care**

Cancer care is the healthcare given to patients with cancer. This care includes surgery, immunotherapy, inpatient services, outpatient services. These services have been affected by the COVID-19 pandemic (Rosenbaum, 2020). Institutions offering cancer care had to choose between provision of care and prevention of Coronavirus. This led to subjecting patients to Covid-19 tests and waiting for results before procedure could be carried out on them. This resulted in stress, anxiety and even financial strain on the part of the patients. Lack of personal protective devices (PPE) also complicated the situation.

Cancer patients are prone to infection due to their low immunity status especially those with advanced disease and those undergoing radiotherapy and chemotherapy. Delaying cancer treatment may affect patients (Neal et al., 201, Liang et al., 2020). In such cases patients are left with the option to select between going for treatment and deferring therapy to avoid getting infected with the virus (Burki, 2020).

## **2.7 Experiences and perspectives of Cancer patients**

Experiences of cancer patients at the care facility involve the health services offered to them. The experience of patients involves the interaction with nurses, physicians and other healthcare staff in the course of their treatment. The experience is individualised and patient centered. Expectations of patients and how they are met will determine patient experience (Wolf, 2014). This study will seek to establish what expectations the patient had in their care and the level at which they were met.

ASCO, (2020) in Singapore found that 66% of patients, 72.8% of caregivers, and 41.6% of healthcare workers had a high level of fear from Coronavirus. Patients had 19.1%, caregivers had 22.5% while healthcare workers had 14% prevalence of anxiety (Ting et al., 2020). Coronavirus has disrupted cancer care world over. This study differs from another that established low confidence in patients on government response and emphasizes the important role that healthcare workers and authorities play in allaying the fears that many patients and caregivers have (Wolf et al., 2020). Patients with cancer require frequent visits to health care centres to get treatment and any barriers to this may affect them (Neal et al., 2015). Cancer patients are prone to infections due to their low immunity especially when having advanced disease and undergoing radiotherapy or chemotherapy. Poor patient outcome is expected in case they get infected with COVID-19 while seeking treatment (Liang et al., 2020). As a result, cancer patients are left to select from going for treatment and differing treatment to avoid infection (Burki, 2020). Social distance observance and isolation leave patients with loneliness. Those diagnosed with cancer may be psychologically affected together with their families. This requires psychological support (Smith et al., 2011) which prevents morbidity and mortality among cancer patients (Pinquart and Duberstein, 2010). Cancer patients fear to die alone hence the need for family support.

Coronavirus disease affected cancer patient social spheres. According to de Joode et al., 2020, the most frequently reported consequence of covid-19 pandemic was mode of treatment, rescheduling of clinics and change in treatment modalities. Curfews were also introduced to restrict movement to certain times of the day and night (MOH, 2020). This in essence restricted patients, cancer patients included, from seeking care. The Kenyan government recommended postponement of surgeries to reduce strain on resources (L. Y. W. Lee et al., 2020). This may have had an effect on patients who were in dire need of surgical services. On the contrary Kenya Society of Hematology and Oncology recommended resumption of cancer surgery for both new and ongoing patients (Kassaman et al., 2020). Hospitals came up with health protocols and initiated phone consultations of patients among other protocols.

Coronavirus pandemic left patients at risk particularly in patients currently receiving or recently having received cancer drugs or bone marrow transplant (Kassaman et al., 2020). According to Joode et

al 2020, cancer patients were affected in various ways. This included concern for infection by COVID-19 and concern about the prognosis of their condition. There was a reduction in the number of services provided to cancer patients during the Coronavirus period (Rappaport, 2020). According to Joode et al 2020 coronavirus impacted negatively on patient care and recommended research to assess effects of COVID-19 at patient level.

Two main components of the patient perspective can be highlighted. The views of the patient about their health conditions and views of the patient about treatments and their expectations with regard to recovery or management (Zanini et al., 2014). For this study the perspective of the study will explore patient views on COVID-19 protocols and cancer care.

There were high burnouts among healthcare workers. On the other hand, patients had low confidence in government response on COVID-19 pandemic (Wolf et al., 2020). Support from families and friends is key in protecting against psychological symptoms (Smith et al., 2011). This is protective against physical morbidity and mortality (Pinquart and Duberstein, 2010). The negative effects of Coronavirus 2019 in low and middle countries can be brought by few health care institutions that lead to delays in care (Belkacemi et al., 2020) affecting patients' perspective on cancer care. The study seeks to establish adult patients' experiences and perspectives of the coronavirus 2019 preventive protocols on cancer care at Kenyatta National Hospital Cancer Treatment Center.

## **2.8 Patients Coping Mechanisms during COVID-19 Period**

COVID-19 disease affected patients physical and psychosocial wellbeing. The preventive protocols against the disease, mainly social restrictions posed a risk for developing depressive and anxious symptoms (Mariani et al., 2020). Family support accordingly reduces loneliness and mitigate depressive symptoms.

Resilience among patients undergoing cancer treatment is key for well-being and it involves strategies by patients to respond to health-related stressors (Windle et al., 2011). It assists the patients with abilities to cope and manage stress and adversity (Grafton et al., 2010). The innate energy of a patient is key to coping and adaptation. There is a relationship between life satisfaction and perceived stress and is partially mediated by coping mechanisms, positive attitude and mature defenses (Gori et al., 2020).

Patients with cancer have high resilient states of being. Hope for survival assists in boosting courage and resilience (Coolbrandt and Grypdonck, 2010). Writing a positive story about cancer experiences helps in coping through finding meaning behind the suffering that comes with the treatment. Patients rely on healthcare workers to keep them encouraged though the overall process of taking an

active role instead of a passive one can give patients a sense of autonomy and enhanced resilience (Coolbrandt and Grypdonck, 2010).

Attitude plays a role in oncology patients and can be beneficial in other situations related to a cancer diagnosis. Nurses can help patients develop autonomy and coping skills through psychosocial services. During COVID-19 period patients may have developed coping mechanisms to help avoid harm.

## **2.9 Strategies adopted by the Hospitals against COVID-19 effects**

There are no international protocols to apply in care of patients of cancer in times of pandemics as a result of limited data (Al-Shamsi et al., 2020). This resulted in regions affected by pandemics to come up with protocols to help contain the situation and avoid spread of the infection and reduce human suffering. The Coronavirus pandemic has effects on care afforded to cancer patients around the globe due to logistical and psychosocial reasons (Ting et al., 2020). In the Philippines and for those working under similar circumstances various recommendations were proposed to guide in the management of cancer patients. They included prioritisation of cancer care and availing a safe working environment both for patients and health workers.

In a study in Canada, healthcare workers resorted to supporting patients by means of messages. There was an increase in virtual support of patients (Klaassen and Wallis, 2021). As the Return-to-Work in China, more protocols were instituted to prevent spread of infection to other places (Pan *et al.*, 2020).

More hospitals were built in China to increase the capacity of healthcare systems to manage cases of COVID-19 disease. There was a shift to centralized quarantines in fixed sites for better monitoring and managing infections and preventing further outbreaks. Besides these measures, confirmed new cases remained high (Pan *et al.*, 2020). Recommendations helped reorganization in hospitals and other healthcare facilities in patient selection, management that was centered to the patient (Belkacemi et al., 2020). Services were scaled down in most health facilities geared towards preventing spread of infections. Recommendations were implemented to help manage cancer cases appropriately (Jazieh et al., 2020).

## **2.10 Literature gap**

The reviewed literature was based mostly on quantitative data and effects on patient care. Limited literature exists on patients' experiences and perspectives as variables in cancer treatment centre studies. This study proposed to fill the gap in qualitative literature about cancer care from a patient's experiences and perspective in a national referral hospital setting.

## 2.11 Theoretical framework

The study was guided by Sister Calista Roy adaptation Model (RAM) which was developed in 1976. The model envisages the person as systems interconnected and sustaining balance of many stimuli. Many people diagnosed with cancer encounter complex problems including physiological, social, spiritual and psychological issues. The model has contributed immensely in practice, research and management (Ursavaş et al., 2014).

Diagnosis of cancer and treatment can bring biological and psychosocial problems to patients. Sister Callista Roy has a view that people adapt when they respond to the environmental changes in a positive way. The concepts were the person, health, environment and nursing. The person is the individual who receives care, the health is the health-continuum where the person navigates and is a state of being or becoming whole or integrated. The environment has focal, contextual and residual components. It includes the internal and external environment of the person; the contextual part is all stimuli that affects the focal part while residual includes beliefs and personal experiences that this research seeks to study.

Nursing is the care afforded to the patient to help him or her adapt during health and disease. This leads to improvement in quality of life (Ursavaş et al., 2014). The families and communities offer support to the cancer patient and enhance social and psychological wellbeing.

COVID-19 pandemic and preventive protocols implementation effects may have affected cancer care and therefore need for adaptation on the part of the patient to cope with the situation. The interdependence part takes care of social integrity such as the balance between independence and interdependence in a person's relationships with other people for the purpose of coping with various life phenomena. Caregivers including nurses help clients to deal with their conditions and various problems including physiological, psychological, social and spiritual problems. Cancer clients are expected to adapt to these complex problems and also meet their basic needs. The adaptation model envisaged by Sister Callista Roy shows interrelationship of various variables and concepts. Another effect caused by COVID-19 disease and preventive protocols is a change in the lives of clients and families. Clients and families must be able to adapt to the changes that occur through psychological support by the caregivers and family members in the form of emotional support, information, material, or energy. The inability to adapt is at risk of causing adaptive mal behavior. Nurses as members of multidisciplinary teams help clients and families to develop the care management plans. Nurses need to know the client's self-concept to help clients adapt to the changes experienced so that the quality of life of clients would be optimal. Roy's adaptation concepts and theories, help in focusing nursing and other healthcare workers care provided and improve patients' perception and result in supportive and favourable cancer care. The



model is supported by the theory of self-concept and psychosocial support so that care is given comprehensively because in addition to paying attention to physical aspects but also psychological and spiritual aspects so that it is expected that the care provided can improve the quality of life for cancer patients. This resonates well with the study to explore experiences and perspectives of cancer patients on care during implementation of Coronavirus 2019 preventive protocols.

Figure 1: Roy Adaptation Model

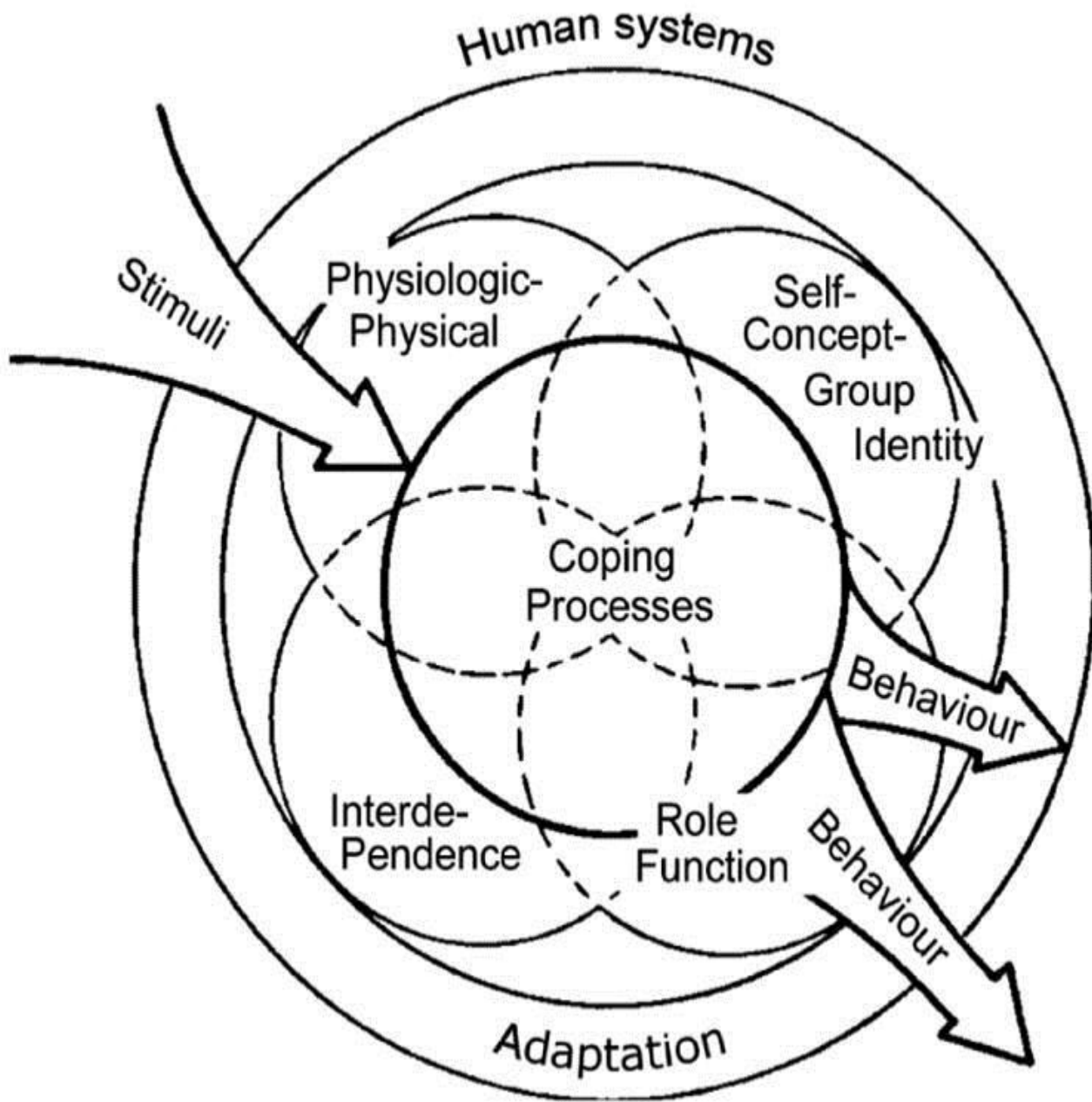


Figure 1: Roy adaptation model

Source: (Jennings, 2017)

## 2.12 Conceptual framework

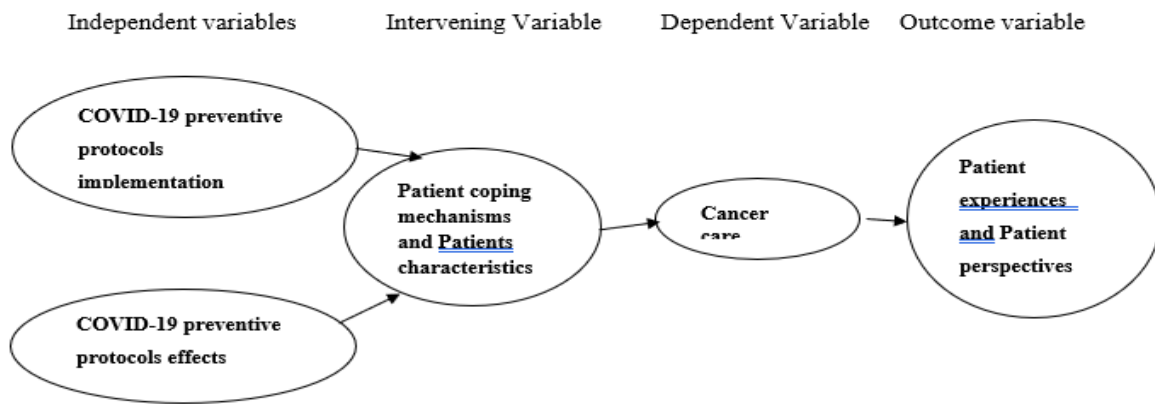


Figure 2: Conceptual framework (Source: Researcher formulation)

### 2.12.1 Explanation of relationships of variables in the Conceptual Framework

The conceptual framework showed interrelationship among various variables. COVID-19 preventive protocols implementation (curfews, isolation, quarantine, social distancing, control of visits, wearing of face masks, restrictions on movement, infection prevention measures including need for COVID-19 testing, rescheduling of service; clinics, surgeries) and COVID-19 Preventive Protocols effects (physical, economic, social and psychological) are independent variables that influence experience which is a dependent variable (Accessibility, clinic appointments, waiting time, clinic scheduling, consultations, treatment modalities, treatment plans, timeliness of care, continuity of care). Other variables like patients characteristics (Age, religion, gender, level of education, marital status, socio-economic status, mode of financing, mode of transport, diagnosis and coping mechanisms (personal coping strategies, relaxation, faith activity/prayer, calling a relative/friend/family, belonging to the support group, prayer, sport activity) which are intervening variables may influence cancer care. Overall, all these variables have influence on the outcome variable which is cancer patients' experiences

(Care received, frequency of clinic visit, consultations received) and perspectives (Concern for COVID-19 disease, expectations, satisfaction) of cancer care.

## **CHAPTER 3: METHODOLOGY**

### **3.1 Introduction**

The study adopted a qualitative phenomenology approach where qualitative data was collected and thematic analysis done, interpreted and conclusions drawn.

### **3.2 Research design**

Cross sectional qualitative survey was employed.

### **3.3 Study area**

Kenyatta National Hospital is situated in Nairobi, Kenya. It is a tertiary referral and teaching health institution that was founded in 1901 (["https://knh.or.ke, retrieved 12 January, 2020\),"](https://knh.or.ke) 2020). Kenyatta National hospital offers different health services which include medical and surgical outpatient services, in-patient services, various clinics which include comprehensive care clinics and cancer treatment centre clinics.

Among the departments in the hospital is the Cancer Treatment Center (CTC) which offers cancer services including advanced comprehensive treatment for cancer. The cancer treatment Centre offers both outpatients and inpatients services to patients with cancer. The services include review of new patients and referrals, chemotherapy admissions, review of patients with results, marking for radiotherapy, out-patient chemotherapy, nuclear patients review, follow-up of patients, joint radiotherapy and ear nose and throat clinic, emergency for radiotherapy (["https://knh.or.ke, retrieved 12 January, 2020\),"](https://knh.or.ke) 2020) It also has an in-patient unit where long duration chemotherapy are administered to patients.

### **3.4 Study population**

All adult patients with cancer who were on active treatment or follow-up at KNH cancer treatment centre between March 2020 and May 2021 formed the population of the study. The study was carried out in the month of September, 2021.

#### **3.4.1 Inclusion criteria**

Patients who were 18 years and above, diagnosed with cancer and were either on active treatment or follow up at KNH CTC between March 2020 and May 2021. Consenting adults who understood English and/or Kiswahili language.

#### **3.4.2 Exclusion criteria**

Any patient with signs and symptoms or suspected to have Coronavirus 2019 and patients who were bedridden. Adults who did not consent in participating in the study or who did not understand English and or Kiswahili language.

### **3.5 Sample size determination**

This was determined by data saturation. Data was collected till a point where no new data has additional insight to the study. The data saturation was at twelve participants. This was in line with other researchers most of whom recommend a sample size of between 5 and 30. Eight up to fifteen respondents can be recommended though this can vary (Schneider et al., 2012).

### **3.6 Sampling procedure**

Participants were selected using consecutive purposive sampling both from outpatient and inpatient. Patients with cancer who were 18 years and above and met the inclusion criteria and were willing to take part in the study were selected consecutively as they consented during clinic days at LINAC (cancer clinic follow up unit), GFC (out-patient chemotherapy administration unit) and in the GFD ward (in-patient chemotherapy and radiotherapy unit) for the study. This continued till the data saturation was reached, a point where no new data had additional insight to the study.

### **3.7 Participant recruitment**

The researcher sought permission to collect data from Kenyatta National Hospital management. The researcher notified the staff and the potential study participants about the study. The study participants who met the inclusion criteria and consented to participate were recruited consecutively from both the out-patient and in-patient.

#### **3.7.1 Participant Consenting Procedure**

Consent was sought from identified patients before or after they had been reviewed by the clinical team. To ensure privacy and also minimize interruption of services, the researcher liaised with the unit in-charge to facilitate the allocation of a designated room in the unit where consenting procedures and interviews were conducted. The researcher took the participants through the participants' information statement sheet and consent form. The researcher explained to the participants the crucial aspects of the study including study background, nature and objectives, the purpose of the study, the implications of participation in terms of benefits, utility and risks if any that would have resulted due to participation in the study.

The participants were allowed to ask questions to clarify any aspects relating to the study. Participants were taken through the statement of consent declaration. Once the participant expressed an

understanding of the terms agreed and expressed interest to participate in the study, they were given a consent form to sign.

### **3.8 Data collection**

#### **3.8.1 Research Instrument**

The researcher used a semi structured interview guide to collect data for the study in the month of September, 2021.

#### **3.8.2 Pre-test of the study tool**

Testing of the study instrument was done in the cancer unit at KNH-CTC that did not take part in the main study. This took place at haemato-oncology clinic 23 and adult oncology ward 8C at KNH which are separate sites from where enrolment of study participants took place. Pretesting data was collected, analyzed and necessary corrections were made on the data collection tool. Expert advice was also sought to improve the study instrument.

#### **3.8.3 Reliability**

Although reliability may not be achieved easily because it is difficult for qualitative study to be repeated to generate the same results, the researcher coded the data into two separate data and analyzed them independently. The findings from the identified patterns were discussed separately and the consensus regarding the data findings reached and adopted.

#### **3.8.4 Validity**

Validity is the level that the study measures the exact elements that are to be measured. To ensure validity, the researcher continually checked, questioned and theoretically interpreted the findings to ensure that the study fulfilled its research aims. Verbatim quotes from respondents' report were used to support themes.

#### **3.8.5 Data collection procedure**

Data was captured consecutively from consenting adult cancer patients who were 18 years and above, understood English and/or Kiswahili and were attending KNH CTC (LINAC, GFC and GFD ward). The consented participants recruited for the study individually took part in the 20 to 30 minutes in-depth interview in a private room at cancer treatment centre. Permission to audio record the interview was sought from the study participant.

An interview guide was used to guide the researcher during the in-depth interview session with the study participant. The guide outlined how the interview was set up including structured probe questions, follow-up questions and finally exit questions. Permission to use an interview room within the cancer treatment centre was obtained from the oncology nurse manager. The consented respondents were taken into an interview room within the unit where the interview took place. The researcher and the study participant were the only people who were in the room to ensure confidentiality. An interview guide was used to coordinate the discussions and ensure the relevant information was captured. Audio recorded interviews enable the researcher to concentrate on research respondents (Meadows, 2003). All the sessions were audio recorded using a digital voice recorder and interview notes were taken during the interview to ensure quality.

### **3.9 Data Management plan**

#### **3.9.1 Data cleaning and entry**

The audio recorded data was transcribed on a daily basis and entered into the computer program (QSR NVivo) for analysis after data cleaning to ensure transcription errors as well as omission of important details were fixed. Demographic data was checked for completeness and keyed into a computer program, statistical package for social scientist version 28.0 for analysis.

#### **3.9.2 Data storage**

Principle of participants anonymity was maintained by ensuring that all interview notes, transcript print outs and audio recordings were allocated continuous serial codes and stored in a cupboard under lock and the key. Besides, any soft data entered in the computer was protected by a password and only accessed by the principal researcher. The interview notes and the participants verbatim typed and print outs were locked away in a filing cabinet immediately after the data was entered into the computer. The keys to the filing cabinet were only handled by the researcher to ensure confidentiality.

#### **3.9.3 Data analysis, presentation and de-identification**

According to Parahoo (2006), data collection and analysis are done at the same time and after the interview. Demographic data were keyed in the computer Statistical Package for Social Sciences (SPSS) version 28.0 for analysis and analyzed descriptively by summarizing the socio-demographic data and clinical characteristics using frequency distribution and percentages. Audio recorded data was transcribed and entered into a computer. Content analysis was done via QSR International's NVivo 11



Software program. This program assisted in searching and grouping of data into patterns or categories after coding data segments. This was done to de-identify the data.

Research demographic findings were presented using frequency distribution tables and percentages. Data that was transcribed and interview notes were arranged and filed immediately, as per the study objectives to ensure that there was no mix up during the analysis and the researcher used thematic analysis to analyze the data as per the study objectives and emerging themes. The researcher used verbatim text quotes and member-check from participants (informant feedback/ respondent validation) during the interview for clarification and reinforced conclusions to affirm credibility, truthfulness and accuracy of the study.

Audio recordings were collected using interviews, all the 12 interviews recordings were then transcribed into text format by the researcher. After the audio files were transcribed into texts, the researcher reviewed the transcripts while listening to the audio recordings to ensure transcription errors as well as omission of important details were fixed. The researcher also referred to the initial notes to familiarize with the content of the transcript and identify possible themes.

A major concern with qualitative data is availability of cues, which might reveal respondents' identity. For this reason, data de-identification is needed to remove such cues. The interview guide was designed to ensure that names and other direct identifiers were avoided during the interview.

A deductive coding approach was adopted in NVivo, to group text responses into these respective discussion themes. This is analogous to the traditional color-coding technique used to mark codes where there is no software this process was as shown in the figure 3 below:

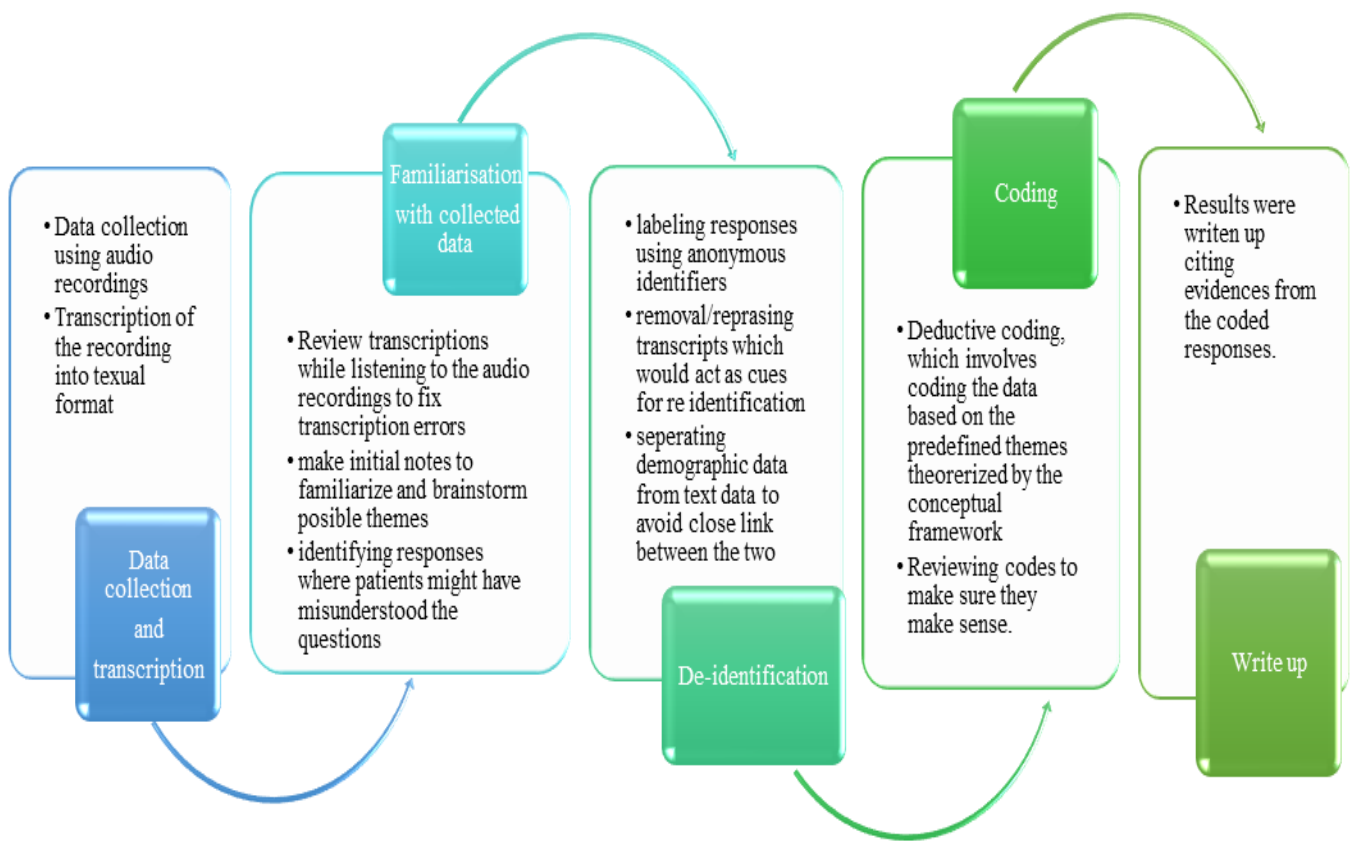


Figure 3: Data analysis framework

**Figure 3: Data analysis framework**

The researcher categorized data and then assigned codes to describe the content. Constant comparisons were made to create patterns. Eventually, the patterns were refined and interpreted. Finally descriptive findings were reported illustrated by verbatim quotes to explain and reflect the participant perspectives and lived experiences concerning the study phenomenon. The researcher kept the data collected during the in-depth interview true to the oral statements of the participants during transcription.

**3.9.4 Dissemination of study findings**

The report from this study has been shared with KNH-UoN research ethics committee, KNH and University of Nairobi library and a soft copy for archiving in the University of Nairobi repository. The researcher endeavour to present the findings in appropriate academic and scientific conferences and also publish in relevant journals.

**3.10 Robustness of the research**

Rigour involves the strive by the researcher for excellence and how they adhere to detail and accuracy. Parahoo, 2006 opined that researcher want their findings to reflect truthfully the phenomenon they are studying and to contribute to knowledge that is beneficial to others. Credibility is the

confidence in the truth of the data and interpretations of them. According to Polit and Beck, 2010 it is considered by Lincoln and Guba to be the fundamental goal of qualitative research. Furthermore, member checking is deemed an important technique for establishing credibility in qualitative research. This was done by continually checking, questioning and theoretically interpreting the findings to ensure that the study fulfilled its research aims.

Dependability is the ability of the data to remain stable over time. The researcher used an audit trail to enhance the dependability of the study. An audit trail was maintained by documenting the steps taken and decisions made, that could be followed by another researcher in future studies.

Confirmability is the ability of data representing the information participants provided by clarifying all information. The researcher used verbatim text quotes and member-check from participants that reinforce conclusions to affirm confirmability.

In this study it was envisaged that data saturation was to ensure that data are complete and that key aspects of a phenomenon were captured for interpretation.

### **3.11 Covid-19 Prevention/Safety Measures**

To safeguard the study participants from Covid-19 the researcher ensured that the interviews were held in a well ventilated and spacious room. A social and physical distance of one and a half meters was observed to prevent interpersonal transmission. The environmental cleaning and disinfection were maintained in between clients/ after every interview. Before the participants were ushered into the room, they were screened for any symptoms of Coronavirus 2019 disease such as fever, nasal congestion, rhinorrhea, sore throat or cough. If present the patient were referred according to Hospital COVID-19 preventive protocols and were exempted from taking part in the study.

The researcher also ensured that all the participants wore face masks at all times and directed participants to a place with soap and running water for washing hands or sanitized with alcohol-based hand sanitizer with at least 70% alcohol and encouraged frequent hand hygiene to limit or prevent the person-to-person transmission. The proper personal protective devices including masks were worn all the time during the data collection period. The researcher underwent screening for Covid-19 daily to rule out infection while working within the hospital.

### **3.12 Ethical Consideration**

Permission to conduct research was approved by KNH-UoN ethics review board reference number KNH-ERC/A/305 dated 06 September, 2021 (P353/05/2021). The researcher also got authority to carry out the study from Kenyatta National Hospital management and unit head to reach the study participants.

Confidentiality of data was ensured by using collected data for intended purpose only. No name of the participants was required on the in-depth interview guide. Codes were used to maintain anonymity. The data collected was locked in the cupboard which was only accessed by the researcher.

A voluntary informed consent was sought from the respondents by the researcher before participation. Participants were briefed on their rights and the expected benefits of the study. There was no coercion or incentives for participants. The identity of participants was not indicated on all interview notes. Transcript print outs and audio recordings were stored in a cupboard under lock and key and on the computer under password respectively. The participants were informed of the potential benefits of the study and risk before they participated in the study. The contact of ethics review committee and supervisors were availed to study respondents for clarification if any. The participants understanding of the study was ensured before they signed the consent forms. There was no conflict of interest regarding this study to be communicated.

The participants were assured of the right to withdraw from the research process when they felt they were pressured or coerced in any way or their rights were violated. Respect was assured to the participants by giving due diligence to a person's judgment and ensuring that the participant was free to choose without interference. Data stored on the computer was protected by a password only known to the researcher. Data will be destroyed after completion of the study. Informed consent was ensured and participation was voluntary. Kenyatta National Hospital management and cancer treatment center heads of department were requested to authorize the conduct of the study and this was granted. There was strict adherence to Ministry of Health COVID-19 prevention protocols during the data collection exercise.

## CHAPTER 4: RESULTS

### 4.1 Socio-demographic and clinical characteristics of respondents

This chapter presents results of the study. Socio-demographic characteristics and clinical characteristics are presented in the frequency tables 1 and 2 respectively. Themes are presented in the narrative form.

#### 4.1.1 Socio-demographic characteristics of the respondents

The respondents' socio-demographic characteristics included age, religion, gender, level of education among others. Frequency tables were used to visualize distribution of socio-demographics of respondents across the categories of respondents. *Table 1* reports these frequency distributions and frequency percentages.

*Table 1: Socio-demographic characteristics of respondents (n=12)*

| <i>Variable</i>            |                                       | <i>Count</i> | <i>n %</i> |
|----------------------------|---------------------------------------|--------------|------------|
| Gender                     | Male                                  | 8            | 66.7%      |
|                            | Female                                | 4            | 33.3%      |
|                            | Other                                 | 0            | 0.0%       |
| Marital status             | Married                               | 12           | 100.0%     |
|                            | Single                                | 0            | 0.0%       |
|                            | Separated                             | 0            | 0.0%       |
|                            | Divorced                              | 0            | 0.0%       |
|                            | Other                                 | 0            | 0.0%       |
| Residence                  | Urban                                 | 5            | 41.7%      |
|                            | Rural                                 | 7            | 58.3%      |
|                            | Other                                 | 0            | 0.0%       |
| Level of education         | Primary                               | 5            | 41.7%      |
|                            | Secondary                             | 5            | 41.7%      |
|                            | Tertiary                              | 2            | 16.7%      |
|                            | Other                                 | 0            | 0.0%       |
| Religion                   | Christian                             | 12           | 100.0%     |
|                            | Muslim                                | 0            | 0.0%       |
|                            | Other                                 | 0            | 0.0%       |
| Age                        | 18 – 40 years                         | 1            | 8.3%       |
|                            | 40 - 65 years                         | 6            | 50.0%      |
|                            | 65 – 75 years                         | 4            | 33.3%      |
|                            | 75 years or older                     | 1            | 8.3%       |
| Transport used to hospital | Public transport                      | 11           | 91.7%      |
|                            | Personal car                          | 1            | 8.3%       |
|                            | Motorbike                             | 0            | 0.0%       |
|                            | National health insurance (NHIF)      | 12           | 100.0%     |
| Mode of Care Payment       | Private health insurance              | 0            | 0.0%       |
|                            | Out-of-pocket                         | 12           | 100.0%     |
|                            | Contributions from family and friends | 8            | 66.7%      |
|                            | Other                                 | 0            | 0.0%       |

#### 4.1.2 Clinical characteristics of the respondents

Table 2: Clinical characteristics of the respondents (n=12)

| Variable   |  | Count | n %   |
|--|--|-------|-------|
| What situation applies best to you                               | I have cancer and I am awaiting to start treatment                                     | 0     | 0.0%  |
|  | I am currently under treatment for cancer  | 9     | 75.0% |
|  | My cancer treatment has been completed and I am currently in follow-up at the hospital | 3     | 25.0% |
| Type of cancer   | Breast cancer  | 2     | 16.7% |
|  | Cancer of the Tongue   | 1     | 8.3%  |
|  | cervical cancer  | 1     | 8.3%  |
|  | Chronic Myeloid Leukemia   | 1     | 8.3%  |
|  | Colorectal cancer  | 1     | 8.3%  |
|  | Esophageal cancer  | 1     | 8.3%  |
|  | Head tumor   | 1     | 8.3%  |
|  | Neck Cancer  | 1     | 8.3%  |
|  | Prostate Cancer  | 3     | 25.0% |
| Did you – as far as you are aware of- have (had) the coronavirus | Yes, I have been tested and the test result was positive                               | 0     | 0.0%  |
|  | Possibly,  | 0     | 0.0%  |
|  | No, I have been tested and the test result was negative.                               | 3     | 25.0% |
|  | No, I have not been tested and I did not have any flu-like symptoms                    | 9     | 75.0% |
|  | Other  | 0     | 0.0%  |

Chemotherapy was the most common cancer treatment option as 35% of the respondents had at least undergone chemotherapy. The remaining respondents indicated treatment type as; Surgery (15%), Radiotherapy (20%), Hormonal therapy (5%), Target therapy (5%) and others (20%).

#### 4.2 Emerging themes

In this section, different themes are presented in relation to cancer patients' experiences and perspectives of cancer care Vis a Vis the COVID-19 pandemic preventive protocols implementation. There were different experiences and perspectives narrated by respondents interviewed. Thematic analysis was based on the emerging themes. There were several themes identified in the study under

experiences of adult cancer patients on cancer care, perspectives of adult cancer patients on cancer care, effects of COVID-19 preventive protocols implementation, coping mechanisms employed by adult cancer patients and suggestions for improvement in access to cancer care.

#### **4.2.1 Disrupted care**

It was not possible for some of adult cancer patients to readily access the services because sometimes the clinic schedule was reorganized as the hospital set up a priority approach for COVID-19 patients as cancer patients were urged to stay at home.

Interviewee 1 stated:

*“..... I had remained with thirteen days of treatment when the machine for radiotherapy (LINAC) broke down and were told to stay home for two weeks. We were called after two weeks, while we were trying to find out where else we can receive (radiotherapy) treatment, to come and receive treatment with COBALT radiotherapy machine.”*

Interviewee 2 stated that, *“.....delays, you don't have to overcrowd. They have to restrict the number of patients. Patients have failed to come for clinics, have decided to stay at home .....”*.

Interviewee 8 stated:

*“I was not attending hospital clinics, did not receive care.”*

These findings indicated that COVID-19 disease curtailed cancer care provision in healthcare facilities and affected cancer care. Some of these impacts included rescheduling of clinics, missing out on various investigations, and anxiety among patients not forgetting the financial constraints the patients faced.

Here another interviewee 4 stated:

*“It has affected, people with cancer sometimes have no means of getting money if people don't have NHIF card to get treatment is difficulty.”*

#### **4.2.2 Challenging Access to care**

COVID-19 preventive protocols implementation affected access of cancer services at the hospital. It led to some patients attending clinic while others could not attend as many patients were not allowed to avoid crowding.

Interviewee 4 stated, *“Corona has made us not to receive treatment, transportation coming to this area.”*

Respondent 6 stated that,

*“Attended clinic although not many patients were allowed.”*

Another patient, interviewee 5 stated,

*“Drugs I come sometimes I don’t get due to lateness, lack of bus fare, sometimes you come you are late you are forced to go home at night.”*

Interviewee 6 stated that, *“Received services normally. I was not affected personally with the services.”*

Some respondents had a different experience whereby they could not attend clinic until the lifting of COVID-19 preventive measures the ministry of health declared to be followed, such as restricted movement through the curfews and attending cancer management program.

One of the respondents (Interviewee 9) stated that,

*“Hard. No means of transport, needed authority of the doctor to travel.”*

Another interviewee 5 said,

*“Hard due to travelling sometimes they close and open it becomes hard.”*

Some patients missed cancer services as a result of fewer means of transport. Interviewee 8 stated that,

*“Cancelled due to restricted travelling, few transport means, I was not attending hospital clinics, did not receive care....”*

Interviewee 9 said,

*“Received treatment, used referral letter to allow me access cancer services.”*

Interviewee 7 stated, *“Yes, I followed instructions, had a letter that allowed me to come to hospital.....”*

This was voiced by interviewee 1 thus,

*“.... Covid-19 protocols did not affect me much since I used to stay at home. I could come for treatment and go back home. I received treatment till the last day. I was not affected by the COVID-19 protocols.”*

Travel restrictions negatively affected adult cancer patients. Some cancer patients did not access the clinics until the government lifted the travel bans or lock down from different areas as advised by their healthcare workers. Another respondent 6 stated that,

*“Follow-up, completed treatment in 2019, lock down found me at home I only managed to attend clinic after lifting of the lock down by the government”*

The restrictions led to an increase in traveling costs and difficult in accessing cancer care services. Patients could not access cancer care consistently due to travel restrictions that led to increase in transport cost as the vehicles restricted the number of passengers. Interviewee 9 stated that, *“Cost of living has gone up. Cost of transport has gone up.”*



### **4.2.3. Availability of essential cancer care services**

Services at the study site were available during the implementation of COVID-19 preventive protocols period. There were respondents who stated continuity of accessing cancer services at the study site.

Interviewee 1 stated, *“I got 33 days for radiotherapy and 3 sessions for chemotherapy.”*

Interviewee 7 stated, *“I have not seen anything. Protocols have not affected cancer service provision”* revealing that cancer services were available.

Interviewee 9 stated, *“Received treatment.....”*

### **4.2.4 Cancer care services received**

Adult patients were able to receive various cares at the study site. These cares included treatment modalities, consultations and follow up services. They regularly interacted with healthcare providers, urged to put on face mask and given respective medicine to go and use at home - Interviewee 12.

The services that were received at the study site were consultations, chemotherapy, radiotherapy, targeted therapy and surgery.

Interviewee 1 stated *“.....radiotherapy and chemotherapy, drugs for preventing stomach gas (gastid), drugs for constipation that goes with morphine were provided.”*

Another patient stated having received cancer care services thus,

*“Testing..... surgery, chemotherapy and radiotherapy.”*

Interviewee 2 stated *“.....chemotherapy, radiotherapy all those.”*

Interviewee 3 stated, *“Testing, consultation yes.”*

Interviewee 5 said, *“Targeted therapy.”*

Interviewee 12 stated, *“.....surgery, chemotherapy and radiotherapy”*

### **4.2.5. Patient’s satisfaction**

Most of the respondents were satisfied with the cancer services during the implementation of COVID-19 preventive protocols and some wished that the protocols should continue as they protected them from infections.

Interviewee 1 stated,

*“I was not affected much. I feel the preventive protocols to continue. Let them space out clinics’ days even if it is twice a year”.*

Interview 2 stated, *“They are ok. you have to be taken care of. Covid restrictions are required to prevent ourselves.”*

Interviewee 3 stated, *“Good, yes, I am satisfied, they have done their best.”*

Interviewee 4 stated, "I am satisfied, yeah."

Interviewee 6 stated, "*They are just ok.....I am satisfied with the services.*"

Interviewee 11 said, "*Treated properly, satisfied.*"

#### **4.2.6. Subjective evaluation of respondents' own health condition and healthcare services**

Respondents liked the way cancer services were offered stating that healthcare workers were nice to them and liked their advice.

Interviewee 12 said, "*They are nice, the doctors are encouraging saying it is treatable. They are telling me that I will be very ok.*"

*On their physical health the respondents felt it had improved.*

Interviewee 2 stated, "*It is ok. I am ok (alright) even working. I don't have any problem.*"

Interviewee 5 stated "*It is not that bad though I am feeling body weakness a little*".

Interviewee 6 stated, "*I am better off.*"

Interviewee 12 stated, "*.... better because when I came it was serious, I could not talk well I could not*

*Understand but now I understand things that I am told, I normally do things with my will.*"

#### **4.2.7. Complications associated with restricted access to cancer care**

Limited accessibility of cancer care led to complications among patients hence becoming very sick during the period of COVID-19 preventive protocols implementation. Interviewee 1 stated that,

*"... later we started using our vehicle when I started becoming very sick"*

Interviewee 5 stated that, "*It is not that bad though I am feeling body weakness a little; sometimes drugs affect you and you have to go home resting on the way*"

Interviewee 6 stated that,

*"Lost weight."* Interviewee 7 also reported having lost weight thus *"Have lost weight."*

Interviewee 4 stated that, "*It is not good, I have diabetes and hypertension, arthritis; it has affected me because before I was working now I cannot. Yes.*"

#### **4.2.8 Economic impact**

It was noted in the interview findings that the respondents were economically affected in a negative way due to the implementation of COVID-19 pandemic preventive protocols. Some respondents lost jobs and others lost income or had a reduction in income.

One respondent, interviewee 1, stated that,

*“.....later we started using our vehicle when I started becoming very sick; even financially I can't help anyone since I don't have money to contribute to people since I am always on bed and I didn't work then....my finances (income) have gone down as I don't work.”*

Another respondent, interviewee 3 said,

*“So much, so much because I can't meet my clients and discuss, net effect has reduced income, I rely on government contracts that is not there anymore, don't have alternatives of income, I find it difficult to meet my obligations, I find it difficult even paying for my medical, even buy food, even support family the best way possible. So, the effects economically have been many and diverse.”*

Interviewee 4 stated that,

*“It has affected me because before I was working now I cannot. Yes; I cannot do any work. Financially I don't get anything.”*

Interviewee 6 stated that,

*“.....only money shortage till I missed clinic due to financial constraints.”*

Interviewee 7 stated that,

*“It has affected me because it has affected our children. They used to help us, now they are complaining about low income. Life has become expensive.”*

The findings indicated that the cancer patients who participated in the in-depth interviews had lived experiences of facing scarce resources as a result of COVID-19 preventive protocols implementation.

Interviewee 8 stated that, *“in most ways, being out of work, did not have capital, no money to pay for house rent, no money to finance budget.”*

Interviewee 10 stated that,

*“Affected me.my children lost their job. I have lost farming; my coffee and my tea is rotting in the farm. I didn't go home. I didn't take drugs to my sister. I did not take drugs to my mother.”*

Interviewee 9 stated, *“My job had issues. Business went down.....”*

One respondent 12 said,

*“It has been tough. Managed to get money through NHIF and family contributions. I lost my job. I got sick. It has been very hard getting a job.”*

#### **4.2.9 Psychological effects; fear and depression**

Respondents expressed fear of contracting COVID-19 disease. They also expressed sorrow after having lost some of their loved ones apart from having been mentally disoriented. Interviewee 1 stated,

*“It has affected me since when you stay for a while you hear my relatives have fallen (have died) (due to CORONA) and I get affected psychologically; You can't meet people since when I get corona and I have this one (cancer) I will die. I don't go to church due to (social) distance; .... patients have failed to come for clinics, have decided to stay at home due to fear of infection.”*

Interviewee 3 stated,

*“You know when you limit physical conducts it gives you mental disorientation because you are not meeting your friends, chats and discussing it has given me mental disorientation and reorganizations.”*

Interview 2 stated that,

*“Fearing to do certain jobs. Yea welfare has been affected”*

Interviewee 4 stated that, *“It has affected me psychologically because the family says this disease has affected them. Sometimes it has depressed me.”*

#### **4.2.10 Social Isolation and domestic confinement**

Respondents experienced isolation as a result of the restrictions of movement and associated that were instituted to help curb the spread of coronavirus. Respondents decided to stay indoors most of the times, avoided crowds whenever outside their residential places. This may have led to loneliness and limited interactions and missing out on spiritual nourishment due to restricted movements.

This was voiced by interviewee 1 thus,

*“... I don't want to gather with people to prevent being infected; it has affected me. You can't meet people since when I get corona and I have this one (cancer) I will die. I don't go to church due to (social) distance.”*

Respondent 1 further stated,

*“Anyway, it has affected me since I can't stay with many people. I stay away from many people. I pray that normality can come back to resume normal way of life.”*

Interviewee 3 stated,

*“Oh negatively. Because I have not been able to meet many people that I don't associate with friends because of fear of getting COVID-19, and that a lone is kind of delimiting the socialization giving you mental disorientation you have to find coping mechanism in dealing.”*

Another respondent (interviewee 8) stated that,

*“No family around when admitted. Families were visiting once in a while. Limited movement.”*

Respondent number 2 stated,

*“No communication socially, even gatherings, even going to church, we don't go to churches.”*

Interviewee 6 stated, *“no social gatherings, no visiting.”*

#### **4.2.11. Coping mechanisms employed by respondents**

Cancer care through nursing and other services afforded to the adult cancer patients helped them to adapt during the COVID-19 pandemic hence improved quality of service delivery. Cancer patient families offered them support to access their medical care while promoted social and psychological well-being. The subthemes under coping mechanisms were seeking divine intervention through prayers, being hopeful, seeking family and friends support, adherence to COVID-19 preventive protocols, enablers of cancer care and disablers of cancer care accessibility.

#### **4.2.11.1 Seeking divine intervention through prayers**

The respondents resorted to divine interventions by praying that normality may resume.

Interviewee 2 stated that,

*“..... I pray, keep myself busy”*

Another respondent 1 stated,

*“.....I pray that normality can come back to resume normal way of life.”*

Another respondent number 3 stated that,

*“.....Yes, I do pray that the pandemic goes away, and also that I am safe from it and Kenyans at large and for people.....”*

Interviewee 6 stated that,

*“.....prayers in church.”*

Interviewee 7 stated, *“I used to listen to radio and pray God to assist us. I just asked God to help me.”*

#### **4.2.11.2 Being hopeful**

Maintaining hope was one-way respondents coped with the situation during the Covid-19 pandemic.

Interviewee 2 stated that,

*“.....it will not last for long (hope), give ourselves hope that we will stay the way we used to stay, better life.”*

Another respondent 10 stated,

*“Not able to give up, move on, life must continue.”*

Interviewee 4 said, *“...it will end God willing it will end.”*

#### **4.2.11.3 Seeking family and friends' support**

Some respondents sought support from family members and relatives to help them cope with stresses brought about by implementation of COVID-19 preventive protocols.

Interviewee 2 stated that,

*“Regular visiting of relatives.....”*

Another respondent number 3 stated that,

*“.... developed social isolation mechanisms, adaptation, limiting only to the family and very rarely from outside.”*

Interviewee 5 Stated

*“Just sleeping in relatives place near Nairobi before attending clinic.....sometimes I borrow money from well-wishers.”*

Interviewee 8 said, *“.....talking to family and friends through WhatsApp groups.”*

#### **4.2.11.4 Adherence to COVID-19 preventive protocols**

Following advice from healthcare workers and following COVID-19 preventive protocols were key in coping with the situation. Interviewee 1 stated that,

*“I listened to doctors’ advice; I follow all instructions.....I sanitize and use my personal car to evade travel restrictions and prevent being infected”.*

The COVID-19 preventive protocols were explored based on lived experiences and perspectives of cancer patients attending CTC at KNH. The participants in this research admitted that indeed there were preventive protocols that were instituted by the ministry of health and various institutions to help curb the spread of COVID-19 disease.

Interviewee 1 stated,

*“Sanitizing of hands, masking, social distance.”*

Interviewee 2 stated,

*“Keeping distance, sanitizing, masking, not attending mass/congregation, even church, even not travelling so much.”*

Interviewee 3 stated,

*“Washing hands, keeping social distance, sanitizing those are the relevant ones.”*

Interviewee 7 stated that

*“They said we put on masks, hand wash, social distance, avoid places where many people are gathered, and curfew.”*

This revealed that most of the respondents were aware of the preventive protocols instituted by various institutions to curb the spread of COVID-19 disease.

Interviewee 3 stated that, *“Restricted my movement, my socialization but have given me protection as I have tried to follow the restrictions, yes.”*

#### **4.2.11.5 Enablers of cancer care**

Respondents developed various communication ways to help them navigate and cope in the pandemic time.

Another respondent number 3 stated that,

*“.... Economically I have developed different communication skills to reach my clients, to reach job opportunities, to reach consultancy opportunities through phone, digital.”*

Besides, the cancer patient admitted development of different skills to cater for cancer care services. Interviewee 6 stated that,

*“Chatting on phone, harambee (fund raising) to cater for clinic attendance.....”*

Several factors enabled the provision of services during the COVID-19 pandemic protocol implementation. This included allowance of provision of services at the cancer treatment centre. Despite the COVID-19 protocols implementation cancer services were allowed to continue at CTC. This enabled patients to access much needed care, monitoring and consultations included hence reduced stress. Other enablers included adherence to COVID-19 preventive protocols. The compliance with the preventive protocols helped patients to navigate cancer care process with ease. Those who complied with the protocols were allowed to access cancer care. The protocols put forth helped to prevent spread of infection. A respondent (Interviewee 2) felt that the protocols were there to safeguard them and therefore viewed them positively.

*“They have prevented. they have done well. When you are a cancer person due to the disease you have to be very careful. These protocols have made us to be on safer side. The have safeguarded us.”*

Interviewee 9 stated that he used a referral letter to enable access of services thus,

*“Received treatment, used referral letter to allow me access cancer services.”*

One of the enablers of care was opening of the road for resumption of transport services. This helped patients who had stopped care to access cancer services as stated by interviewee1, *“It has not affected me much. When they opened the road and I was given a return date, I just came during clinic(appointment) day.”* Opening of the road blocks and lockdowns helped cancer patients to access cancer care and hence coped well.

#### **4.2.11.6 Disablers of cancer care**

Cancer care was negatively affected by travel restrictions, high cost of transport, requirement of doctor’s referral letter, fear of infection, financial constraints and reduction in the number of booked patients at cancer treatment Centre. This disrupted healthy coping among adult cancer patients. This was voiced by interviewee 1 who stated,

*“The month of June was hard. Movement had been restricted.”*

Interviewee 9 stated that,

*“Cost of living has gone up. Cost of transport has gone up.... hard. no means of transport, needed authority of the doctor to travel”*

Interviewee 1 stated that, *“.... patients have failed to come for clinics, have decided to stay at home due to fear of infection.”* Staying at home for fear of infection may have affected cancer patients psychological well-being and affected their physical health due to missing out on clinic appointments.

Respondent 6 stated that,

*“Attended clinic although not many patients were allowed. “Limiting the number of patients who attended clinics affected cancer patients care continuum.*

### **4.3 Suggestions for improvement in access to cancer care.**

Respondents were asked for their suggestion for helping cancer patients receive care. Various suggestions for improvement of cancer care came out in the interviews as subthemes. They were increase in the cancer care resources including availing more radiotherapy machines, cancer drugs and provision of accommodation for patients, offering financial support and NHIF to cover most cancer services and devolving of cancer care services to counties-local levels.

#### **4.3.1 Increase cancer care resources**

Respondents suggested that more resources should be availed in cancer centres to help cancer patient receive services whenever in need.

One of the responded, interviewee 1, stated that,

*“People of cancer to be helped by adding more radiotherapy machines.....special diet to be provided to patients with cancer.”*

Interviewee 5 stated that,

*“They can give us a place for accommodation whenever we come to clinic to avoid harm.”*

Another respondent, interviewee 3 stated that,

*“...yes, suggestions will be real let the drugs be available. Because sometimes you are prescribed drugs are not available and are very expensive. Alright. So, when I talk of drugs, I mean including chemotherapy, radiotherapy and all that. Let them be accessible and affordable. Because cancer patients’ treatment is long term and is not short term. So that is one. There must be readily available facilities.”*

Interviewee 4 stated that, *“Government to assist people with cancer. Let them be given drugs.....”*

#### **4.3.2 Offering financial support and National Hospital Insurance Fund (NHIF) subsidy**

Financial assistance to cater for the services required for cancer patients also came out of the interviews conducted.

Interviewee 2 stated that,

*“.....the government to financially support them. With cancer you need to eat well, when you go down you have to bother somebody, and you feel down. But when supported financially you keep on going”.*

Interviewee 6 stated that,

*“Support financially, food, radiotherapy machines to be bought for counties to enable patients receive care near their homes.”*

Interviewee 8 stated that,

*“Government to give free health policy, most of us are struggling to get money for treatment, cancer treatment to be free since we contribute to NHIF and yet they ask us to buy or pay treatment (top-up payment). Government to stop hospitals from retaining patients due to non-payment of bills. Instead to allow patients go home to look for money to come and pay bills later.”*



Interviewee 7 stated that, *“Let the government assist us, since we are not working and treatment of this disease(cancer) is expensive. Let the NHIF to pay all services including laboratory services, all services and every hospital without choosing which hospitals.”*

Another respondent 9 said,

*“... increase money on NHIF and let them pay for services. Free medicine like HIV patients the way they are paid for drugs. Free medicine.”*

Another respondent, interviewee 3 stated that,

*“...I think the government and the NHIF should really thing of heavy subsidization of this. NHIF should enhance their coverage and limits of various cancer treatment.”*

Another respondent 10 said,

*“...at least treatment to be free from day one. Because nowadays most of people are marginalised people. They don't have economic factors to afford treatment.”*

Interviewee 12 stated that, *“If NHIF is not paying all sessions of radiation there should be plan to assist pay for them to avoid missing treatment. Organisations that deal with cancer people to help.”*

#### **4.3.3 Devolving of cancer care services to counties**

The respondents also suggested that cancer services once devolved to counties more patients will benefit from them.

Another respondent, interviewee 3 stated that,

*“...in Kenya we have very few treatment centres. Suggesting to increase cancer treatment centres. If I were not in Nairobi, if I were in rural areas, it will be very difficult, I will be forced to come to Nairobi to access the treatment.”*

Interviewee 6 stated that,

*“.....radiotherapy machines to be bought for counties to enable patients receive care near their homes.”*

Interviewee 7 stated that,

*“.....let extension health workers come to villages too see and assist cancer patients.”*

Another respondent 10 said,

*“... we require county hospitals to be properly equipped.”* Respondent 10 further stated, *“Thank you very much. Tell them instead of people coming to (study site) let them equip county hospitals to allow cancer patients to access care at local level.”*

## **CHAPTER 5: DISCUSSION, CONCLUSION AND RECOMMENDATIONS**

The chapter presents discussion of findings of the study and compares with available literature. The chapter also has conclusions, recommendations and suggestion for further research.

### **5.1 Introduction**

The sampled population had varied socio-economic and clinical characteristics as shown in the results chapter. Most were male, 66.7%, this could be as a result of possibility of males having more economic resources compared to women hence could access referral cancer care more easily. The respondents were largely from rural set up (58.3%). A larger percentage of respondents comprised of primary and secondary school graduates each with 41.7% share of the sample which could point to the fact that lower level of education respondents attend public health facility compared to those with tertiary level of education who could be well off economically and choose to maybe seek cancer services from private institutions.

A higher percentage of the respondents used public transport to access cancer care facility (91.7%). With restriction of movement being one of the implemented protocols, it is expected that a higher percentage of sample were affected with this kind of frequency distribution. The Kenyan government policy of two-third capacity for public transport vehicles may have restricted more patients to attend cancer care. Most of the participants used public means of transport pointing to the socioeconomic status of the adult cancer patients who attend KNH CTC, a public health referral facility.

For COVID-19 tests, 75% of the respondents had not yet tested for COVID-19 by the time of this study, the remaining 25% had been tested and emerged negative. This could be due to logistical requirement for testing hence less participants did not have a Covid-19 test. Only those who had signs and symptoms suggestive of coronavirus disease or who required invasive care like surgery were required to test. The testing cost was also a deterrence from subjecting a large number of the population to a Covid-19 test.

Chemotherapy was the most common cancer treatment option as 35% of the respondents had at least undergone chemotherapy. The remaining respondents indicated treatment type as; Surgery (15%), Radiotherapy (20%), Hormonal therapy (5%), Target therapy (5%) and others (20%). This was in part due to the fact that during the period covered there were restrictions on the number of patients who underwent surgery. The LINAC radiotherapy machine had also broken down as reported by one of the respondents in the findings section and therefore patients relied on COBALT radiotherapy machine only.

According to the KNH data, there was a reduction in number among the treatment modalities of those who received COBALT (20%), LINAC (23%) and chemotherapy (33%) services in 2020

compared with 2019. For brachytherapy the trend has an increasing trend from 2018 to 2020 (“Statistics unit, KNH (unpublished),” 2021).

The most common cancer type on the sample is prostate cancer 3 respondents (25%) and breast cancer two respondents (16.7%) of the sample. Prostate and breast cancer were the most common cancer type among the study participants. These types of cancer have high prevalence rate among cancer cases in Kenya.

NHIF (100.0%) and out-of-pocket (100.0%) method is the most popular mode of payment among these respondents, followed by contributions from family and friends (66.7%). Most cancer patients enrolled in the national insurance scheme as they foresee high cost of cancer care in the country. The scheme is meant to cover various consultations, tests and treatment modalities. The scheme does not cover every cancer cost and patients are left with the option of seeking funds and other support like transport cost and accommodation costs from friends, relatives and well-wishers.

All the respondents indicated their marital status as married, and their religion as Christian. It is expected that effects of the implemented protocols on Christian and married couples is best captured by the sample as compared to the other groups. This is also due to the fact that Kenya is a Christian country and therefore most of patients are likely to be Christian. The marital status of the respondents could be explained by the age group half of the sampled individuals (50%) indicated their age as 40 -65 years of age, 33.3% indicated their age as 65-75 years while 8.3% indicated their age as 18-40 years same as 75 years and above.

## **5.2 Respondents’ experiences and perspectives on cancer care**

Many patients had different experiences in their access to cancer care services following the COVID-19 outbreak. Experiences explored included disrupted cancer care, accessibility of cancer care, cancer care availability and the type of cancer care services provided during the implementation of COVID-19 preventive protocols at the study site.

According to data records at KNH, there was a decrease of 31% patients’ attendance at outpatient CTC in 2020 compared to 2019. Cancer treatment centre attendance reduced from 27375 in 2019 to 21620 in 2020 which is 21% decrease while in-patient number reduced from 6459 in 2019 to 4954 in 2020 (23%) (“Statistics unit, KNH (unpublished),” 2021).

It was not possible for some respondents to readily access the services because sometimes the clinics schedule was reorganized as many hospitals set up a priority approach for COVID-19 patients as cancer patients were urged to stay at home. Regularly, on interacting with healthcare providers, patients were urged to put on face mask and given respective medicine to go and use at home (Interviewee 12).

Some respondents could not attend clinic until the lifting of COVID-19 preventive measures the ministry of health declared to be followed, such as restricted movement and curfews.

Some respondents did not access the clinics until the government lifted the travel bans or lock down from different areas as advised by some of their follow-up healthcare caregivers. The protocols were instituted to prevent the spread of COVID-19 disease to the population.

These findings indicated that COVID-19 disease curtailed cancer care provision in healthcare facilities and affected cancer care. Some of these impacts included rescheduling of clinics, missing out on various investigations, and anxiety among patients not forgetting the financial constraints the patients faced.

However, a large number of respondents continued receiving services using referral letters from referring health care facilities. This enabled them to be allowed by law enforcers to pass through road blocks on their way to seek cancer care.

The ministry of health implemented protocols that were developed to guide management of patients including cancer patients in various counties (“The evolution of the COVID-19 pandemic in Kenya | RSTMH,” 2020; MOH, (2020)). Besides, cancer care institutions were found to be in urban areas (Makau-Barasa et al., 2020). Cancer patients travelled from respective counties to get cancer care services at study site. Some patients admitted having no finances or reduced income. This may have resulted from loss of income sources and reduced volume of business due to the restricted movements, ban on gatherings and social distance maintenance as well as closure of business premises. As a result, limited accommodation was available in urban centers which denied the cancer patients timely and effective health care. Delaying cancer treatment may affect patients (Neal et al., 201, Liang et al., 2020). In such case patients are left with option to select between going for treatment and differing therapy to avoid getting infected with the virus (Burki, 2020).

COVID-19 preventive protocols implementation included imposition of curfews, social isolation, quarantine, social distancing, control of cancer care visits, wearing of facemasks and restrictions on movement. Often cancer patients were needed to undergo COVID-19 testing, rescheduling of services like clinics and surgeries. COVID-19 Preventive Protocols effects such as physical, economic, social, and psychological were independent variables that influenced cancer care which is a dependent variable. Patients had different experience in their social interactions such as loneliness upon the observance of COVID-19 preventive protocols such as social distancing and social confinement.

Expectations of patients and how they are met determine patient experience (Wolf, 2014). The findings of this study compare well with other studies done before for example the respondents in this study expressed having felt fearful. ASCO, (2020) in Singapore found that 66% of patients, 72.8% of

caregivers, and 41.6% of healthcare workers had a high level of fear from Coronavirus. In another study, prevalence of anxiety among respondents was distributed as follows; patients had 19.1%, caregivers had 22.5% while healthcare workers had 14% (Ting et al., 2020). Cancer patients are prone to infections due to their low immunity especially when having advanced disease and undergoing radiotherapy or chemotherapy. Poor patient outcome is expected in case they get infected with COVID-19 while seeking treatment (Liang et al., 2020). Coronavirus disease affected cancer patient social spheres. According to (de Joode et al., 2020) the most frequently reported consequence of covid-19 pandemic was mode of treatment, rescheduling of clinics and change in treatment modalities. Coronavirus pandemic left patients at risk of infection particularly in patients currently receiving or recently having received cancer drugs or bone marrow transplant (Kassaman et al., 2020).

There was reduction in the number of services provided to cancer patients during Coronavirus period. These findings are supported by Rappaport, 2020 and Joode et al 2020 who reported that corona virus impacted negatively to patient care and recommended research to assess effects of COVID-19 at patient level.

The negative effects of Coronavirus 2019 in low and middle countries may have been compounded by few health care institutions mostly situated in urban centres that lead to delays in care (Belkacemi et al., 2020) and affected patients' perspectives on cancer care.

Perspectives of adult cancer patients were also explored in this study. It was revealed that respondents were satisfied with the cancer care services received. They were also happy with their health conditions and progress of their disease as reported in the findings of this study. The respondents also expressed satisfaction with health care workers services and commitment to duty. This points to the fact that the study site much as it was offering services to COVID-19 patients, cancer care services did not suffer a lot. According to Sister Callister Roy Adaptation model person is envisaged as systems interconnected and sustaining balance of many stimuli. Many people diagnosed with cancer encounter complex problems including physiological, social, spiritual and psychological issues (Ursavaş et al., 2014). The adaptation of cancer patients and the health system in general had influence on the way cancer patients perceived care services. This study resonates with a study that found that there is a relationship between life satisfaction and perceived stress and is partially mediated by coping mechanisms, positive attitude and mature defenses (Gori et al., 2020).

The preventive protocols put forth by the ministry of health were aimed at prevention of spread of COVID-19 pandemic to the large population. However, this had various effects on the cancer patients and their care. The study found effects such as deterioration of physical health, economic impacts, psychological effects and social isolation among cancer patients attending study site. These findings are

in congruent with a study by Nnaji and Moodley, 2021 that found the coronavirus 2019 disease affected medical and surgical services across the world especially oncological services. Social and psychological well-being was also affected. The study is also in congruent with a study by Klaassen and Wallis, (2021) who found that requirement to maintain social distance led to mental disorders, demotivation, and self-concept issues among cancer patients.

The effects of COVID-19 pandemic preventive protocols were explored in relation to lived experiences and perspectives of cancer patients at KNH CTC. The findings revealed that the effects of COVID-19 pandemic preventive protocols resulted in different psychological, sociological, economic and physical health outcomes. This study compares with other studies on the same topic. It was found that hospital admissions fell dramatically due to the pandemic most of them operating below their capacity (Cigna, 2020). Birkmeyer et al. (2020) found that patients especially from minority or low-income neighborhoods may have experienced difficulties in accessing healthcare during the pandemic.

Due to the risk of infection the cancer patients may not have followed the appointments for consultant review and investigations needed for their monitoring and care. Karacin et al found that the number of patients in both clean and pandemic hospitals decreased significantly during the pandemic compared with the previous year recommending the need for local strategies during Coronavirus pandemic (Karacin et al., 2021). These studies are line with the findings of this study where many patients experienced various effects during the Coronavirus pandemic. Effects included depression and anxiety (Klaassen and Wallis, 2021). Prior to making cancer patient-centered measures, this information can aid public health institutions in evaluating the needs of these patients and formulate relevant supportive mechanism that ultimately enhance their coping techniques.

Curfews were also introduced to restrict movement to certain time of the day and night (MOH, 2020). This in essence restricted patients, cancer patients included, from seeking care. The Kenyan government recommended postponement of surgeries to reduce strain on resources (L. Y. W. Lee et al., 2020). This may have had effect on patients who were in dire need of surgical services. On the contrary Kenya Society of Hematology and Oncology recommended on resumption of cancer surgery for both new and ongoing patients (Kassaman et al., 2020). Hospitals came up with health protocols and initiated phone consultations of patients among other protocols.

Some patients admitted having no finances, limited and poor-quality infrastructure, limited space in healthcare facilities for cancer patients as COVID-19 patients were given the priority. As a result, limited accommodation was available in urban centers which denied the cancer patients timely and effective health care. Also, the stringent protocols instituted by the Kenya Government in April 2021 restricted inter-county movement affected cancer care experience among adult patients. Institutions

offering cancer care had to choose between provision of care and prevention of Coronavirus. This left cancer patients subjected to Covid-19 tests and waiting for results before getting cancer care services procedure could be carried out on them. This resulted into stress, anxiety, and even financial strain as well as lack of personal protective devices on the part of the patients that worsened their cancer care experience.

This information is meaningful in the field of public health care since it can offer insights about the urgency to develop effective policy measures that promote service delivery on those active and follow-up cancer patients. Ways to navigate the COVID-19 implications on disease management can be explored.

### **5.3 Copying mechanisms employed during implementation of COVID-19 Preventive protocols**

Cancer clients are expected to adapt to these complex problems and also meet their basic needs. The adaptation model as envisaged by Sister Callista Roy shows interrelationship of various variables and concepts which include. Social, psychological, role function, spiritual aspects and adaptive behaviours. Patients had to adapt to stay afloat.

Coping mechanisms helped patients to navigate cancer care continuum. It is was most needed during the pandemic period. The preventive protocols against the disease mainly social restrictions posed a risk for developing depressive and anxious symptoms (Mariani et al., 2020). There is a relationship between life satisfaction and perceived stress and is partially mediated by coping mechanisms, positive attitude and mature defenses (Gori et al., 2020).

In this study adult cancer patients employed various ways to manage the effects of COVID-19 pandemic. Some of these mechanisms were seeking divine intervention through prayers, maintaining hope that the situation was to normalize with time, seeking assistance from families and friends, adherence to COVID-19 preventive protocols and use of NHIF cards to offset hospital bills. There were also enablers and disablers of cancer care continuity that were expressed by the respondents. praying, following the preventive protocols and seeking financial and social support from healthcare workers relatives and family members. A study in Canada found that healthcare workers resorted to supporting patients by means of messages. There was an increase in virtual platforms that offered support to patients (Klaassen and Wallis, 2021). Patient support is necessary to help them navigate the pandemic period as they for through cancer continuum. To curtails spread of infection there was need to institute preventive protocols. This study is in agreement with another that found that during the Return-to-Work period in China, more protocols were instituted to prevent spread of infection to other places (Pan *et al.*, 2020).

Support from families and friends is key in protecting against psychological and physical symptoms (Pinquart and Duberstein, 2010; Smith et al., 2011). Clients and families must be able to

adapt to the changes that occur through psychological support by the care givers and family members in form of emotional support, information, material, or energy. The inability to adapt is at risk of causing adaptive mal behavior. Overall, the coping mechanisms employed helped patients cope with the situation and move on with life. This is in line with a study that found that there is a relationship between life satisfaction and perceived stress and is partially mediated by coping mechanisms, positive attitude and mature defenses (Gori et al., 2020).

#### **5.4 Suggestions for improvement in access to cancer care**

The respondents suggested that investment in cancer service provision infrastructure and devolvement of cancer services to counties should be effected. This would improve accessibility and quality of services afforded to patients. Increase in cancer resources, financial support and NHIF subsidy and devolving cancer services were fronted by respondents as the main suggestions for improvement of cancer service provision. Cancer care services are required by patients for long and cost quite highly. This calls for financial support or even waiving of some costs to enable services to be affordable by many. This will also help realize universal health coverage. Goals. Radiotherapy machines are expensive to install and maintain though very needful by cancer patients for their treatment. It will be a big relief if the governments both at national and county level pool resources and provide such machines plus other facilities required to enable smooth provision of cancer services. Devolving cancer services to regional levels will make a large population to access care within their home areas and will reduce the cost of accommodation and traveling to far places in search for cancer care services.

In general, the above findings and discussion are in congruent with the conceptual framework that was adopted in this study. The experiences and perspectives of the cancer patients may have been influenced by various factors that include implementation of COVID-19 preventive protocols, patients socio-economic and demographic characteristics and coping mechanisms employed as well as the cancer care the received at the study site.

#### **5.5 Conclusion**

*The respondents continued receiving cancer care at study site of which most of the respondents were able to access, though some patients could not access the cancer services due to COVID-19 preventive protocols implementation. Some experienced reduced health services utilization. Chemotherapy was the most services received by respondents in the study. Most of the respondents were satisfied with the cancer services provided to them at the study site and felt that their health statuses had improved. These preventive protocols implementation had effects that included physical health deterioration, adverse financial effects, social isolation and adverse psychological well-being such fear of coronavirus infection.*



Patients adopted various coping mechanisms including observance of COVID-19 preventive protocols to prevent infection with corona virus, seeking divine intervention like through prayers, being hopeful and seeking support from families and friends.

### **5.6 Recommendations**

COVID-19 pandemic preventive protocols to be reviewed in consideration of adult cancer patients needs such as increase clinic days to include weekends to cater for the rescheduled clinic bookings, homebased care and online consultations and telemedicine to be embraced especially to patients who are in hard-to-reach places, avail cancer treatment facilities and drugs available in the county hospitals and cancer centres ought to be decentralized to enable patients to access cancer services in their counties. The study also recommends that referral letters which enabled cancer patients to access care in referral centre to be utilized. This will enable patients access referral services with ease. Various coping mechanisms can be adopted to help patients cope in times of stress and challenges in adult cancer care.

### **5.7 Suggestion for further study**

A longitudinal qualitative study on the same population is proposed to explore patients experiences and perspectives of care over a longer duration.

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## APPENDICES

### Appendix I: KNH-UoN Ethics Review Committee Approval Letter



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**KENYATTA NATIONAL HOSPITAL**  
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Ref: KNH-ERC/A/305

Fredrick Manyasi Sifuna  
Reg. No. H56/33590/2019  
School of Nursing Sciences  
College of Health Sciences  
University of Nairobi

6<sup>th</sup> September, 2021

Dear Fredrick,

**RESEARCH PROPOSAL: CORONAVIRUS 2019 PREVENTIVE PROTOCOLS AND CANCER-CARE; EXPERIENCES AND PERSPECTIVES OF ADULT CANCER PATIENTS AT KENYATTA NATIONAL HOSPITAL CANCER TREATMENT CENTRE (P353/05/2021)**

This is to inform you that the KNH- UoN Ethics & Research Committee (KNH-UoN ERC) has reviewed and **approved** your above research proposal. The approval period is 6<sup>th</sup> September 2021 – 5<sup>th</sup> September 2022.

This approval is subject to compliance with the following requirements:

- i. Only approved documents (informed consents, study instruments, advertising materials etc) will be used.
- ii. All changes (amendments, deviations, violations etc.) are submitted for review and approval by KNH-UoN ERC before implementation.
- iii. Death and life threatening problems and serious adverse events (SAEs) or unexpected adverse events whether related or unrelated to the study must be reported to the KNH-UoN ERC within 72 hours of notification.
- iv. Any changes, anticipated or otherwise that may increase the risks or affect safety or welfare of study participants and others or affect the integrity of the research must be reported to KNH- UoN ERC within 72 hours.
- v. Clearance for export of biological specimens must be obtained from KNH- UoN ERC for each batch of shipment.
- 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.

Protect to discover

This information will form part of the data base that will be consulted in future when processing related research studies so as to minimize chances of study duplication and/ or plagiarism.

For more details consult the KNH- UoN ERC website <http://www.erc.uonbi.ac.ke>

Yours sincerely,



**PROF. M.L. CHINDIA**  
**SECRETARY, KNH- UoN ERC**

- c.c. The Principal, College of Health Sciences, UoN  
The Senior Director, CS, KNH  
The Chair, KNH- UoN ERC  
The Assistant Director, Health Information, KNH  
The Director, School of Nursing Sciences, UoN  
Supervisors: Dr. Lucy Kivuti-Bitok, School of Nursing Sciences, UoN  
Dr. Angeline C. Kirui, School of Nursing Sciences, UoN

Appendix II: Kenyatta National Hospital Research Registration Certificate-  
MEDICINE

KNH/R&P/FORM/01



KENYATTA NATIONAL HOSPITAL  
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### Study Registration Certificate

1. Name of the Principal Investigator/Researcher

FREDRICK MANYASI SIFUMA

2. Email address:

fsifuma@students.vonbi.ac.ke

Tel No.

0726772774

3. Contact person (if different from PI)

4. Email address:

Tel No.

5. Study Title

CORONA VIRUS 2019 PREVENTIVE PROTOCOL AND  
CANCER CARE! EXPERIENCES AND PERSPECTIVES  
OF ADULT CANCER PATIENTS AT KENYATTA NATIONAL HOSPITAL ETC

6. Department where the study will be conducted

(Please attach copy of Abstract)

PRETESTING OF STUDY

AT CLINIC 23 (ADULT HEMATO-  
AND MARD SC ONCOLOGY)

7. Endorsed by KNH Head of Department where study will be conducted.

Name:

Dr. K. Kelle

Signature

AK

Date

17.9.21

8. KNH UoN Ethics Research Committee approved study number

(Please attach copy of ERC approval)

Appendix III: Kenyatta National Hospital Research Registration Certificate-CTC

KNH/R&P/FORM/01



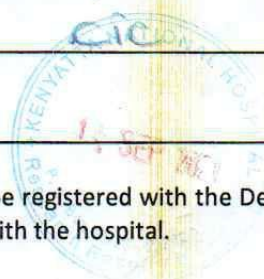
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**Study Registration Certificate**

1. Name of the Principal Investigator/Researcher  
..... FREDRICK MANYASI SIFUNA .....
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3. Contact person (if different from PI).....
4. Email address: ..... Tel No. ....
5. Study Title  
..... CORONA VIRUS 2019 PREVENTIVE PROTOCOLS AND  
..... CANCER-CARE: EXPERIENCES AND PERSPECTIVES OF  
..... ADULT CANCER PATIENTS AT KENYATTA NATIONAL HOSPITAL CTC .....
6. Department where the study will be conducted CANCER TREATMENT CENTRE  
(Please attach copy of Abstract)
7. Endorsed by KNH Head of Department where study will be conducted.  
  
Name: DR C MJO NGESE Signature: [Signature] Date: 10/9/21
8. KNH UoN Ethics Research Committee approved study number P353/05/2021  
(Please attach copy of ERC approval)
9. I FREDRICK MANYASI SIFUNA commit to submit a report of my study findings to the Department where the study will be conducted and to the Department of Medical Research.  
  
Signature: [Signature] Date: 10/09/2021
10. Study Registration number (Dept/Number/Year) CTC / 120 / 2021  
(To be completed by Medical Research Department)
11. Research and Program Stamp \_\_\_\_\_

All studies conducted at Kenyatta National Hospital **must** be registered with the Department of Medical Research and investigators **must commit** to share results with the hospital.





## Appendix 1Va: Participants information statement sheet

**Study Title: Coronavirus 2019 preventive protocols and cancer-care: Experiences and perspectives of adult cancer patients at Kenyatta National Hospital Cancer Treatment Centre.**

**INVESTIGATOR:** Fredrick Manyasi Sifuna. Tel: 0726772774  
School of Nursing Sciences  
University of Nairobi  
P.O Box 19676, Nairobi

### **Introduction:**

I am a student at The University of Nairobi pursuing a Masters of Science Degree in Nursing (Nursing Oncology). I am conducting a study titled: “**Coronavirus 2019 preventive protocols and cancer-care: Experiences and perspectives of adult cancer patients at Kenyatta National Hospital Cancer Treatment Centre.**” The purpose of this information is to give you details about the study that will enable you to make an informed decision regarding your participation. You are free to ask questions to clarify any of the aspects we will discuss in this information and consent form. The researcher will also ask you questions regarding the study before you sign the consent form to ascertain your comprehension of the information provided.

### **The Purpose of the study:**

The purpose of this study is to explore and understand adult cancer patients experiences and perspectives of COVID-19 preventive protocols on cancer-care at Kenyatta National Hospital Cancer Treatment Center. The aim is to draw on patients experiences and perspectives and on how implementation of COVID-19 prevention protocols have influenced cancer care. This will inform best design and review of the implementation approaches to ensure cancer care services are provided with minimal interruptions.

**i). Risks:** There are no economic or physical risks to participating in the study. However, due to the time taken in responding to question, you may take a longer time than usual at your clinic. Also, during the interview, some questions will require you to disclose some personal information that might trigger some negative feelings and possibly anxiety. If this happens, the researchers will refer you to the hospital counsellor. The researcher will also endeavour to spend approximately 10 minutes with you.

**ii). Confidentiality:** Confidentiality will be maintained and the information you provide will only be used for the intended purpose of the study. Besides, your name will not be required on any forms or used during publication of the final report thus ensuring your anonymity. All materials used during the study will be under lock and key and only the persons involved in this study will have access to them. Electronic files will be saved on password protected laptop.

**iii). Voluntary Participation:** Participation in this study is voluntary. Refusal to take part will not attract any penalty. You retain the right to withdraw from the study without any consequences. You are free not to answer any question during the interview.

**iv). Compensation:** There is no compensation for participating in the study. But these proposed study results may benefit other people like you in the future.

**v). Conflict of interest:** The researcher confirms that there is no conflict of interest.

## **Kiambatisho IVb: Karatasi ya taarifa ya maelezo**

**Kichwa cha Utafiti:** Utafiti: Masharti ya kuzuia virusi vya Corona 2019 na Matibabu ya Saratani: Uzoefu na mitazamo ya wagonjwa wa saratani ya watu wazima katika Kituo cha Matibabu cha Saratani ya Hospitali ya rufaa ya Kenyatta

**Mtafiti:** Fredrick Mathasi Sifuna. Simu: 0726772774

Shule ya Sayansi ya Uuguzi

Chuo Kikuu cha Nairobi

SLP 19676, Nairobi.

### **Utangulizi:**

Mimi ni mwanafunzi katika Chuo Kikuu cha Nairobi ambaye anasomea Shahada ya Sayansi ya Uuguzi. Ninafanya utafiti kuhusu masharti ya kuzuia virusi vya Corona 2019 na Matibabu ya Saratani: Uzoefu na mitazamo ya wagonjwa wa saratani ya watu wazima katika Kituo cha Matibabu cha Saratani ya Hospitali ya rufaa ya Kenyatta. Madhumuni ya habari hii ni kukupa maelezo juu ya utafiti ambao utakuwezesha kufanya uamuzi sahihi kuhusu ushiriki wako. Uko huru kuuliza maswali kufafanua mambo yoyote ambayo tutazungumzia katika fomu hii ya habari na idhini. Mtafiti pia atakuuliza maswali kuhusu utafiti kabla ya kusaini fomu ya idhini ili kuhakikisha kuelewa kwako wa habari iliyotolewa.

### **Kusudi la utafiti**

Madhumuni ya utafiti huu ni kuchunguza na kuelewa uzoefu wa wagonjwa wa saratani ya watu wazima na mitazamo ya masharti ya kukinga zidi ya COVID-19 juu ya matibabu ya saratani katika Kituo cha Matibabu cha Saratani ya Saratani ya Kenyatta. Kusudi ni kujua juu ya uzoefu na mitazamo ya wagonjwa na jinsi utekelezaji wa itifaki za kuzuia COVID-19 umeathiri utunzaji wa saratani. Hii itaarifu muundo bora na hakiki ya njia za utekelezaji ili kuhakikisha kuwa huduma za utunzaji wa saratani zinapewa kipawo mbele.

i) Hatari: Hakuna hatari za kiuchumi au za mwili za kushiriki kwenye utafiti. Walakini, kwa sababu ya wakati uliochukuliwa kujibu swali, unaweza kuchukua muda mrefu kuliko kawaida katika kliniki yako. Pia wakati wa mahojiano, maswali kadhaa yatakuhitaji kufichua habari fulani ya kibinafsi ambayo inaweza kusababisha hisia hasi na uwezekano wa wasiwasi. Ikiwa hii itatokea, mtafiti atakuelekeza kwa mshauri wa kisaikolojia wa hospitali. Mtafiti pia atajitahidi kutumia takriban dakika 10 kukushukulikia.

ii). Usiri: Usiri utatunzwa na habari unayotoa itatumika tu kwa madhumuni yaliyokusudiwa ya utafiti. Mbali na hilo, jina lako halitahitajika kwa aina yoyote au kutumiwa wakati wa kuchapisha ripoti ya mwisho na hivyo kuhakikisha kutokujulikana kwako. Vifaa vyote vinavyotumiwa wakati wa utafiti vitakuwa chini ya kufuli na ufunguo na ni mtafiti katika

utafiti huu ndio atakaopata. Faili za elektroniki zitawekwa kwenye kompyuta ndogo iliyolindwa.

iii) Ushiriki wa hiari: Ushiriki katika utafiti huu ni wa hiari. Kukataa kuhusika haitavutia adhabu yoyote. Unahifadhi haki ya kujiondoa kwenye utafiti bila matokeo yoyote. Uko huru kutojibu swali lolote wakati wa mahojiano.

iv). Fidia: Hakuna fidia ya kushiriki katika utafiti. Lakini matokeo haya ya utafiti yatakayopendekezwa yanaweza kufaidi watu wengine kama wewe katika siku zijazo.

v). Ugomvi wa riba: Mtafiti anathibitisha kwamba hakuna mgongano wa riba.

## Appendix Va : Consent Form

Serial no.....

**Study Title: Coronavirus 2019 preventive protocols and cancer-care: Experiences and perspectives of adult cancer patients at Kenyatta National Hospital Cancer Treatment Centre.**

**Principal investigator: .....**

**Background:** I propose to conduct one to one in-depth interviews with cancer patients. These interviews will be audio recorded in an ease voice recorder mobile app and all data will be stored, managed and disposed of as per Data Protection Acts Data Compliance Guidelines. I am aware that findings may be published but no identifiable data will be included. The data provided will not be used for any other study.

**Declaration:** I have read, or has been read to me, the information leaflet for this research project and I understand the contents. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights. I understand that I may withdraw from the study at any time and I have received a copy of this agreement.

**Participant's signature: .....Date: .....**

### Statement of investigator's responsibility

I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

**Investigator's signature: ..... Date: .....**

### For any Clarification, please contact

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Or

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Or

The Chairman

KNH-UoN Ethics and Research Committee

P.O Box 20723,

Nairobi.

Tel: 2726300 ext 44102, email [uonknh\\_erc@uonbi.ac.ke](mailto:uonknh_erc@uonbi.ac.ke)

## **Kiambatisho Vb: Fomu ya idhini**

Nambari ya fomu.....

Kichwa cha Utafiti: Masharti ya kuzuia virusi vya Corona 2019 na Matibabu ya Saratani: Uzoefu na mitazamo ya wagonjwa wa saratani ya watu wazima katika Kituo cha Matibabu cha Saratani ya Hospitali ya rufaa ya Kenyatta

Mtafiti mkuu: .....

Asili: Ninapendekeza kufanya mahojiano ya kina na wagonjwa wa saratani. Mahojiano haya yatarekodiwa kwa urahisi katika programu ya simu ya kinasa sauti na data zote zitahifadhiwa, kusimamiwa na kutumiwa kama ilivyo kwa Miongozo ya Usimamiaji wa data. Ninajua kuwa matokeo yanaweza kuchapishwa lakini hakuna data inayonitambua itajumuishwa. Data iliyotolewa haitatumika kwa utafiti mwingine wowote.

Azimio: Nimesoma, au nimesomewa, kijikaratasi cha habari cha mradi huu wa utafiti na ninaelewa yaliyomo. Nimepata nafasi ya kuuliza maswali na maswali yangu yote yamejibiwa kwa kuridhika kwangu. Ninakubali kwa hiari na kwa uhuru kuwa sehemu ya utafiti huu wa utafiti, ingawa bila ubaguzi kwa haki zangu za kisheria na za maadili. Ninaelewa kuwa naweza kujiondoa kwenye mahojiano au utafiti wakati wowote na nimepokea nakala ya makubaliano haya.

Saini ya mshiriki:.....Tarehe:.....

Taarifa ya jukumu la mpelelezi

Nimeelezea asili na madhumuni ya utafiti huu, taratibu zinazopaswa kufanywa na hatari zozote ambazo zinaweza kuhusika. Nimejitolea kujibu maswali yoyote na kujibu maswali kikamilifu. Ninaamini kuwa mshiriki anaelewa maelezo yangu na ametoa idhini ya habari kwa uhuru.

Saini ya Mtafiti :..... Tarehe: .....

Kwa Umaelezo zaidi, tafadhali wasiliana

Fredrick Manyasi Sifuna

Simu ya No: 0726772774

Shule ya Sayansi ya Uguzi

Chuo Kikuu cha Nairobi

SLP 19676,

Nairobi

Au

Dk Lucy W. Kivuti-Bitok

Mhadhiri Mkuu, Kitengo cha Utawala na Elimu,

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Mwenyekiti

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## **Appendix VIa: Interview guide**

**Serial no.....**

**Study Title: Coronavirus 2019 preventive protocols and cancer-care: Experiences and perspectives of adult cancer patients at Kenyatta National Hospital Cancer Treatment Centre.**

### **Introduction**

Greetings! My name is (name) and I will be facilitating the in-depth interview. This is (name) and he/she will be taking notes and helping me. Thank you so much for taking the time to be with us today. The interview seeks to explore and understand your experiences and perspectives on cancer care following implementation of COVID-19 preventive protocols. This will inform best design and review of the implementation approaches to ensure cancer care services are provided with minimal interruptions. This information will be anonymized and will be treated confidentially. You may withdraw at any time during the interview if you feel uncomfortable answering questions. The interview will be recorded for further analysis later and notes will also be taken during interview. All recordings and notes taken will be kept safely. (Confirm that the participant consent on recording before proceeding if not end the interview). The interview will take about 30-45 minutes.

Before we begin do you have any question?

### **Participants Demographical data**

1. What is the reason for visiting the hospital today?

- a. Consultation
- b. Treatment
- c. Follow up
- d. Other (please specify).....

2. What is your place of residence?

- a. Urban
- b. Rural
- c. Other (specify)

3. What means of transport do you use to hospital?

- a. Public transport
- b. Personal car
- c. Motorbike
- d. Hired car



e. Other (specify).....

4. What is your marital status?

a. Married

b. Single

c. Separated

d. Divorced

e. Other

5. How do you pay for your treatment and other cancer services? (may choose more than one)

a. National health insurance (NHIF)

b. Private health insurance

c. Out-of-pocket

d. Contributions from family and friends

e. Other (specify).....

6. What is your gender?

a. Male

b. Female

c. Other

7. Level of education

a. Primary

b. Secondary

c. Tertiary

d. Other (specify).....

8. Religion

a. Christian

b. Muslim

c. Other

9. What is your age?

a. 18 – 40 years

b. 40 - 65 years

c. 65 – 75 years

d. 75 years or older

10. What situation applies best to you?

a. I have cancer and I am awaiting to start treatment

b. I am currently under treatment for cancer

c. My cancer treatment has been completed and I am currently in follow-up at the hospital

d. Other (specify).....

11. Which type of cancer do you have (or did you have)? (In case you have (had) multiple cancer types, you may state more than one).....

12. When were you enrolled in the cancer care clinic at KNH (specify year and month).....

13. Which of the descriptions below matches your current situation the best?

a. I am (probably) cured from cancer

b. I have (probably) curable disease

c. I have (probably) incurable disease

d. I don't know

e. Not applicable

14. Which treatment(s) do you currently have or (would you) soon have? (May fill more than one if it applies to participants)

a. Surgery

b. Chemotherapy

c. Radiation therapy

d. Hormonal therapy

e. Immunotherapy

f. Targeted therapy

g. Stem cell transplantation

h. Active surveillance / watchful waiting

i. Ostomy surgery

j. Symptom/pain management

k. I don't know which treatment(s)

l. Not applicable

m. Other (Please specify).....

15. Did you – as far as you are aware of- have (had) the corona virus?

a. Yes, I have been tested and the test result was positive

b. Possibly, I have/had airway complaints and/or fever ( $\geq 38$  degrees Celsius) and/or two or more symptoms of: flu-like symptoms) or malaise, muscle soreness, headache, pain in the eye, and/or have been in contact with someone who is/was infected with the corona virus

c. No, I have been tested and the test result was negative.

d. No, I have not been tested and I did not have any flu-like symptoms

e. Other (specify).....

**Probing questions:**

This list of questions will guide the researcher. It does not have to be adhered to systematically or completely and the participant's response will guide the questions also.

1. Could you tell me a bit about your current health condition?
2. What are coronavirus preventive protocols that were put in place to curb the spread of COVID-19? You may probe for more preventive protocols.
3. What cancer care services did you receive during early COVID-19 period? Probe for how the participant managed to receive services during COVID-19 period?
4. What do say about the cancer services you have received during coronavirus pandemic period? Probe for level of satisfaction or dissatisfaction with the care, ask why?
5. What are your experiences of cancer care in the presence of COVID-19 preventive protocols?
6. How has COVID-19 restrictions put in place to limit its spread affected you?
7. What is your perspective of COVID-19 preventive protocols as it pertains cancer care?
8. What are the effects of COVID-19 preventive protocols on cancer services provision?
9. What coping mechanisms did you use during implementation of COVID-19 preventive protocols?
10. What will be your suggestion for helping cancer patients receive care?
11. Do you have anything to add on what you have said?
12. Thank you.

**Prompts:**

1. What do you say about this.....
2. May you explain on your answer.....
3. Anything else you would like to add.....

## **Kiambatisho VIb: Mwongozo wa mahojiano**

Numbari ya fomu.....

Kichwa cha Utafiti: Masharti ya kuzuia virusi vya Corona 2019 na Matibabu ya Saratani: Uzoefu na mitazamo ya wagonjwa wa saratani ya watu wazima katika Kituo cha Matibabu cha Saratani ya Hospitali ya rufaa ya Kenyatta.

Utangulizi:

Salamu! Jina langu ni (jina) na nitakuwa nikiwezesha mahojiano ya kina. Huyu ni (jina) na atakuwa akichukua maelezo na kunisaidia. Asante sana kwa kuchukua wakati wa kuwa na sisi leo. Mahojiano hutafuta kuchunguza na kuelewa uzoefu wako na maoni juu ya utunzaji wa saratani kufuatia utekelezaji wa masharti ya kuzuia virusi vya COVID-19. Hii itaarifu muundo bora na hakiki ya njia za utekelezaji ili kuhakikisha kuwa huduma za utunzaji wa saratani ni bora. Habari hii haitajulikana na itawekwa kwa siri. Unaweza kujiondoa wakati wowote wakati wa mahojiano ikiwa hujisikii vizuri kujibu maswali. Mahojiano yatarekodiwa kwa uchambuzi zaidi baadaye na maelezo pia yatachukuliwa wakati wa mahojiano. Rekodi zote na noti zilizochukuliwa zitahifadhiwa salama. (Dhibitisha kwamba mshiriki anakubali kurekodi kabla ya kuendelea ikiwa hataki basi maliza mahojiano). Mahojiano yatachukua kama dakika 30-45.

Kabla hatujaanza una swali lolote?

Data ya Mushirika

1. Je! Ni nini sababu ya kutembelea hospitali leo?

- a. Ushauri
- b. Matibabu
- c. Uchunguzi
- d. Nyingine (tafadhali taja).....

2. Je! Unaishi wapi?

- a. Mjini
- b. Vijijini
- c. Nyingine (taja).....

3. Je! Unatumia njia gani za kusafiri unapokuja hospitalini?

- a. Usafiri wa umma
- b. Gari la kibinafsi
- c. Pikipiki
- d. Teksi
- e. Nyingine (taja).....

4. Je! Hali yako ya ndoa ni nini??

- a. Nimeolewa/owa
- b. Naishi peke yangu
- c. Kutengwa
- d. Talaka
- e. Nyingine

5. Je! Unalipaje matibabu yako na huduma zingine za saratani? (unaweza kuchagua zaidi ya moja)

- a. Bima ya afya ya kitaifa (NHIF)
- b. Bima ya afya ya kibinafsi
- c. Nalipa kutoka mfukoni
- d. Mchango kutoka kwa familia na marafiki
- e. Nyingine (taja).....

6. Jinsia yako ni nini?

- a. Mwanaume
- b. Mwanamke
- c. Nyingine

7. Kiwango cha elimu

- a. Shule ya Msingi
- b. Shule ya Sekondari
- c. Chuo kikuu
- d. Nyingine (taja).....

8. Dini

- a. Mkristo
- b. Mwislamu
- c. Nyingine

9. Umri wako ni nini?

- a. Miaka 18 - 40
- b. Miaka 40 - 65

c. Miaka 65 - 75

d. Miaka 75 au zaidi

10. Je! Ni hali gani inayotumika kwako bora?

a. Nina saratani na ninangojea kuanza matibabu

b. Hivi sasa niko chini ya matibabu ya saratani

c. Tiba yangu ya saratani imekamilika na kwa sasa ninafuatiliwa hospitalini

d. Nyingine (taja).....

11. Una saratani ya aina gani (au ulikuwa nayo)? (Ikiwa una (ulikuwa na) aina nyingi za saratani, unaweza kusema zaidi ya moja).....

12. Ulijiandikisha lini kliniki ya utunzaji wa saratani hapa KNH (taja mwaka na mwezi).....

13. Ni yapi ya maelezo hapa chini yanafanana na hali yako ya sasa bora?

a. Mimi (labda) nimepona saratani

b. Nina (labda) ugonjwa unaoweza kupona

c. Nina (labda) ugonjwa usioweza kupona

d. Sijui

e. Hakuna yenye inaniusu

14. Je! Una au umepokea matibabu gani hivi karibuni? (unaweza kujaza zaidi ya moja)

a. Upasuaji

b. Madawa

c. Tiba ya mionzi

d. Tiba ya homoni

e. Tiba yakinga ya mwili

f. Tiba iliyokusudiwa

g. Kupandikiza kwa seli ya shina

h. Kungojea kwa uangalifu

i. Upasuaji wa Ostomy

j. Tiba ya maumivu

k. Sijui ni matibabu gani

l. Hainiusu

m. Nyingine (Tafadhali taja).....

15. Je! Wewe - mbali kama unavyojua – umewahi kuwa na virusi vya corona?

a. Ndio, nimepimwa na matokeo yalikuwa mazuri

b. Labda, nina / nilikuwa na malalamiko ya njia ya hewa na / au homa ( $\geq 38$  digrii Celsius) na / au dalili mbili au zaidi za: dalili kama homa) au maumivu ya mwili, uchungu wa misuli, maumivu ya kichwa, maumivu kwenye jicho, na / au umekuwa ukiwa katika kuwasiliana na mtu ambaye ameambukizwa na virusi vya corona

c. Hapana, nimepimwa na matokeo ya yalikuwa hasi.

d. Hapana, sijapimwa na sikuwa na dalili zozote za homa

e. Nyingine (taja).....

Kuuliza maswali:

Orodha hii ya maswali itamuongoza mtafiti. Sio lazima kufuata kwa utaratibu au kabisa na majibu ya mshiriki yataongoza maswali pia.

1. Je! Unaweza kuniambia kidogo juu ya hali yako ya sasa ya afya?

2. Je! Umekuwa ukipokea huduma kwa muda gani katika mpangilio huu wa huduma ya afya?

3. Je! Ni masharti gani ya kuzuia ugonjwa wa coronavirus ambayo iliwekwa ili kuzuia kuenea kwa COVID-19? Unaweza uliza masharti zaidi ya kuzuia.

4. Je! Umepokea huduma gani wa matibabu ya saratani wakati wa kipindi cha mapema cha COVID-19? Uliza jinsi mshiriki aliweza kupokea huduma wakati wa COVID-19?

5. Je! Unasema nini juu ya huduma za saratani ambazo umepokea wakati wa janga la coronavirus? Uliza kiwango cha kuridhika au kutoridhika na matibabu, uliza kwanini?

6. Je! Ni nini uzoefu wako wa huduma ya saratani mbele ya masharti ya kuzuia COVID-19?

7. Je! Umeathiriwa vipi na masharti ya kuzuia COVID-19?

8. Je! Ni maoni yako gani ya masharti ya kuzuia COVID-19 na kuweco kwa huduma ya saratani?

9. Ni nini athari za masharti ya kuzuia COVID-19 juu ya utoaji wa huduma ya saratani?

10. Jinsi gani, kwa maoni yako, masharti ya kuzuia COVID-19 imeathiri yafuatayo?

a. Afya ya mwili

b. Ustawi wa kisaikolojia

c. Ustawi wa kiuchumi

d. Ustawi wa kijamii

11. Je! Ulitumia njia gani za kukabiliana wakati wa utekelezaji wa masharti ya kuzuia COVID-19?

12. Je! Maoni yako yatakuwa nini kwa kusaidia wagonjwa wa saratani kupata huduma?

13. Je! Una chochote cha kuongeza juu ya kile umesema?

14. Asante.

Ahadi:

1. Unasema nini juu ya hii.....

2. Naomba ueleze juu ya jibu lako.....

3. Kitu kingine chochote ungependa kuongeza.....



## Appendix VII: Code Book

| <b>THEMES</b>  | <b>DEFINITION</b>  |
|--|--|
| Disrupted care   | Postponement, deferring and discontinuity of care                                |
| Challenging accessibility to care  | Difficult of reaching care services  |
| Cancer care services received  | Treatment modalities and other care services afforded to patients                |
| Availability of essential cancer care services                                 | Presence of care services  |
| Patient satisfaction   | Extent to which services gratify the desires of patients                         |
| Personal views of patients   | How patients perceive care received  |
| Subjective evaluation of respondent's own health condition and health services | Physical health condition of patients  |
| Complications associated with restricted access to cancer care                 | Adverse effects as a result of not receiving cancer care                         |
| Economic impact  | Financial effects, income effects  |
| Psychological effects  | Effects on patients' mind  |
| Social isolation and domestic confinement.                                     | Inability to meet other people, restrictions on movement out of residential area |
| Seeking divine intervention through prayers                                    | Call for spiritual assistance through praying                                    |
| Being hopeful  | State of having hope and faith   |
| Seeking family and friends support   | Asking for assistance from family members and friends                            |
| Adherence to COVID-19 preventive protocols                                     | Following laid down guidelines to prevent spread of coronavirus                  |
| Enablers of cancer care accessibility  | Factors that facilitated cancer care   |
| Disablers of cancer care accessibility.  | Factors that hindered cancer care  |
| Increase in the cancer care resources  | Addition of cancer care facilities and drugs                                     |
| Offering financial support and NHIF subsidy to cover most cancer services      | Monetary need to support cancer patients   |
| Devolving cancer care services to counties                                     | Availing cancer services at local level  |

**Appendix VIII: Study Area: Kenyatta National Hospital (source Google map)**



**Figure 4: Map of KNH**

## Appendix IX: Similarity Index

### Coronavirus 2019 preventive protocols and cancer-care: Experiences and perspectives of adult cancer patients at Kenyatta National Hospital Cancer Treatment Centre.

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