CHARACTERIZATION OF DISTRESSING SYMPTOMS AND COPING STRATEGIES AMONG BREAST CANCER PATIENTS UNDER TREATMENT AT KENYATTA NATIONAL HOSPITAL

JOYSTACY KENDI MUTEGI

REG. NO: H56/38256/2020

A THESIS REPORT SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENT FOR THE DEGREE OF MASTER OF SCIENCE IN NURSING (ONCOLOGY) OF THE UNIVERSITY OF NAIROBI

December 2022

DECLARATION

I, Joystacy Kendi Mutegi, declare that this thesis is my original work and has not been submitted for award of degree in any university.

Signature   Date: 2nd December 2022

SUPERVISORS' APPROVAL

This dissertation has been presented for assessment with our authorization as academic supervisors. This is in partial fulfillment of the University of Nairobi's award of the Master of Science in Nursing (Community Health) degree.

Signature: .... Date: 29/11/2022

Dr. Samuel Kimani
PhD, MSc, BScN
Senior Lecturer, Department of Nursing Sciences,
Faculty of Health Sciences
The University of Nairobi.

Signature: .... Date: 30/11/2022

CHAIRMAN
30 NOV 2022

Dr. Emmah Matheka
PhD, MSc, BScN
Department of Nursing Sciences
Faculty of Health Sciences
The University of Nairobi

TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

LIST OF ABBREVIATIONS AND ACRONYMS

ADP:	Adenosine Diphosphate
BRCA:	Breast Cancer Gene
CTC:	Cancer Treatment Center
ERC:	Ethics and Research Committee
GLOBOCAN:	Global Cancer Observatory
HER:	Human Epidermal Growth Factor Receptor
KNH:	Kenyatta National Hospital
SMT:	Symptom Management Theory
SPSS:	Statistical Package of Social Sciences
UON:	University of Nairobi
WHO:	World Health Organization

OPERATIONAL DEFINITIONS

Characterization: This is the description of the unpleasant manifestations experienced by the patients under treatment.

Coping strategies: These are mechanisms employed by the patient as a way of adapting or dealing with distressing symptoms.

Distressing symptoms: These are unpleasant manifestations that put a patient in a desperate need and may interfere with the performance of the day-to-day activities.

Patient satisfaction: This refers to a state fulfillment, contentment or gratification with the services offered to in management and assessment of distressing symptoms.

ABSTRACT

Background: Cancer is ranked as the second cause of death globally, in 2020 it accounted for about10 million deaths mostly among women. Patients with breast cancer may experience various physical and emotional distressing symptoms during diagnosis, treatment and recovery mainly associated with cytotoxic agents and radiotherapy treatment. However, there are few or no studies focusing on these distressing symptoms in patients with breast cancer treatment in Kenya affecting planning and implementation of coping strategies.

Objective: This study sought to determine the distressing symptoms and coping strategies associated with breast cancer treatment among patients attending CTC in KNH.

Methodology: This was a descriptive cross-sectional study that involved both qualitative and quantitative methods. A questionnaire and focused group discussions were used for data collection at CTC in KNH and the target population was breast cancer patients on treatment and follow-up at the center. The sample size was made up of ninety-two participants with breast cancer who consented to the study. Simple random sampling was used to select the study participants and the study tools were pretested in female medical ward where breast cancer patients were admitted to check for reliability and validity. Ethical approval was sort from Kenyatta National Hospital-University of Nairobi Ethics and Research Committee board and permission to conduct the study from the Chief Executive Officer of Kenyatta National Hospital. Data analysis was done using SPSS and presented through pie charts and tables while thematic analysis was used for qualitative data.

Results: The response rate in this study was 100%, majority (65.2%) of the respondents were married, Christians (91.2%), with an income of below 10000 Kenya shillings (55.4%) and the mean age was 48.49 years. The most, distressing symptoms was fatigue, pain, lack of appetite, drowsiness, nausea, anxiety, vomiting, depression, diarrhea, constipation and least symptom experienced was shortness of breath and the severity was anxiety, lack of appetite, loss of well-being, fatigue, nausea, pain and drowsiness. The coping strategies used were seeking spiritual help, maintaining hope and emotions, expressing emotions to friends, facing reality, reaching out for support to friends, distracting yourself by use of music, using positive affirmations, family support, group support, performing relaxation exercises, staying in the house and praying to God. There was satisfaction with management of distressing symptoms due to good treatment, affordable services, good treatment outcome, well-trained staff. The reasons for not being satisfied were long waiting time before start of treatment and lack of drugs.

Conclusion: In Kenya patients diagnosed with breast cancer are more distressed by fatigue and pain but anxiety is more severe. There is a difference in the appearance of the distressing symptoms in different environments and patients use different coping strategies to cope with the distressing symptoms. There was lack of patient education at the Cancer Treatment Centre in Kenyatta National Hospital among breast cancer patients on coping strategies of the distressing symptoms arising from treatment of cancer. To better manage distressing symptoms among breast cancer patients, improve on timely services, drug supply and affordability of services. Irrespective of the management of the distressing symptoms patients are satisfied with the services offered at Cancer Treatment Centre in Kenyatta National Hospital.

Recommendations: Characterizing of the distressing symptoms and coping strategies among breast cancer patients will help in incorporation of distress symptom assessment in the day-to-day care of cancer patients hence improving the compliance to treatment modalities leading to better outcomes and improved quality of life.

CHAPTER ONE: INTRODUCTION

1.1 Background of the study

Cancer is ranked as the second cause of death globally, accounting for about10 million deaths in 2020 and about 19 million new cases having been diagnosed in 2020 (GLOBOCAN, 2020). The number of new cases in Africa is estimated to be about 1.1 million cases and 42,116 of these were from Kenya (GLOBOCAN, 2020). As cancer episodes continue to increase, the proportion of cancer patients on various therapy modalities including radiotherapy and chemotherapy also increases.

The Global Cancer Registry, (Globocan, 2020), indicates that breast, colorectal, lungs, cervical and thyroid cancers respectively constitute the leading top five cancers among women in terms of occurrence. Breast cancer has the highest prevalence followed by colorectal, thyroid, cervical and corpus uteri cancer. In terms of incidence and mortality among women, breast, colorectal and lung cancers come in first, second and third respectively (GLOBOCAN, 2020; Sung *et al.*, 2021).

Cancer of the breast was the most common type of cancer amongst African women in 2020, affecting 129 000 women who were newly diagnosed and 6,799 of these cases were from Kenya (Nounou *et al.*, 2015; GLOBOCAN, 2020; WHO, 2021a).

During diagnosis, treatment and recovery, patients with breast cancer may experience a wide spectrum of physical and emotional distressing symptoms. Despite the influence on daily functioning, distressing symptoms in patients with cancer are neglected and undertreated, potentially resulting in poor treatment compliance and survival. Some of the leading distressing symptoms on diagnosis are: anxiety, depression, self-image concerns and anger (Liao *et al.*, 2015).

Distressing symptoms are those that might make a person feel dissatisfied, fearful, depressed, nervous, or isolated. The National Cancer Institute defines them as emotional, spiritual, social, or bodily pain or suffering. People under distress may find it difficult to control or cope with changes brought on by everyday activities or by the diagnosis of a condition, such as cancer, which makes it difficult for them to deal with their disease's diagnosis, physical symptoms, or treatment (NCI Dictionary, 2022). Distressing symptoms entails uncontrolled side effects related to cancer and its treatment modalities. Side effect arelargely considered as an undesired secondary consequence that occurs in addition to a drug's intended therapeutic benefit and vary from person to person (Drugs.com, 2022).

Patients with cancer receiving treatment regularly experience a variety of symptoms that give them excessive distress and interfere with their daily activities. These distressing symptoms are mainly associated with cytotoxic drugs and radiotherapy (Henson *et al.*, 2020). Cytotoxic chemotherapy is used to treat a variety of malignancies, whether as an adjuvant or palliative treatment. Chemotherapy increases cancer survivability, but the side effects frequently result in major physical and psychological consequences (Thiagarajan *et al.*, 2016).

Moreover after initiation of the treatment patients experience pain, fatigue, nausea, vomiting, breathlessness, confusion, insomnia, constipation and diarrhea in addition to symptoms that are related to the disease process at the time of diagnosis (Liao *et al.*, 2015; Guan *et al.*, 2017; Henson *et al.*, 2020). If the forementioned symptoms are not well managed they make it difficult for patients to adhere to their treatment and it affects patients performance of the activities of daily living (Henson *et al.*, 2020).

patients with tumors experience symptoms which vary in their prevalence and severity which depends on the cancer type, stage, treatment(s), and other comorbidities (Henson *et al.*, 2020). At any given time, patients may suffer more than one symptom but with good symptom management, there is good treatment compliance and a better quality of life for the patient and the family.

Patients with cancer are plagued by symptoms connected to the disease or the side effects of numerous treatment options. Patients' quality of life and ability to function are severely harmed by unresolved symptoms. These symptoms may also cause treatment to be interrupted and have a detrimental impact on its effectiveness (Cleeland *et al.*, 2000).

Effective symptom management, as demonstrated in various studies, calls for regular and accurate symptom evaluation and communication between patients and health care practitioners. (Cleeland *et al.*, 2000; Henson *et al.*, 2020). Effective symptom management is linked to higher patient and family satisfaction, better treatment adherence, and possibly even survival benefits. Despite these positives, symptoms are regularly mismanaged and/or under treated, underlining the need for further care improvements (Henson *et al.*, 2020).

Symptoms can be so distressing and complete symptom assessment is rarely done as part of recommended cancer care. Before formally assessing patients, health care providers frequently wait until they spontaneously complain of symptoms. Patients may be hesitant to report symptoms for a variety of reasons. (Cleeland *et al.*, 2000; Borjeson, 2012). Patients may fear that reporting about symptoms diverts doctors' attention away from the cancer management, undermines their efforts to be "good" patients, entails the use of a new group of drugs with uncertain negative effects, or indicates that their condition is progressing (Cleeland *et al.*, 2000; Borjeson, 2012; Stark *et al.*, 2012). Most patients do not report symptoms until they have progressed to the point where they require emergency treatment or hospitalization, significantly increasing the cost of therapy and disrupting the patient's and family's routines (Cleeland *et al.*, 2000; Henson *et al.*, 2020).

Nurses need to enquire about the most distressing symptoms in patients which helps the nurses prioritize care to the patients, provision of health education and support the patients (Borjeson, 2012; Stark *et al.*, 2012; Lavdaniti, 2015).

An empirical investigation on symptom profile among breast cancer patients in Nigeria showed that most of the patients on treatment presented with pain, feeling sad, insomnia weight loss and worrying. These symptoms hindered adherence to treatment among some of the patient. High-quality symptom assessment and management are required to provide holistic, patient-centered treatment that leads to good results for patients and their families (Anderson *et al.*, 2000; Henson *et al.*, 2020; Isiaka-Lawal *et al.*, 2021).

A Kenyan study on symptom burden among breast cancer patients revealed that most of the patients presents with nausea (33%), bowel issue (25%), weight loss (20%) and fatigue (19%) while 50% of the respondents reported to have depression, worry and stress (Tarus *et al.*, 2021). Other than this study, there were no researches undertaken to determine the priority distressing symptoms in patients undergoing cancer treatment in Kenya and thus this study aimed at filling the gap.

1.2 Problem Statement

After infectious and cardiovascular disorders, cancer is Kenya's third largest cause of death and breast cancer is rated first followed by cervical, prostate, esophageal and colorectal cancers (GLOBOCAN, 2020). As cancer cases increase, more patients are being initiated on treatment which have got various symptoms and side effects that need to be addressed.

Recently, there has been an increase in study interest in certain cancer-related symptoms like pain, exhaustion, mucositis and nausea/vomiting. Despite advancements in this field of research, it has been revealed that evaluating a single symptom is not always beneficial in directing treatment therapy when patients have many symptoms at the same time (Molassiotis, Stamataki and Kontopantelis, 2013; Lavdaniti, 2015).

Chemotherapy patients encounter a variety of symptoms, some of which are quite severe. As such, nurses should consider distressing symptoms findings and develop appropriate care plans and interventions to alleviate suffering and improve patients' quality of life (Lavdaniti, 2015). At KNH, the only data that exists is the number of the patients on chemotherapy treatment and the type of the treatment but there are no records for the symptoms and side effects experienced by the patients as a result of treatment (Bosire, 2019).

Breast cancer is the most common cancer in incidence, prevalence and mortality in Kenya and worldwide hence becoming the focus of this study. With the increasing incidence of breast malignancies, more patients will be started on treatment in Kenya and globally. Characterizing the symptoms helps the healthcare workers to pick them early and address them hence improving these patients' compliance to treatment and the quality of life. Addressing distressing symptoms is also a component of evidence-based practice (Muzzatti *et al.*, 2020; Deshields *et al.*, 2021).

Symptom distress is associated to a lower quality of life, reduced treatment adherence and efficacy, death and a higher risk of suicide. As a result, healthcare workers should work to improve patients' quality of life while also lowering medical expenditures by reducing patient suffering (Chiou *et al.*, 2016).

1.3 Research Questions

i. What are the distressing symptoms associated with breast cancer in patients under treatment at Kenyatta National Hospital?

ii. What is the severity of the distressing symptoms as expressed by breast cancer patients attending Cancer Treatment Center at Kenyatta National Hospital?

iii. What are the coping strategies for dealing with distressing symptoms associated with breast cancer treatment?

iv. What is the level of satisfaction of breast cancer patients with the management of the distressing symptoms?

1.4 Study Objectives

1.4.1 Broad Objective

To characterize distressing symptoms and coping strategies among breast cancer patients under treatment at Kenyatta National Hospital

1.4.2 Specific objective

1. To identify the distressing symptoms associated with breast cancer treatment among patients at Kenyatta National Hospital.
2. To determine the severity of distressing symptoms as expressed by breast cancer patients attending Cancer Treatment Center at Kenyatta National Hospital.
3. To determine the coping strategies for dealing with distressing symptoms associated with breast cancer treatment.
4. To determine the level of satisfaction of breast cancer patients on treatment with the management of the distressing symptoms.

1.5 Hypothesis

Null hypothesis: Patients with coping strategies will not have different experiences in distressing symptoms compared to those without.

1.6 Justification

This study explored the priority distressing symptoms expressed by patients receiving treatment for breast cancer at Kenyatta National Hospital and the coping mechanisms that they use in the management of the symptoms. The results of this research will form the basis for standardized assessment, management and subsequent policy for care of patients with breast cancer in Kenya. This is because there are few studies carried out in Kenya on the distressing symptoms that patients with cancer experience and especially those with breast cancer.

Understanding of the distressing symptoms that patients with cancer experience, helps in accurate diagnosis and thus management of the distressing symptoms which subsequently leads to improved treatment outcomes and eventually improved quality of life for both the patient and the family. This guarantees attainment of right of patients as stated in the constitution of Kenya article 43 which emphasis that every person has a right to the highest attainable standard of health and thus identification and management of the distressing symptoms will be in its fulfillment.

Consequently, this will have an impact on policy on the management of breast cancer patients, as well as other cancers, ensuring that distressing symptoms that affect quality of life are assessed and handled early, resulting in better treatment outcomes. This could also encourage the introduction of the use of various assessment tools in the assessment of the distressing symptoms.

1.7 Study Variables

The dependent variable for this study is characterization of the distressing symptoms.

The independent variables for this study are: Socio-demographic factors (age, marital status, residence, monthly house income, social support), clinical factors (Staging of breast cancer, pathologic sub-type treatment modalities, stage) and patient disclosure of the presenting symptoms.

The intervening variables are the institutional factors (standard operating procedures or guidelines, personnel factors and infrastructural factors).

The outcome variable for this study is the coping strategies and the patients' satisfaction.

1.8 Conceptual Framework

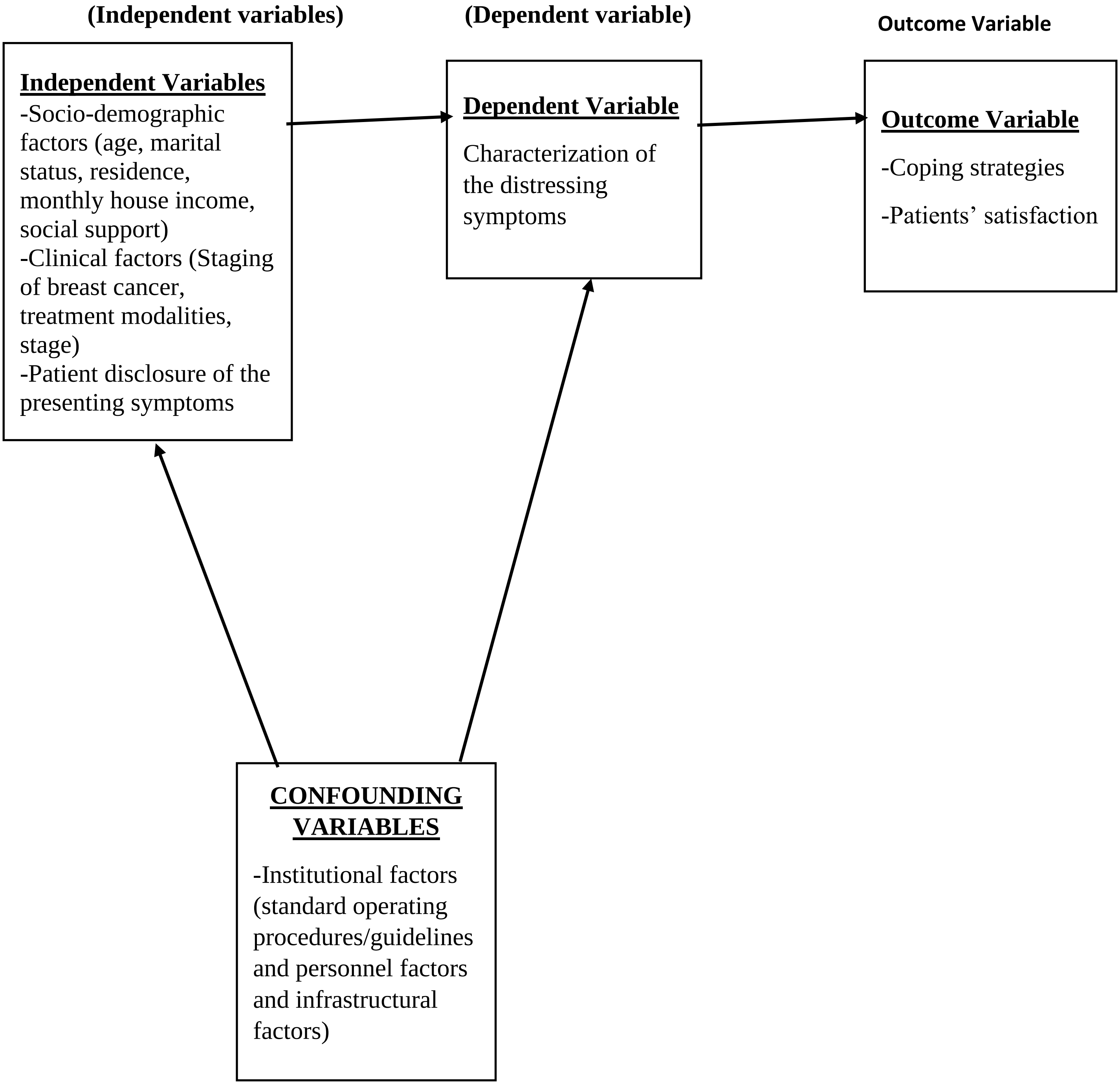


Figure 1: Conceptual Framework

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

This section comprises a review of the numerous scientific publications, reports and books that the author studied during the research process. Google scholar, Hinari and Pubmed were used to conduct the literature search. The key terms used were: distressing symptoms, severity, coping strategies and patient satisfaction.

2.2 Background on Cancer

The World Health Organization (WHO, 2021b) defines cancer as a universal term for a wide range of diseases that can involve any part of the body. The defining characteristic of malignant tumors is the rapid formation of abnormal cells that extend beyond their original margins, and which can then invade neighboring parts of the body and proliferate to other organs (WHO, 2021b).

According to Global Cancer Observatory (GLOBOCAN, 2020) registry; breast, colorectal, lungs, cervical and thyroid cancer respectively are the top five leading cancer among women in terms of incidence. When it comes to prevalence, the leading cancer is breast followed by colorectal, thyroid, cervical and Corpus uteri cancer respectively. Breast cancer is the most frequently diagnosed malignancy in women and the major cause of cancer mortality, followed by colorectal and lung cancer in relation to occurrence and mortality (Globocan, 2020).

Cancer of the breast is the leading cancer worldwide with varying survival rates and in Africa in the year 2020, it was the most frequent kind of cancer in women where it affected 129 000 women who were newly diagnosed and 6,799 of these cases were from Kenya(Nounou *et al.*, 2015; Globocan, 2020; WHO, 2021a).

According to a study done in Greek, chemotherapy patients experience a wide range of symptoms, some of which are fairly severe. As a result, nurses should take these findings into account when developing care plans and treatments to relieve symptoms and improve patients' quality of life (Lavdaniti, 2015). This will lead to improved satisfaction with the services being offered.

According to (Nounou *et al.*, 2015) the common treatment modalities for breast cancer are surgery, hormonal therapy, radiation therapy, chemotherapy and targeted therapy. The treatment options vary depending on the molecular subtype, and it is managed in a multidisciplinary manner that includes surgery, radiation therapy and systemic treatments. Endocrine therapy for hormone receptor-positive cancer, chemotherapy, anti-HER2 therapy for HER2-positive disease, bone stabilizing medicines, poly (ADP-ribose) polymerase inhibitors for BRCA mutation carriers, and, most recently, immunotherapy are among the systemic treatments. According to (Harbeck *et al.*, 2019) upcoming treatment strategies for breast cancer purpose at personalized management and treatment reduction and increase depending on cancer biology and previous therapy response.

2.3 Distressing symptoms in breast cancer patients

Presence of distressing symptoms is related to decreased quality of life, therapy adherence and effectiveness, higher mortality and an increased chance of self-destruction. As a result, healthcare workers should work to improve patients' quality of life as well as lowering their medical expenditures by reducing patient suffering (Chiou *et al.*, 2016).

Distress exists on a spectrum of care of breast cancer patients, varying from day-to-day feelings of susceptibility, sorrow and fear to more serious issues like anxiety, panic, social isolation, depression, existential and spiritual predicament. Poorly and not managed distresses negatively impacts on the well-being of the patients and cancer related fatality (Syrowatka *et al.*, 2017).

A study done in Norway on the frequency of the distressing symptoms among patients with chronic conditions like cancer revealed that depression (41%), extreme tiredness (56%), dryness of the mouth (58%) and dyspnea (70%) were among the leading distressing symptoms (Sigurdardottir and Haugen, 2008). Others pers this study were anxiety and pain. Staffs attending to these patients need extra skills to identify the symptoms so as to manage them and consequently improve the quality of management offered to these patients (Sigurdardottir and Haugen, 2008).

2.4 Severity of the distressing symptoms among breast cancer patients

Being aware of the prevalence of symptoms, at the time of clinical practice, is critical as it helps to anticipate patient issues and needs; to organize patient treatment and to train clinical staff to focus on specific symptoms. For the healthcare workers, the first stage in establishing an effective distress symptom management care system for patients is to explain symptom prevalence and understand patient requirements (Yamagishi *et al.*, 2009).

A number of tools like the distress thermometer and Anderson symptom inventory have been developed to address the distressing symptoms amidst patients with cancer for effective management. These distressing symptoms have been classified into psychosocial problems; nutritional and gastrointestinal issues; fatigue and pain, dyspnea and numbness (Koedoot *et al.*, 2003; Yamagishi *et al.*, 2009; Spichiger *et al.*, 2011).

Chemotherapy treatment induces various distressing symptoms among the patients. In a study done in Swiss showed that fatigue was the highest ranked distressing symptom at 97%, among cancer patients on chemotherapy. It further showed that 50% of the respondents complained of pain, nausea, vomiting, constipation, insomnia and lack of appetite (Spichiger *et al.*, 2011).

A significant proportion of patients with cancer reports pain as one of the distressing symptoms. The pain becomes more severe as the proportion of the chemotherapy cycles they receive increases. Patients with metastatic disease and on chemotherapy treatment reports more severe levels of pain (Tantoy *et al.*, 2018). Most of the patients reported the pain to be distressing to them and they were not able to perform their activities of daily living.

Lack of energy has been reported by 80% of the patients on chemotherapy treatment to be among the severe experiences. It was related to age and the time that had lapsed after cancer diagnosis at the time of registration (Tantoy *et al.*, 2018). From this study, the likelihood of a patient reporting fatigue increased by 1.17 times for every year after their cancer diagnosis. The number of previous cancer therapy was associated to the intensity of fatigue at the time of enrolment to care and as the number of previous cancer therapy rose, the risk of sliding one point higher on the lack of energy severity scale increased 1.33 times.

2.5 Coping strategies for addressing distressing symptoms

Coping refers to the behavior and attitudes you adopt to preserve your mental well-being and cope with the stresses caused by cancer. People deal with stress in a variety of ways, and some approaches are more efficient than others in promoting emotional well-being and psychological adaptation (Kneier, Rosenbaum and Rosenbaum, 2021).

A breast cancer diagnosis, regardless of the stage, is stressful, affects numerous aspects of life and disrupts patients and family physical state, mental, spiritual health and personal connections (Elsheshtawy *et al.*, 2014). The study further states that ability to adjust, the patient must use some coping strategies in order to have a better quality of life.

Various coping mechanisms among cancer patients identified by (Kneier, Rosenbaum and Rosenbaum, 2021) include: facing reality to illness; expressing emotions; retaining hope and optimism; proportion and balance; seeking help; taking an active role; discovering positive meaning; spirituality, religion and prayer; preserving one's self-esteem and learning to deal with mortality (Kneier, Rosenbaum and Rosenbaum, 2021).

Coping methods can have an impact on treatment results and survival rates for women with breast cancer. Coping tactics are a combination of behavioral and psychological techniques that people apply to handle stress (Khalili *et al.*, 2013). Problem-focused and emotional-focused coping techniques are the most common. Taking proactive steps to alleviate or improve stressful situations is what problem solving is all about and the Emotion–focused approaches seeks to regulate the emotional consequences of stressful situations and to restore affective and emotional equilibrium (Carver *et al.*, 1993; Khalili *et al.*, 2013).

Cancer patients usually endure a range of both physical and emotional challenges and they employ different strategies in order to cope. An Iranian study revealed that women use various coping strategies to deal with distressing symptoms during their treatment with cancer and these included spirituality, positive cognitive restructuring and detachment (Sajadian *et al.*, 2017). The effectiveness of coping was found to be determined based on the stage cancer, therapy, duration of disease and sort of coping measure adopted.

In a study done by Khalili indicated the value of considering individual coping techniques when assessing the effects of cancer on physical and mental health outcomes in order to assist in identifying patients who require further counseling and support, as well as arranging for appropriate nursing care for these patients. They further stated that the knowledge of coping mechanisms of women with breast cancer is required for nurses participating in the treatment process it can be utilized to build a nursing approach to enhance proper coping in breast cancer patients, as well as give healthcare workers better knowledge of these women as they face the diagnosis (Khalili *et al.*, 2013).

A study done in Poland showed that patients who used constructive coping techniques had higher quality of life scores, whereas those who used destructive coping strategies had considerably poorer quality of life scores (O´smiałowskao´smiałowska *et al.*, 2021). It further stated that a battling spirit, positive reframing and worrisome concern were among the cancer coping mechanisms reported.

According to Montgomery and (Montgomery and McCrone, 2010), the adoption of active coping methods has been linked to lower levels of distress and education and counseling have found a link between educational satisfaction and reduced psychological distress. They went further say that women who are well-informed about the process had less psychological anguish.

Following a diagnosis, the most popular coping mechanisms included soliciting social support, positive cognitive restructuring, making adjustments and religion. Detachment wishful thinking and keeping sentiments to self-coping mechanisms were the least employed coping strategies (Sajadian *et al.*, 2017).

Active coping strategies like positive cognitive restructuring (also known as positive reappraisal), acceptance, emotional processing, or emotional responses have a good quality of life than inactive coping strategies such as evading or downplaying the severity of their cancer. The type of coping measure utilized, as well as the stage of cancer, treatment and duration of the disease, all influenced the effectiveness of coping (Sajadian *et al.*, 2017).

A study in USA in 2011 showed that religious coping techniques were widely used; up to 73 percent of patients used positive religious coping strategies to some extent during surgery and up to 53 percent had religious/spiritual issues. Patients may benefit from having their spiritual needs handled, according to the study, because religious/spiritual struggle can be a barrier to sickness adjustment (Thuné-Boyle *et al.*, 2010).

Relaxation together with distraction, have been found to be useful coping methods for cancer treatment of distressing symptoms such as nausea. The effects of relaxation found in this research are comparable to those found in the study by (Wambalaba *et al.*, no date) which revealed that relaxation and guided imagery reduced fatigue (Browall and Kenne Sarenmalm, 2015).

Acceptance is one of the most commonly employed coping methods and it has been linked to healthy emotional functioning and adjustment. After treatment, it was also discovered to be one of the most common strategies of coping utilized by long-term cancer patients and female cancer survivors (Browall and Kenne Sarenmalm, 2015).

Breast cancer patients who have a high level of self-acceptance have more positive feelings about themselves and are better able to suppress their disease-related frustrations. Patients with low to moderate acceptance frequently felt pain and lacked enthusiasm for the chemotherapy and drug regimens. Several respondents were depressed and a few even sobbed and lamented about their illness. These results are consistent with the findings of a previous research (Chen *et al.*, 2017) found that breast cancer patients with low self-acceptance frequently experience loss of self-confidence, low self-esteem and a refusal to follow their chemotherapy regimen (Merlin, Anggorowati and Ropyanto, 2019).

2.6 Patients' satisfaction with the management of the distressing symptoms

Patients' satisfaction is one of the indicators of quality healthcare in a given population (Lam *et al.*, 2018; Djambazov, Giammanco and Gitto, 2019). Higher patient acceptance, compliance to stipulated medical care, improved practice guideline adherence, and lower inpatient mortality rates have all been linked to patient satisfaction (Lam *et al.*, 2018). Patient fulfilment surveys aids in development of standards and protocols, making patient aid and support are a top priority in any cancer-related service (Djambazov, Giammanco and Gitto, 2019; Tobias *et al.*, 2020).

The availability of care and the treatment setting, the technical characteristics of care, the patient's education, the relational aspects of care, the information provided by medical workers, the staff's receptiveness to the patient's condition and the personal problems associated with cancer treatment, the personnel's understanding of the patient's psychological requirements and the staff's skill to convey information all contribute to patient contentment in cancer care (Lam *et al.*, 2018; Djambazov, Giammanco and Gitto, 2019).

Patient satisfaction is especially significant as an outcome indicator for patients who have been diagnosed with a chronic or severe condition, like cancer, and require continuing medical care to manage the condition (Lam *et al.*, 2018). Studies conducted to examine patients' satisfaction in oncology patients revealed a high level of satisfaction. This is mostly associated with how the distressing symptoms were addressed by the healthcare workers (Lam *et al.*, 2018).

Patient satisfaction is linked to patient variables like gender, age and type of cancer, as well as patient care elements such as information availability, doctor-patient rapport, and continuity of care. Patient-centered satisfaction and information supply are essential elements in predicting satisfaction, however demographic characteristics of patients have been demonstrated to be inconsistent in predicting satisfaction levels (Lam *et al.*, 2018; Tobias *et al.*, 2020). Aside from patient features/characteristics, hospital-related factors like personnel, waiting times, amenities and processes have an impact on the level patient satisfaction with cancer care, which includes the management of distressing symptoms (Tobias *et al.*, 2020).

China conducted a study to survey patients satisfaction in women with advanced disease showed that during the initial treatment period, patients who had several underlying issues for disease, therapy information and continuity of care were more likely to be dissatisfied in the long term (Lam *et al.*, 2018).

Patients' experiences with the healthcare system are used to gauge patient satisfaction, which enables researchers, industry experts and legislators to diagnose issues and areas of improvement in order to ensure equal access to the available of care services (Lam *et al.*, 2018; Djambazov, Giammanco and Gitto, 2019; Tobias *et al.*, 2020).

2.7 Theoretical Model

In this study, the symptoms Management Theory will be used to guide the research. The model was developed as the Symptom Management Model by nursing faculty at the University of California San Francisco in 1994 and passed through a series of updates. It describes the multidimensional nature of symptoms and can be used to develop effective intervention strategies to enable proper symptom management. Consequently, it also includes information on the probable consequences of other associated studies in regard to the delivery of primary care.

It is an important model for enhancing the experiences of patients and reducing the symptom burden. The model is divided into three parts namely: the symptom experience component, symptom management strategies and the outcomes component(Silva, Lopes and Mercês, 2021).

The purpose of the symptom experience component is to use an individual's perception of their symptoms to characterize their symptoms, how this discernment can be evaluated, and potential responses as expressed by the patient. The second component is meant to assist the healthcare team in the intervention selection process while the outcomes component contains all potential repercussions that may follow from both symptoms and management efforts (Silva, Lopes and Mercês, 2021).

The symptom experience component will be used to describe and list all the symptoms as experienced/perceived by the breast cancer patients in course of their treatment. It will also be used to explain the severity of these symptoms. Whereas the second component of symptom management strategies will be used in this study to assess the various coping strategies used by the patients while dealing with their presenting distressing symptoms. These strategies could be through support from the family friends and healthcare providers. The outcome component which entails symptoms and their management will be used to assess the level of satisfaction with the services offered at the CTC.

This study will utilize the first two components of the theory where the first component will include the assessment of the distressing symptoms present and their severity and the second component will address the coping strategies applied by the patients in dealing with the distressing symptoms.

THEORETICAL FRAMEWORK DIAGRAM

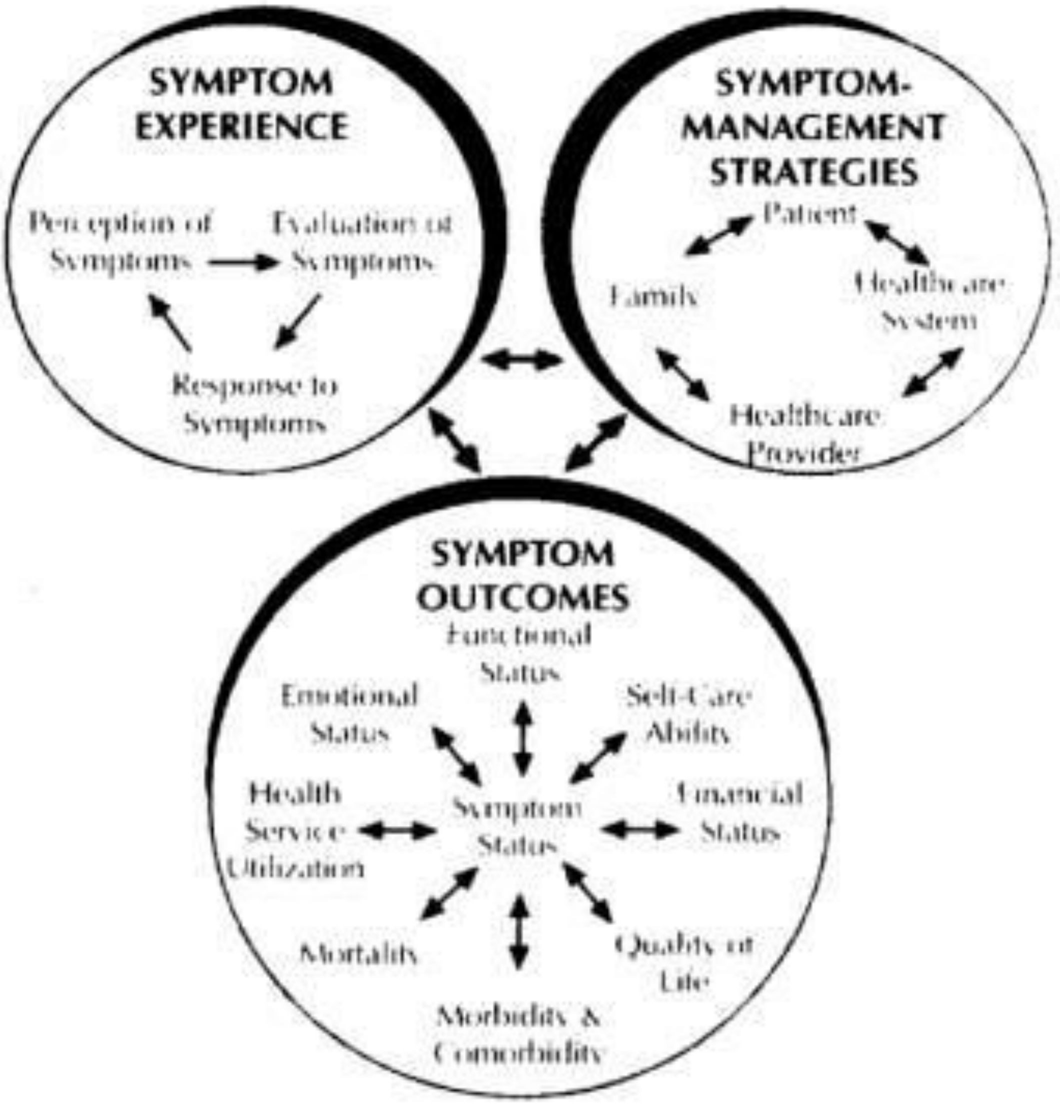


Figure 2: Theoretical Framework

CHAPTER THREE: METHODOLOGY

3.1 Introduction

This chapter describes approaches that were used in data collection as per the objectives of this study. It encompasses study design, study site, study population and sample size determination, sampling techniques, data management, quality assurance and ethical considerations.

3.2 Study Design

This study used descriptive cross-sectional study design and data was collected for a period of three weeks. In this design, the data was collected from study participants at a single point in time that provides a snap shot of a given situation at the specific time of data collection. It is a relatively cheap and easy to conduct design, since there is no follow up. It also saves on time
since data is collected once. Methodological triangulations were used with both qualitative and quantitative methods.

3.3 Study Area

The study was carried out at Kenyatta National Hospital (KNH) which was founded in the year 1901. KNH is the largest referral and teaching hospital in Nairobi County, about 3.5 kilometers west of the city's central business center. It is one of the national training hospitals in Kenya.

KNH is the country's principal referral hospital for cancer patients and it is among the three public hospitals that provides comprehensive cancer care. Chemotherapy, surgery, immunotherapy, radiotherapy, brachytherapy, hormonal therapy, and palliative care are some of the major therapeutic options available to cancer patients at the hospital. As a result, KNH is an ideal location for the research. This study will be conducted in the Cancer Treatment Centre which runs the following outpatient clinics: the radiotherapy, the chemotherapy and the palliative unit clinic. Patients diagnosed with breast cancer are seen and treated in the Cancer Treatment Centre and those that require surgical intervention will be admitted in the surgical ward (5A) through the outpatient breast cancer in clinic (clinic 24). Patients presenting with complications like anemia and severe dehydration are admitted in medical ward (ward 8C) for stabilization. For these reasons, KNH was an ideal location for the research.

3.4 Study Population

This study targeted patients diagnosed with breast cancer and on treatment at cancer treatment center (CTC).

3.5 Eligibility Criteria

3.5.1 Inclusion Criteria

All female breast cancer patients who consented to take part in the study and had been on active management for a period of more than three months.

3.5.2 Exclusion Criteria

Breast cancer patients who failed to consent to take part in the study and those who had started treatment in less than three-month period by the time of the study. Breast cancer patients who were mentally unstable or in coma at the time of the study.

3.6 Sample Size Determination

Fisher's formula was used to determine the sample size which was a representative of the population (Fisher's et al., 1998).

$$\boldsymbol{n = \frac{Z^2Pq}{d^2}}$$

In this case:

n = Sample size [for population >10,000]

Z = level of confidence according to the standard normal distribution. It was 95%, **Z**-Value at 95% is 1.96.

P = Proportion of the population estimated to have a characteristic of interest.

Q = Proportion of the population without characteristic of interest.

d^2= Tolerable margin of error; will be at 5%

The percentage of the breast cancer patients with distressing symptoms was unknown hence 50% of the population was included

$$\boldsymbol{n = \frac{Z^2P(1-P)}{d^2}}$$

$$n = \frac{I.96*1.96\ [0.5]\ [0.5]}{[0.05]\ [0.05]} = 384.16$$

In the current study, the number of breast cancer patients on treatment at KNH-CTC is 120 patients per month, hence the formula for infinite population will be utilized as described below

$$\boldsymbol{nf = \frac{n}{1 + {}^{n}\!/_{N}}}$$

Where:

nf = the intended sample size when population under study is less than 10,000

n = desired sample size when the total population >10,000

N = the calculated sample size.

$$\boldsymbol{nf = \frac{384}{1 + {}^{384}\!/_{120}}}$$

$\boldsymbol{nf}$**= 91.428**

$\boldsymbol{\sim 92}$

3.7 Sampling Technique

This involves selection of the study participants. The sampling frame included all the breast cancer patients who met the inclusion criteria. Simple random sampling method was used. Simple random sampling method ensures that all the participants have an equal chance of taking part in the study and helps eradicate biasness.

3.8 Data Collection tools

3.8.1 Questionnaire

Data was collected using a self-administered questionnaire. The questionnaire will be composed of three sections namely: demographic section and distressing symptoms and severity. The section two of the questionnaire is a modified Edmonton Symptom Assessment Scale (ESAS) which was used. This scale has been adopted and applied in most settings in the assessment of the distressing symptoms and the severity. Validity and reliability of the tool has been tested in the past before being applied in various setting (Chang, Hwang and Feuerman, 2000; Hui and Bruera, 2017). The tool has a numeric rating scale (NRS) ranging from 0 (no symptom) to 10 (worst possible) which helps in assessing severity. The severity for a symptom is classified into four categories depending on the score: No symptom (0), Mild (1-3), moderate (4-6) and severe (7-10).

3.8.2 Focused group discussion

A focused group discussion guide was used to explore coping mechanisms of the patients. The guide contained questions that guided the moderator to direct the discussion and probe further response from the study participants. The guide will be prepared based the study objectives. Digital audio recorder was used to record each of the sessions. Two focused group discussions were held; one at the chemotherapy treatment area in the room next to the treatment room and the other in the radiotherapy department in the triage room before the start of services like triage and consultation. Both discussions were held on the day the patients were coming for their consultation in the department. On the day of the discussions the researcher and the research assistant arrived early and set up the room for the discussion, the seats were arranged in a circle such all the respondents and research team were able to look at each other as the discussions went on. The video recorder was tested to ensure that it was working well and the roles of the research assistants were re-emphasized. The researcher and one research assistant took notes during the discussion while the other research assistant was doing the recording.

A mixture of both Kiswahili and English, the first discussion lasted 60 minutes and the second took 50 minutes. Once the participants arrived, they were welcomed, introductions of all present done, they were given the purpose of the discussion and they were given an explanation of what was to happen. Then the principal investigator requested for informed consent from the participants which was done through signing of the consent sheet. The whole group agreed on the pseudo names to be used during the discussion, all were encouraged to participate freely and the ground rules were set.

Once everything was set, the research assistant in-charge of recording alerted the whole team that the recording was starting. The principal investigator moderated the discussion, took notes and clarified points that were not clear. All participants were given equal opportunities to participate and controlled the flow of the discussion to avoid deviating from the main points of discussion. Once the discussion was over the recording was stopped and the participants were informed and the researcher thanked them on agreeing to be part of the study. The research team and the group members willing to be present listened to the recording to ensure that all areas were well captured and all present agreed that it reflected the discussion that was held. The audio recorder was replayed after every discussion to ensure complete recording of the discussion then it was stored together with the notebooks in a lockable cupboard. The data from the tapes was analyzed and compared with the notes taken on by the researcher and the assistant during both discussions.

3.9 Quality assurance

After the interview, one of the participants was asked to listen to the contents of the recording and she confirmed that they reflected the areas of discussion. Researcher was taking notes during the discussion so as to fill any details that might be missing. The research assistants and the researcher compared the findings during a review meeting in order to come up with a conclusion.

Transferability was ensured through description of the participants experiences as per the particular symptoms to allow other people to make meaning from the content. Some of the patients' words will be quoted directly.

3.10 Pretesting of the Research Tools

Pretesting of 10% of the questionnaire and interview guide was carried out at KUTRRH Cancer Treatment Center. This is because both facilities are level 6 and offer all the treatment modalities for breast cancer patients. All the necessary adjustments to the questionnaires were made as informed by the findings of the pilot study to improve on the reliability of the data to be collected in the main study.

3.11. Data Collection and Storage

Two research assistants were hired, and they were trained on the research's goal and the tools that were utilized to collect data. These research assistants were Bachelor of Science in Nursing students who were on internship and were available during the data collection period. All completed questionnaires were collected on a daily basis and stored in cabinets only the researcher had access to. The data was be accessible to anyone who was not authorized.

3.12 Data Analysis and Presentation

3.12.1 Quantitative Data

The data from the self-administered questionnaire was computed, coded, and analyzed with the Statistical Software for Social Sciences (SPSS) version 23. at a 95% confidence interval and a P-value of 0.05. The data was presented using descriptive statistics extracted from

SPSS, such as mean, median, and mode. To assess the relationship between the research variables and to test the hypothesis, inferential statistics such as the Chi square was used.

Table 1: Dummy table

Variable	Method of analysis	Presentation of Data
Sociodemographic (age, gender, marital status…)	Descriptive	Percentages, proportions, Numbers, frequency tables
Distressing symptoms (Fatigue, Nausea….)	Descriptive	Percentages, proportions, Numbers, frequency tables
Severity of distressing symptoms	Scale (0-10)	Percentage, frequency tables
Coping strategies	Qualitative	Narratives/Quotes
Patient satisfaction	Descriptive	Percentages, proportions, Numbers, frequency

3.12.2 Qualitative Data

Qualitative data helped in understanding the various coping strategies employed by the patients with distressing symptoms.

The data obtained the was reviewed immediately, the audio data was transcribed word for word. Transcripts were verified for completeness and accuracy and notes taken during the meeting were compared to the recorded tape to ensure that the transcripts accurately portray the whole meeting. For qualitative analysis, the transcribed data will be evaluated using the inductive approach with Atlatis.tiV.7.5.2 software. This was done with the help of a statistician who is skilled with utilizing the program to analyze qualitative data.

The principal researcher's notes were cross-checked against the recorded tape. Data was summarized, coded, and arranged into multiple emerging themes using thematic analysis. Prior codes were generated based on the various coping mechanisms as a general frame work while allowing for emergent concepts from the discussion. Emerging themes in relation to the study objectives were then be identified from each category. The two masters' students were involved in recording the discussion, as well as the principal investigator, independently they reviewed the transcripts and then discussed them at a data review meeting in order to compare the individual findings and reach a consensus on the emerging themes; a similar process was followed for each of the group discussions. The results of the group discussions will be considered and integrated into a final report of the study's findings.

3.13 Ethical Considerations

The study's ethical approval was obtained from the KNH-UON ERC. Following the approval, the researcher sought authorization to conduct the study from KNH's Chief Executive Officer through director clinical services. In addition to obtaining an informed consent from the study subjects, they were told about the aims and advantages of the study, the confidentiality of their information and volunteerism. Participants were not be compelled to participate and those who choose not to participate were not be penalized in any way.

Anonymity was used to ensure participant confidentiality, and the study materials were kept under a lock and key cabinet. By ensuring that participants do not enter their identities on the questionnaire, anonymity was preserved throughout the data gathering process.

The researcher reassured the participants that the risks were reduced and attended to promptly if they occurred. Any pain that arose during the interview, the researcher moved quickly to assist. Where there was psychological/emotional distress caused by any of the questions, the interviewer acted quickly to provide assistance. The participant was seen by the hospital counselor based in adjacent chemotherapy ward for counseling at no additional cost. Participants were also be notified that they were not to receive any financial or other advantages from the study, but that it will be used to improve hospital support for patients with distressing symptoms.

3.14 Dissemination Plan

A copy of the research findings will be sent to the ERC. The findings of the study will be shared with the School of Nursing Sciences, and the final research copy will be made available for future reference in the University of Nairobi libraries. The research paper will be published in a peer-reviewed publication and may be presented at conferences.

3.15 Limitations of the study

The study was conducted in one public institution and the results cannot be generalized for all patients receiving breast cancer treatment and the eligibility criteria of the study was that participants had to be mentally and physically able to participate in the study thus it excluded some severely ill patients, who were not asked if they were interested in participating in the study or declined to participate due to very severe disease. In these scenarios the symptom distress burden and prevalence of symptoms might be higher than reported in this study.

CHAPTER 4: RESULTS

4.1 Introduction

This section reports on the findings with regards to the study objectives. A total of 92 participants were interviewed and there was a 100% response rate achieved. Simple random sampling that ensures that all the participants have an equal chance of taking part in the study was used. The participants for the focused group discussion were identified through purposeful sampling. These results are organized according to the study objectives. Descriptive statistics are presented in the form of tables, pie charts and in narrative form. Inferential statistics was done using linear regression and chi-square.

4.2 Socio-Demographic Characteristics

Majority, (55.4%) of the respondents had a monthly house income of below 10,000, 40.2% had a monthly income was between 10000 and 50000. Only 3.3% and 1.1% had a monthly income of 50000-100000 and above 100000 respectively. The age of the respondents ranged from 24 years of age to 78 years with an average of 48.49. Of the 92 participants, 60 were married (65.2%), 11 widowed (12.0%), 8 divorced (8.7%) and 6 singles (6.5%). Majority 91.2% of the respondents (n=83) were Christians with only 8.8% being Muslims (n=8). This is illustrated by **Table 2.**

Table 2: The socio-demographic factors characteristics of the participants

Socio demographic characteristics		**Frequency (n)**	**Percentage (%)**
Monthly House Income	**Below 10,000**	**51**	**55.4**
	10,000_50,000	37	40.2
	50,000_100,000	3	3.3
	Above 100,000	1	1.1
Age	N		92
	Mean		**48.49**
	Std. Deviation		12.533
	Minimum		24
	Maximum		78
Marital status	Single	6	6.5
	Married	**60**	**65.2**
	Divorced	8	8.7
	Widowed	11	12.0
	Separated	7	7.6
Religion	**Christian**	**83**	**91.2**
	Muslim	8	8.8

Table 3:Sociodemographic characteristics of FGD participants

Participant	Age in years	Gender	Marital status	Religion	Disease stage	Treatment modalities given
PPT 1	42	F	Married	Christian	2	Chemotherapy Radiotherapy Surgery
PPT 2	35	F	Married	Muslim	2	Chemotherapy Surgery
PPT 3	38	F	Married	Christian	3	Chemotherapy Radiotherapy Surgery
PPT 4	62	F	Widowed	Christian	4	Chemotherapy Radiotherapy Hormonal therapy
PPT 5	55	F	Married	Christian	3	Chemotherapy Radiotherapy
PPT 6	45	F	Single	Christian	2	Chemotherapy Radiotherapy Surgery Hormonal therapy
PPT 7	29	F	Single	Christian	1	Chemotherapy Surgery
PPT 8	32	F	Separated	Muslim	1	Chemotherapy Radiotherapy Hormonal therapy
PPT 9	41	F	Married	Christian	3	Chemotherapy Surgery
PPT 10	37	F	Separated	Christian	2	Chemotherapy Hormonal therapy Surgery Radiotherapy

4.2.1 Source of Treatment Support

Most of the respondents reported that they received their support from family 40.7%, 33.5% from NHIF and 25.7% received their support from friends and relatives. Majority of those that reported that their support was from family, friends and relatives were respondents who did not have NHIF cover, it had not matured or they had exhausted their NHIF package limit due to the cost of their treatment and thus forced to pay for treatment from their pockets.

The details are as shown by the **figure 4** below.

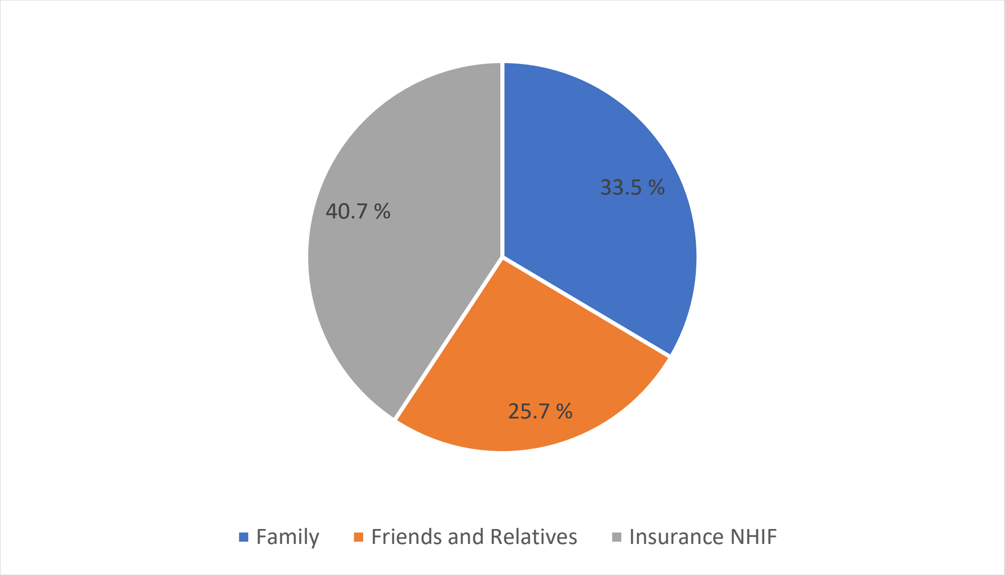


Figure 3: Who supports your treatment

The participants from the FGD reported that they used various coping methods to deal with the distressing symptoms included, watching movies or listening to music, praying, family support, isolating from the rest of the people, support groups in the hospital and support from friends and relatives.

One participant stated that "*were it not for my brothers and sisters, I would be dead by now…*" (PPT 4). Most of them echoed the important role played by the various support groups they are in and one said *"I would never have known how to take care of my self-esteem were it not for the breast cancer support group that taught me how to make a prosthetic breast (PPT 6).*

4.2.2 Staging of the disease

On the staging of the disease, most of the respondents (n=40) had stage 2 breast cancer (44.4%), then stage 3 (n=24), (26.7%) and both stage 1(n=13) and stage 4 (n=13) had 14.4%. this is illustrated in the table 4 below.

Table 4: The disease staging of breast cancer

Diagnosis	**Frequency(n)**	**Percentage (%)**
Stage 1	13	14.4
Stage 2	40	44.4
Stage 3	24	26.7
Stage 4	13	14.4
Total	**90**	**100.0**

4.2.3 Duration Since Diagnosis

Table 5 below shows that the duration since diagnosis ranged between 3 to 288 months with a mean score of 37.14 months and a standard deviation of 46.268.

Table 5: Duration since diagnosis

Duration since diagnosis (days)	Statistics
N	90
Mean	37.14
Std. Deviation	46.268
Minimum	3
Maximum	288

4.2.4 The treatment modality of the participants

Table 6 illustrates that the most common treatment modality among the respondents was chemotherapy which 86 of the 92 patients had received it making a 35.0%. This was followed by surgery (n=62) at 25.5% then radiotherapy (n=55), and lastly immunotherapy whereby 43 of the 92 respondents were on it.

Table 6: The treatment modality of the participants

Treatment modality	Frequency(n)	Percentage (%)
Chemotherapy	86	35.0
Immunotherapy	43	17.5
Radiotherapy	55	22.4
Surgery	62	25.2
Total	**246**	**100.0**

4.2.5 The goal of treatment

The goal of the cancer treatment was curative for 77.2% of the respondents whereas 22.8% had palliation of distressing symptoms as the goal of treatment. This is as shown in the figure 5 below.

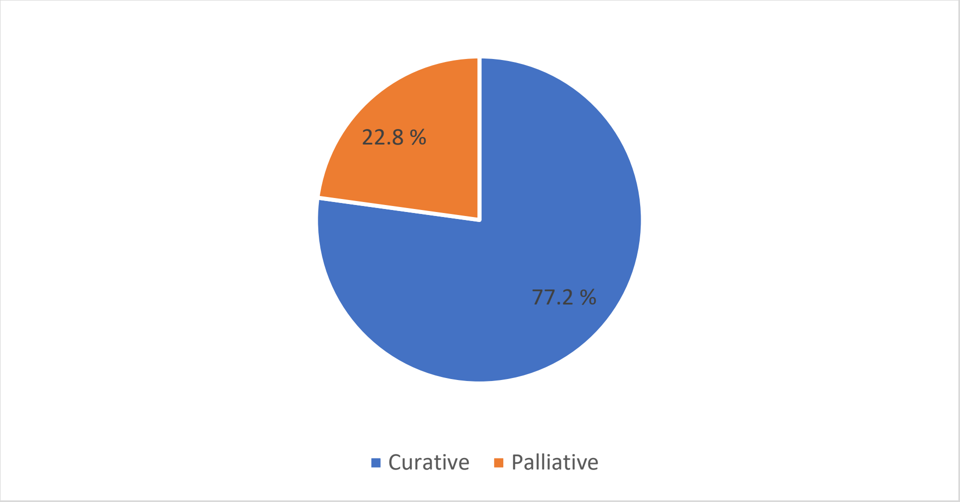


Figure 4: Aim of current treatment

4.3 The distressing symptoms

The most occurring symptoms was fatigue (13.1%), followed by pain (12.7%), lack of appetite (11.4%), drowsiness (11.0%), nausea (11.0%), anxiety (10.7%), vomiting (7.9%), depression (7.2%), diarrhea (7.1%), constipation (4.1%) and least symptom experienced was shortness of breath (3.8%). This is illustrated in Table 7 below.

Table 7: The distressing symptoms

Type of symptom showing	Frequency(n)	Percentage (%)
Fatigue (Lack of Energy)	76	13.1
Pain	74	12.7
Lack of appetite	66	11.4
Drowsiness	64	11
Nausea	64	11
Anxiety (feeling nervous)	62	10.7
Vomiting	46	7.9
Depression (Feeling sad)	42	7.2
Diarrhea	41	7.1
Constipation	24	4.1
Shortness of breath	22	3.8
Total	**581**	**100**

4.4 Additional Symptoms

Apart from the commonly experienced symptoms 52.8% of the respondents had additional symptoms whereas 47.2% did not have. **Figure 6** below highlights those that experienced additional symptoms to those highlighted.

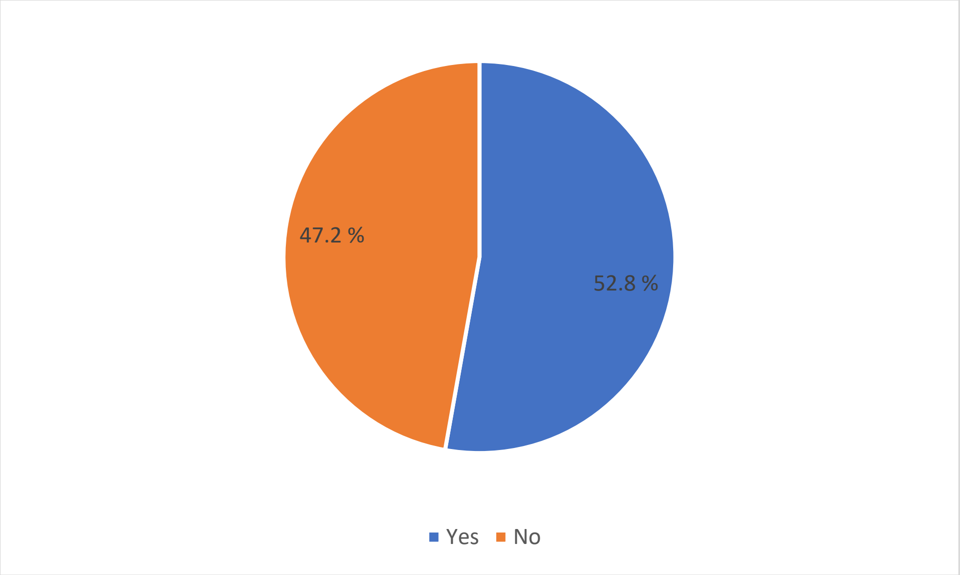


Figure 5: Experiencing other symptoms apart from those stated

4:3:1 Additional distressing symptoms

The table 8 below shows the additional symptoms that the respondents experienced were abdominal pain 18.5%, mucositis 16.6%, insomnia 13.3%, skin color changes 11.7%, 6.7%; skin irritation 5.0%, anger 5.0%, weight loss 3.3%, confusion 3.3% and dizziness 3.3%.

Table 8: Additional symptoms as reported by the respondents

Other symptoms experiencing	Frequency(n)	Percentage (%)
Abdominal pain	11	18.3
Mucositis	10	16.7
Skin changes	10	16.7
Insomnia	8	13.3
Lymphedema	6	10.0
Anger	3	5.0
Weight loss	2	3.3
Confusion	2	3.3
Dizziness	2	3.3
Tingling sensation	2	3.3
Lump in breast	1	1.7
Nipple discharge	1	1.7
Low self esteem	1	1.7
Coughing	1	1.7
Total	**60**	**100.0**

The distressing symptoms as expressed by the FGD respondents included nausea, fatigue, hotness of the body especially in head, depression, hair loss, lymphedema, mucositis, lack of appetite, feeling of pins and needles and tingling of sensation on the fingers and toes, anger, skin changes, vomiting, bone weakness causing pain on the joints, backache and legs.

Some of the respondents' quotes were "*My skin has become very dark and coarse…….".* another explained that *"……the kind of nausea I feel worse than when I was pregnant…."* (PPT 5). And at this point a couple of the participants reported that it was true that the nausea was beyond what they could explain. Another respondent stated that she had sores in the month *"……I could barely put anything in the mouth, even the presence of saliva was painful…."* (PPT 1) and another reported that *"I feel as if my hand is about to burst……". (PPT 8)*

There was a discussion about the worst top five distressing symptoms they experienced and group agreed to have them as nausea, pain- mucositis, fatigue and anxiety. They could not agree on the top most symptoms because everyone described their own symptom as the worst.

4.3.2 Effect of socio-demographic characteristics on severity of distressing symptoms

The purpose of model is to show the relationship between the independent variable (income, age, marital status and religion) and dependent variable (severity).

The correlation between the independent variable and the dependent variable was moderately strong. (R=0.401) thus the data shows moderate linear relationship.R^2 shows how much of the variation in the dependent variable is explained by the model.

Our model explains 16.1% of the variation in the dependent variable (severity of the distressing symptoms), since we had more than one independent variable, the adjusted R^2 was used, It caters for multiplicity of variables and concludes that the model explains 12.2% of the variation in severity.

Table 9: Model summary for Effect of socio-demographic characteristics on severity of distressing symptoms

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.401[a]	.161	.122	1.67624

a. Predictors: (Constant), Religion, Monthly House Income, Age, Marital status

4.3.2.1 Association of socio-economic characteristics on severity of distressing symptoms

Analysis of variance in a linear regression is meant to show if the model is statically significant. Since the P- Value≤0.001(α =0.05) the model is stated to be statistically significant.

Table 10: ANOVA Effect of socio-economic characteristics on severity of distressing symptoms

ANOVA[a]

Model		**Sum of Squares**	**df**	**Mean Square**	**F**	**Sig.**
1	Regression	45.895	4	11.474	4.083	.004[b]
	Residual	238.831	85	2.810		
	Total	284.726	89			

a. Dependent Variable: Severity

b. Predictors: (Constant), Religion, Monthly House Income, Age, marital status

4.3.2.2 The Effect of socio-economic characteristics on severity of distressing symptoms

House income was statically significant at a P- Value of 0.05, which informs that a singular change in income will lead to 0.587 change in severity positively.

Marital status has a statistical significance at a P-Value of 0.013 and a singular change will lead to 0.460 change in severity. The more participants either separated, divorced or widowed leads to them suffering more severe challenges. Irrespective of the distribution of age where age was distributed between 24- 78 years, it does not influence the severity of the distressing symptoms. Age (P-value=0.439) and Religion (P-value=0.060) it also did not influence the severity of the symptoms.

The age of the respondents ranged from 24 years of age to 78 years with an average of 48.49. Of the 92 participants 60 were married (65.2%), 11 widowed (12.0%), 8 divorced (8.7%) and 6 singles (6.5%). Majority 91.2% of the respondents (n=83) were Christians with only 8.8% being Muslims (n=8).

Table 11: Coefficients for Effect of socio-economic characteristics on severity of distressing symptoms

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	1.936	1.122		1.726	.088
	Monthly House Income	**.587**	**.295**	**.204**	**1.988**	**.050**
	Age	-.012	.015	-.081	-.777	.439
	marital status	**.460**	**.182**	**.271**	**2.524**	**.013**
	Religion	1.196	.628	.191	1.903	.060

Coefficients[a]

a. Dependent Variable: Severity

4.4 The severity of the distressing symptoms

With use of the Edmonton Symptom Assessment Scale (ESAS), anxiety was the most severe symptom among the respondents with a mean of 5.7. This was closely followed by appetite at a mean 5.52, well-being 5.43, fatigue 5.24, nausea 5.14, pain 4.84 and drowsiness at a mean of 4.74. The most common symptom among the respondents was pain (n=80, followed by drowsiness (n=79), drowsiness (n=74), nausea (n=73), well -being at (n=72) and appetite and best sleep at n=66.

Table 12: The severity of the distressing symptoms

Variable	N	Mean	Std. Deviation	Minimum	Maximum
Fatigue	**80**	**5.24**	2.78	0	10
Pain	**79**	4.84	2.748	0	10
Drowsiness	**74**	4.74	3.223	0	10
Nausea	73	**5.14**	2.54	0	10
Wellbeing	72	**5.43**	2.55	0	10
Appetite	69	**5.52**	2.253	0	9
Best sleep	69	4.51	2.649	0	10
Anxiety	**66**	**5.7**	3.008	0	10
Depression	63	4.6	3.15	0	10
Shortness of breath	59	1.42	2.207	0	9

4.5 The coping strategies

Most of the respondents (17.8%) coped with the distressing symptoms by seeking spiritual help n=63, 13.8% by maintaining hope and emotions (n=49).This was followed by 11.6% who coped by expressing emotions to friends n=41, facing reality (n=33), reaching out for support to friends n=32, distracting yourself by use of music (n=30), Using positive affirmations (n=27), Family support (n=24), group support (n=17), performing relaxation exercises (n=16), staying in the house (n=13) and praying to God (n=9).

Table 13: Coping strategies to distressing symptoms

Coping with distressing symptoms	Frequency(n)	Percentage (%)
Seeking spiritual help	**63**	**17.8**
Maintaining hope and emotions	**49**	**13.8**
Expressing emotions to friends	**41**	**11.6**
Facing reality	33	9.3
Reaching out for support to friends	32	9.0
Distracting yourself by use of music	30	8.5
Using positive affirmations	27	7.6
Family support	24	6.8
Group support	17	4.8
Performing relaxation exercises	16	4.5
Staying in the house	13	3.7
Praying to God	9	2.5
Total	**354**	**100.0**

Most of the respondents managed their distressing symptoms through taking the pain medications as prescribed by the doctors, performing distracting activities like listening to music or watching movies and having soft massages done to them.

Those that had nausea has a complain managed it through eating little meals at a time, drinking water, adding oranges to warm water, avoiding sugar in tea and reducing amount of oil in food. A respondent stated that *".... I prefer boiled food over fried food...."* (PPT 3)

"The fatigue is so bad but we were taught to take naps and slow exercise like walking when we feel so tired, it has been working for me...." (PPT 7). Another respondent reported that they delegated their duties to other people like the children when they are feeling weak."

In unison they all agreed that they sometimes broke down to tears especially when things were not going as planned. A participant stated, *".....the day I was stopped from receiving chemotherapy due to low blood count, I cried so much...."* (PPT 2). They also agreed that maintaining hope was the best weapon they had and it came through praying and giving themselves the strength that all was going to bel well.

4.6 The Level of Satisfaction

Majority of the respondents 84.4% reported that they rarely received conflicting information whereas 15.5% reported receiving conflicting information from different medical care professionals at the CTC.

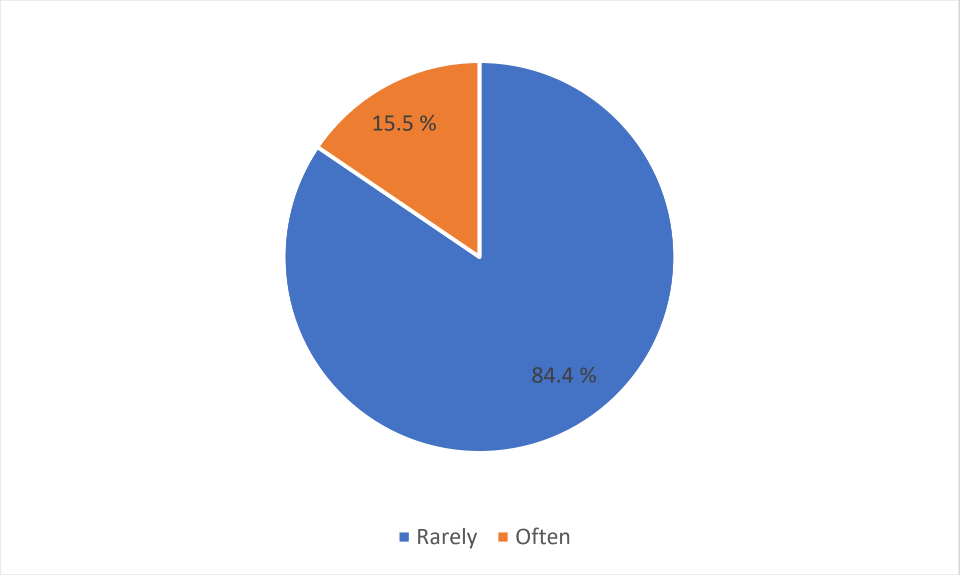


Figure 6: Frequency of receiving conflicting information from different medical care professionals at CTC

According to the study 42.4% of the respondents the professionalism of the staff at the CTC as good, 37% rated it at very good and 20.7% rated the professionalism at 20.7%. The investigative process was rated good by 39.1%, very good by 35.9% and 25% rated it at average. Rating of the counselling process on the expected distressing symptoms was reported to be very good by 43.5%, average by 28.3% and good by 26.1% of the respondents. Rating on the management of the various distressing symptoms you experienced was good by 40.2%, average by 34.8% and very good by 21.7% of the respondents.

Table 14:Rating

Variable	**Rating (%)**				**N**
	Poor	**Average**	**Good**	**Very Good**	
Professionalism of our staff	0	20.7	42.4	37	92
Investigative diagnosis process that one underwent	0	25	39.1	35.9	92
Counselling received on the expected distressing symptoms	2.2	28.3	26.1	43.5	92
Management of the various distressing symptoms you experienced	3.3	34.8	40.2	21.7	92

4.6.1 Arranging for appointment

Majority of the respondents (81.30%) did not have issues with arranging an appointment at the CTC whereas 18.70% reported to have experienced some difficulties which included delayed services despite being punctual because they did not have an appointment, their files missing from the department and negative staff attitude towards them for coming on days that they did not have an appointment.

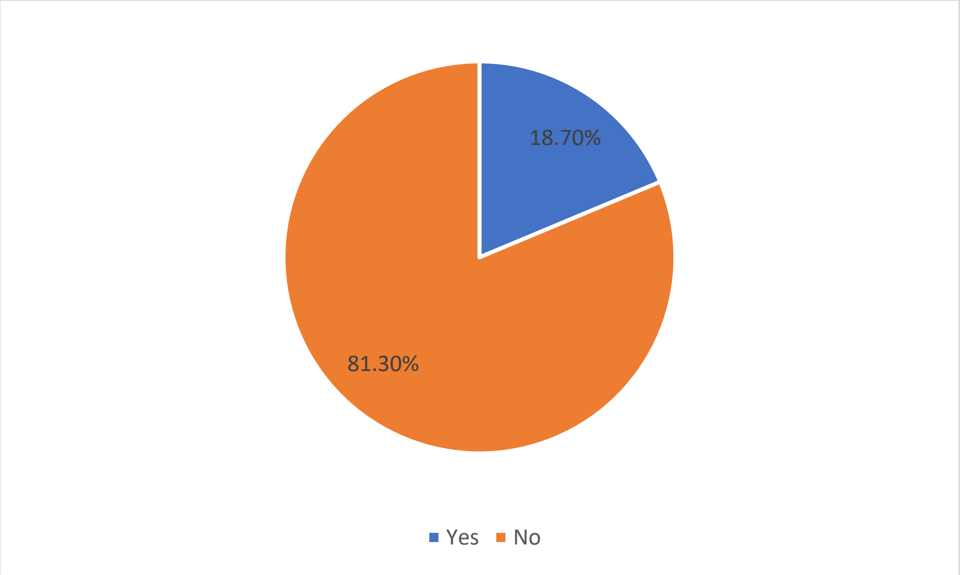


Figure 7: Issuesarranging an appointment at CTC

4.6.2 Satisfaction by the services offered at CTC

In the figure 9 below shows that 82.2% of the respondents were satisfied with the services offered at the KNH CTC whereas 17.80% were not satisfied with the services that were offered.

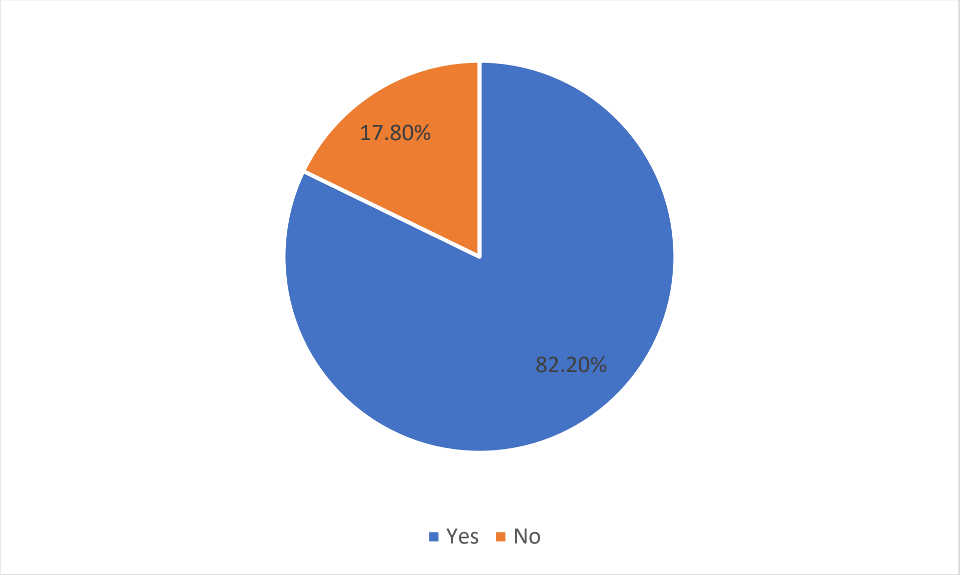


Figure 8: Satisfaction by the services offered at CTC

The reasons for satisfaction from the respondents included good treatment (n=26), affordable services (n=15), good treatment outcome (n=13) and well-trained staff (n=12). Some of the reasons that they stated for not being satisfied included slow services (n=14), long waiting time before start of treatment (n=13) and lack of drugs (n=3).

Table 15: Explanation on the level of satisfaction

Explanation on the level of satisfaction	**Frequency(n)**	**Percentage (%)**
Good treatment	26	26.8
Affordable services	15	15.5
Slow services	14	14.4
Good treatment outcome	13	13.4
Well trained staff	12	12.4
Long waiting time before start of treatment	7	7.2
Enough medicine	4	4.1
Timely appointments	3	3.1
Lack of drugs	3	3.1
Total	**97**	**100**

4.6.3 Recommendations for improvement

The recommendations for improvement by the respondents included improvement of the NHIF package to cover their treatment (25.7%), increase number of staff (13.3%), maintain privacy and confidentiality (13.3%) and increase number of radiotherapy machines (11.5%), improve on drug supply (10.6%), increase the handwashing points (8.8%), improvement of technology (3.5%) and reduce the cost of services to make them more affordable.

Table 16:

Recommendation for improvement	**Frequency(n)**	**Percentage (%)**
NHIF package	29	25.7
Increase number of handwashing points	20	17.7
Good outcome after treatment	19	16.8
Increase number of staff	15	13.3
Maintain privacy and confidentiality	15	13.3
Increase number of radiotherapy machines	13	11.5
Improve on drug supply	12	10.6
Improve on technology	4	3.5
Increase points of payment	3	2.7
Make services affordable	3	2.7
Total	**113**	100

Some of the recommendations from the participants from the FGD included delay in start of the radiotherapy. A participant reported that *“I had to follow up by visiting the hospital before I started my radiotherapy which was 3 months after the planning ..... and a friend of mine just died while waiting the radiotherapy to start.....”* (PPT 3).

They also recommended that the services be made more affordable by reducing consultation fee from 1150 to something to less. *“…… with the high cost living, consultation fees and drugs to buy sometimes you feel so hopeless.....” (*PPT 8), *“I wish the NHIF could support all the services including consultation and medications not just chemotherapy and radiotherapy.*”

Other recommendations were increase the number of staff attending to the patients, consider the distance the patient is travelling *“.....sometimes we end sleeping in bus stops and corridors in the hospital....”* (PPT 1). And improve on the file storage system *“.....my file got lost a year ago, I am currently using with a file that is missing most of my original documents, it is by luck I had kept copies ......”*.

4.6.4 Likelihood of recommending KNH CTC

The figure 10 below illustrates that 94.4% of the respondents stated that they are likely to recommend the KNH CTC to a friend or colleague whereas 5.60% of the respondents would not recommend.

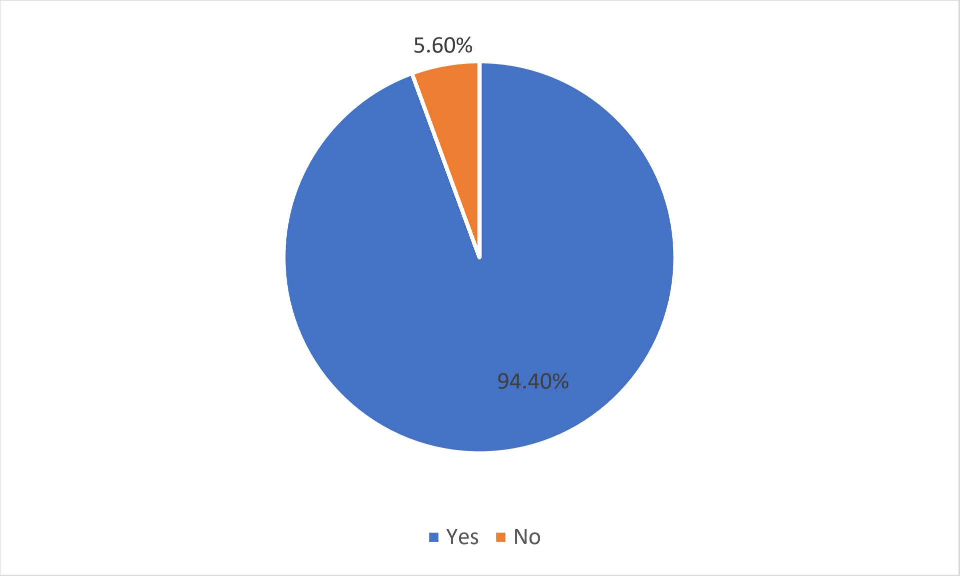


Figure 9: Likelihood of recommending KNH CTC

4.6.5 Reasons for recommending or not

The reasons for recommending were that there was adequate service (28.8%), good treatment support (23.7%), experienced medical staff (17.8%), affordability (12.7%), reliable in-service delivery (2.5%) and availability of drugs. The reasons for not recommending were long waiting time before start of treatment and to receive most services and there were incidences of drug stock outs. This is well demonstrated by the table 14 below.

Table 17:Reasons for recommending or not

Reason for recommending or not	Frequency(n)	Percentage (%)
Adequate services	34	28.8
Good treatment support	28	23.7
Experienced medical staff	21	17.8
Affordability	15	12.7
Long waiting time	10	8.5
Drug unavailability	4	3.4
Reliable in-service delivery	3	2.5
Availability of drugs	3	2.5
Total	**118**	100.0

4.6.6 Association of patients with coping strategies and their experience of distressing symptoms

The most occurring symptom was pain (n=72), followed by fatigue (n=68), Drowsiness at n=54, Nausea (n=45), constipation (n=23), lack of appetite, constipation, diarrhea, depression and least symptom experienced was shortness of breath. Most of the respondents who had pain used facing reality as a coping strategy (34.7%) followed by expressing their emotions (29.2%). Majority of the respondents that had fatigue as a symptom used maintaining of hope and emotions (27.9%) and seeking spiritual help (22.1%) to cope with the symptom whereas those that had drowsiness, nausea and vomiting used seeking spirituality as the major coping strategy. Majority of the respondents with constipation used of distraction with music whereas those with anxiety used support groups to cope with the distressing symptoms. Respondents with depression applied performing relaxation exercises and using positive affirmations to cope and those with shortness of breath used family and group support majorly. Those respondents with lack of appetite applied distracting with music, family and group support to cope the distressing symptoms.

Table 18: Association of coping strategies and their experience of distressing symptoms

Coping strategies	**Type of symptom showing**											**χ2 (p-value)**
	Pain	Fatigue	Drowsiness	Nausea	Vomiting	Constipation	Diarrhea	Lack of appetite	Depression	Shortness of breath	Anxiety	
Facing reality	34.7	7.4	1.9	2.2	0	0	0	0	0	0	7.1	331.002 (≤0.001)
Expressing emotions to friends	29.2	17.6	9.3	0	0	0	8.3	0	14.3	0	7.1	
Maintaining hope and emotions	16.7	27.9	16.7	11.1	8.7	0	0	5.6	0	0	0	
Reaching out for support to friends	6.9	8.8	20.4	13.3	4.3	0	0	11.1	0	0	0	
Seeking spiritual help	2.8	22.1	31.5	22.2	26.1	14.3	8.3	11.1	14.3	0	0	
Performing relaxation exercises	1.4	1.5	1.9	4.4	4.3	7.1	8.3	5.6	28.6	0	0	
Using positive affirmations	1.4	1.5	5.6	11.1	21.7	14.3	16.7	11.1	28.6	0	0	
Distracting yourself by use of music	1.4	4.4	7.4	8.9	21.7	28.6	0	16.7	0	0	7.1	
Family support	1.4	1.5	3.7	13.3	0	14.3	41.7	16.7	0	50	21.4	
Group support	1.4	2.9	0	0	4.3	7.1	8.3	16.7	0	50	42.9	
Praying to God	0	2.9	1.9	4.4	0	7.1	0	5.6	0	0	7.1	
Staying in the house	2.8	1.5	0	8.9	8.7	7.1	8.3	0	14.3	0	7.1	
	72	68	54	45	23	14	12	18	7	2	14	

4.6.7 Association between management of distressing symptomsand patient satisfaction

Majority of those that were not satisfied 66.7% (n=2) with the services at CTC and they had rated the management of the distressing symptoms as poor. Of those satisfied with the services at offered at CTC, 87.5% had rated management of the distressing symptoms as average, 78.4% had rated management of the distressing symptoms as good while 88.9% had rated the management as very good. Despite the good ratings, there was no significant association (P=0.092) between management of distressing symptoms and satisfaction with the services offered at CTC.

Table 19: Association between management of distressing symptomsand patient satisfaction

Rating on the management of the various distressing symptoms you experienced	**On average, would you say that you were fully satisfied by the services offered to you here at CTC**		**N**	**χ2 (p-value)**
	Yes	**No**		
Poor	33.3	**66.7**	3	6.346 (0.092)
Average	**87.5**	12.5	32	
Good	**78.4(29)**	21.6 (8)	37	
Very Good	**88.9**	11.1	18	

CHAPTER 5: DISCUSSIONS, CONCLUSIONS AND RECOMMENDATIONS

5.0 Introduction

The treatment of breast cancer is done using vast treatment modalities which include chemotherapy, radiotherapy, surgery and hormonal therapy amongst others and the different treatment methods lead a number of distressing symptoms. The aim of this chapter was to discuss the results based on the study of the characterization of the distressing symptoms and coping strategies that breast cancer patients on treatment at the CTC in KNH. The discussion is organized into socio demographic factors, the distressing symptoms, the severity, the coping strategies that the patients use to cope with the distressing symptoms and their satisfaction with the management they receive.

5.1 Discussion

5.1.1 Socio- demographic factors

The average age of the study participants was 48.49 (SD=12.53) years which was consistent with other study done by (Huang *et al.*, no date) which found that the average age of breast cancer diagnosis was 48.89+/-8.53. The age distribution is due to the fact that breast cancer is commonly found in the middle-aged patients (Takiar, 2018). Majority (55.4%) of the respondents had a monthly house income of below 10000, 40.2% had a monthly income was between 10000 and 50000. Only 3.3% and 1.1% had a monthly income of 50000-100000 and above 100000 respectively.

Majority of the participants were married (65.2%), widowed (12.0%), divorced (8.7%) and singles (6.5%). Majority 91.2% of the respondents were Christians with only 8.8% being Muslims. In a study by (Syrowatka *et al.*, 2017) showed sociodemographic features that amplified the risk of distress were younger age, non-Caucasian ethnicity, being unmarried, and lower socioeconomic status. In this study the results similarly indicated that younger age, being unmarried and those with an income of below 10000 Kenya Shillings were likely to experience added severe distressing symptoms.

5.1.2 Distressing symptoms in breast cancer patients

According to study the most occurring distressing symptoms was fatigue, followed by pain, lack of appetite, drowsiness, nausea, anxiety, vomiting, depression, diarrhea, constipation and least symptom experienced was shortness of breath. The outcome from this study shows similar distressing symptoms as those of a study that was done in Norway (Sigurdardottir and Haugen, 2008) though the order and percentage of the symptoms is different.

The study found out that anxiety is the most common distressing symptom. This concurs with other studies where psychological symptoms in breast cancer patients, was rated at 10 to 30% (Guan *et al.*, 2017). Similarly, this study found that anxiety was among the chief distressing symptoms with a percentage of 10.7%. The same study also stated that (Guan *et al.*, 2017)anxiety has been shown to cause fatigue and poor treatment outcome, have an effect on the quality of life.

A study done ('Research award', 2022) there is a significant increase in fatigue and psychological distress from pre-chemotherapy to post-chemotherapy and improvement was observed six months after the completion of chemotherapy. A positive or negative change in fatigue was associated with the same in psychological distress. The above symptoms indicate appearance of distressing symptoms after the start of treatment thus treatment related distressing symptoms.

Apart from the commonly experienced symptoms, more than half of the participants had other symptoms that included abdominal pains, mucositis, insomnia, skin changes, anger, weight loss, confusion and dizziness. Correspondingly a study by (Henson *et al.*, 2020) indicated that at any particular time patients typically experience more than one symptom and those with metastatic cancer have, on average 14 symptoms and at the least five.

5.1.3 Severity of the distressing symptoms among breast cancer patients

In this study the Edmonton Symptom Assessment Scale (ESAS), was used to guide in the selection of the distressing symptoms and their severity. Likewise in a study by (Henson *et al.*, 2020) showed different assessment tools that were commonly used for both clinical practice and research were the Edmonton Symptom Assessment System, the Palliative Care Outcome Scale (POS) and the Palliative Performance Scale.

The study established that the distressing symptoms were anxiety, lack of appetite, loss of well-being, fatigue, nausea, pain and drowsiness. This was different from a study done in Switzerland that showed the most distressing symptom was fatigue followed by pain, nausea, vomiting, constipation, insomnia and lack of appetite(Spichiger *et al.*, 2011).

5.1.4 Coping strategies for addressing distressing symptoms

People deal with stress in a diverse ways and some approaches are more efficient than others in promoting emotional well-being and psychological adaptation (Kneier, Rosenbaum and Rosenbaum, 2021). The study showed that most of the participants coped with the distressing symptoms by seeking spiritual help, maintaining hope and emotions, expressing emotions to friends, facing reality, reaching out for support to friends, distracting yourself by use of music, using positive affirmations, family support, group support, performing relaxation exercises, staying in the house and praying to God. There is a lot of similarity of this study with the study (Kneier, Rosenbaum and Rosenbaum, 2021) that coping strategies were majorly facing reality to illness, expressing emotions, retaining hope and optimism, proportion and balance, seeking help, taking an active role, discovering positive meaning, spirituality, religion and prayer; preserving one's self-esteem and learning to deal with mortality.

Similar coping strategies were also highlighted in another study (Sajadian *et al.*, 2017) where positive cognitive restructuring, acceptance, emotional processing, or emotional responses have a good quality of life than inactive coping strategies such as evasion or downplaying the severity of their cancer. The study also exhibited that the type of coping measures utilized, as well as the stage of cancer, treatment and duration of the disease, all influenced the effectiveness of coping (Sajadian *et al.*, 2017).

In a study done in Egypt (Elsheshtawy *et al.*, 2014) a breast cancer diagnosis irrespective of the stage is stressful, affects numerous aspects of life and disrupts patients and family physical state, mental, spiritual health and personal connections. This study further stated that patients apply various coping strategies to be able to cope with their condition and the distressing symptoms that arise from the management of the distressing symptoms associated with the treatment.

The role of understanding the coping strategies applied by the participants in dealing with the distressing symptoms was demonstrated by a study in Poland (O´smiałowskao´smiałowska *et al.*, 2021) that indicated patients who used constructive coping techniques had higher quality of life scores, whereas those who used destructive coping strategies had considerably poorer quality of life scores.

Another study indicated that breast cancer patients who have a high level of self-acceptance have more positive feelings about themselves and are better able to suppress their disease-related frustrations(Chen *et al.*, 2017). In this study, this was seen by the association of patients with coping strategies and their experience of distressing symptoms where it showed that participants with better coping strategies had better experience of the distressing symptoms. Some respondents were depressed and a few even sobbed and lamented about their illness. These results are consistent with the findings of a previous research (Chen *et al.*, 2017)which found that breast cancer patients with low self-acceptance commonly experience loss of self-confidence, low self-esteem and a refusal to follow their treatment schedule(Merlin, Anggorowati and Ropyanto, 2019).

5.1.5 Patients' satisfaction with the management of the distressing symptoms

According to (Lam *et al.*, 2018; Djambazov, Giammanco and Gitto, 2019) patients' satisfaction is one of the indicators of quality healthcare in a given population. This study shows that the reasons for satisfaction with management of distressing symptoms were good treatment, affordable services and well-trained staff. The reasons lack of satisfaction were slow services leading to long waiting time before start of treatment and lack of drugs in the CTC in KNH. Correspondingly, a study done showed that patient features/characteristics, hospital-related factors like personnel, waiting times, amenities and processes have an impact on the level patient satisfaction with cancer care, which includes the management of distressing symptoms (Tobias *et al.*, 2020).

Studies conducted to examine oncology patients' satisfaction, revealed a high level of satisfaction and similarly the participants in this study indicated above average level of satisfaction. They were also satisfied with the assessment and management of the distressing symptoms by the healthcare workers just like in the study (Lam *et al.*, 2018).

Research done by (Lam *et al.*, 2018; Tobias *et al.*, 2020), indicated that patient-centered satisfaction and information supply are essential elements in predicting satisfaction, however demographic characteristics of patients have been demonstrated to be inconsistent in predicting satisfaction levels. This was also was seen because patients reported being taught on the distressing symptoms that could arise from the breast cancer treatment and the demographic factors like age and religion did not have any statistical significance.

5:2 Conclusion

In Kenya patients diagnosed with breast cancer are more distressed by fatigue and pain but then anxiety is more severe. Anxiety causes fatigue, poor treatment outcome and have impact on the quality of life. There is a difference in the appearance of the distressing symptoms in different environments which could be influenced by a number of factors like the orientation, the geography, healthcare system and genetic make-up. Patients apply various coping strategies to be able to cope with their condition and the management of the distressing symptoms. There a noted lack of training at the CTC in KNH among breast cancer patients on coping strategies for dealing distressing symptoms arising treatment of cancer. Patients with better coping strategies manage their distressing symptoms better. Irrespective of the management of the distressing symptoms patients are satisfied with the services offered at CTC in KNH and to further increase patient satisfaction there is need to improve timely services, drug supply and affordability of services.

5.3 Recommendations

5.3.1 Policy and practice

1. There is need to avail policy and guidelines regarding distressing symptoms assessment and management at all points of care for patients undergoing breast cancer treatment.
2. Health care professionals should be adequately trained on the distressing symptoms, their assessment and management.
3. Introduction of standardized distressing symptom assessment tools at all points of care which will form part of the daily assessment of all patients on cancer treatment.
4. There is need for educating breast cancer patients on better coping strategies for the distressing symptoms they experience.

5.3.2 Further research

Further research should be conducted on the distressing symptoms associated with treatment of other types of cancer and studies be carried out on the topic involving more institutions.

REFERENCES

Anderson *et al.* (2000) ‘Assessing Symptom Distress in Cancer Patients’. doi: 10.1002/1097-0142(20001001)89:7.

Borjeson, S. (2012) ‘Common Symptoms and Distress Experienced Among Patients with Colorectal Cancer: A Qualitative part of Mixed Method Design’, *The Open Nursing Journal*, 6(1), pp. 100–107. doi: 10.2174/1874434601206010100.

Bosire, A. M. (2019) ‘Biopsychosocial Effects of Chemotherapy Among Breast and Supervisors ’ Certificat E of Approval’.

Browall, M. and Kenne Sarenmalm, E. (2015) ‘Patient-reported stressful events and coping strategies in post-menopausal women with breast cancer’. doi: 10.1111/ecc.12294.

Carver, C. *et al.* (1993) ‘How coping mediates the effect of optimism on distress: a study of women with early stage breast cancer’, *Journal of personality and social psychology*, 65(2), pp. 375–390. doi: 10.1037//0022-3514.65.2.375.

Chang, V. T., Hwang, S. S. and Feuerman, M. (2000) ‘Validation of the Edmonton Symptom Assessment Scale’. doi: 10.1002/(SICI)1097-0142(20000501)88:9.

Chen, S. Q. *et al.* (2017) ‘Self-acceptance and associated factors among Chinese women with breast cancer’, *Journal of clinical nursing*, 26(11–12), pp. 1516–1523. doi: 10.1111/JOCN.13437.

Chiou, Y. J. *et al.* (2016) ‘Prevalence and related factors of psychological distress among cancer inpatients using routine Distress Thermometer and Chinese Health Questionnaire screening’, *Neuropsychiatric Disease and Treatment*, 12, pp. 2765–2773. doi: 10.2147/NDT.S118667.

Cleeland, C. S. *et al.* (2000) ‘Assessing symptom distress in cancer patients: The M. D. Anderson Symptom Inventory’, *Cancer*, 89(7), pp. 1634–1646. doi: 10.1002/1097-0142(20001001)89:7<1634::AID-CNCR29>3.0.CO;2-V.

Deshields, T. L. *et al.* (2021) ‘Addressing distress management challenges: Recommendations from the consensus panel of the American Psychosocial Oncology Society and the Association of Oncology Social Work’, *CA: A Cancer Journal for Clinicians*, 71(5), pp. 407–436. doi: 10.3322/caac.21672.

Djambazov, S. N., Giammanco, M. D. and Gitto, L. (2019) ‘Factors That Predict Overall Patient Satisfaction With Oncology Hospital Care in Bulgaria’, *Value in Health Regional*

Issues, 19, pp. 26–33. doi: 10.1016/j.vhri.2018.11.006.

Drugs.com (2022) *Drug Side Effects*.

Elsheshtawy, E. A. *et al.* (2014) ‘Coping strategies in Egyptian ladies with breast cancer’, *Breast Cancer: Basic and Clinical Research,* 8(1), pp. 97–102. doi: 10.4137/BCBCR.S14755.

Globocan (2020) ‘Africa’.

GLOBOCAN (2020) ‘Global Cancer Statistics 2020: Kenya’. Available at: https://gco.iarc.fr/today/data/factsheets/populations/404-kenya-fact-sheets.pdf (Accessed: 12 January 2022).

Guan, C. *et al.* (2017) ‘Perceived distress and its association with depression and anxiety in breast cancer patients’, *PLOS ONE,* 12(3), p. e0172975. doi: 10.1371/JOURNAL.PONE.0172975.

Harbeck, N. *et al.* (2019) ‘Breast cancer’, *Nature Reviews Disease Primers 2019 5:1,* 5(1), pp. 1–31. doi: 10.1038/s41572-019-0111-2.

Henson, L. A. *et al.* (2020) ‘Palliative care and the management of common distressing symptoms in advanced cancer: Pain, breathlessness, nausea and vomiting, and fatigue’, *Journal of Clinical Oncology,* 38(9), pp. 905–914. doi: 10.1200/JCO.19.00470.

Huang, H.-Y. *et al.* (2017) ‘Quality of life of breast and cervical cancer survivors’. doi: 10.1186/s12905-017-0387-x.

Hui, D. and Bruera, E. (2017) ‘The Edmonton Symptom Assessment System 25 Years Later: Past, Present and Future Developments’, *Journal of pain and symptom management,* 53(3), p. 630. doi: 10.1016/J.JPAINSYMMAN.2016.10.370.

Isiaka-Lawal, S. *et al.* (2021) ‘Symptoms profile among breast cancer patients accessing care at University of Ilorin Teaching Hospital’, *East African Medical Journal*, 98(6), pp. 3858–3866. Available at: https://www.ajol.info/index.php/eamj/article/view/212975 (Accessed: 13 January 2022).

Khalili, N. *et al.* (2013) ‘Coping strategies, quality of life and pain in women with breast cancer’, *Iranian Journal of Nursing and Midwifery Research,* 18(2), p. 105. Available at: /pmc/articles/PMC3748564/ (Accessed: 28 February 2022).

Kneier, A., Rosenbaum, E. and Rosenbaum, I. R. (2021) *Coping with Cancer | Surviving Cancer | Stanford Medicine*. Available at: https://med.stanford.edu/survivingcancer/coping-with-cancer/coping-with-cancer.html (Accessed: 29 March 2022).

Koedoot, C. G. *et al.* (2003) 'Palliative chemotherapy or best supportive care? A prospective study explaining patients' treatment preference and choice', *British Journal of Cancer 2003 89:12*, 89(12), pp. 2219–2226. doi: 10.1038/sj.bjc.6601445.

Lam, W. W. T. *et al.* (2018) 'Factors predicting patient satisfaction in women with advanced breast cancer: A prospective study', *BMC Cancer*, 18(1), pp. 1–7. doi: 10.1186/S12885-018-4085-3/TABLES/3.

Lavdaniti, M. (2015) 'Assessment of Symptoms in Cancer Patients Undergoing Chemotherapy in Northern Greece', *Materia Socio-Medica*, 27(4), p. 255. doi: 10.5455/MSM.2015.27.255-258.

Liao, M. N. *et al.* (2015) 'Change and predictors of symptom distress in breast cancer patients following the first 4 months after diagnosis', *Journal of the Formosan Medical Association*, 114(3), pp. 246–253. doi: 10.1016/J.JFMA.2013.06.009.

Merlin, N. M., Anggorowati, D. and Ropyanto, C. B. (2019) 'The effects of quantum psychological relaxation technique on self-acceptance in patients with breast cancer', *Canadian Oncology Nursing Journal*, 29(4), p. 232. doi: 10.5737/23688076294232236.

Molassiotis, A., Stamataki, Z. and Kontopantelis, E. (2013) 'Development and preliminary validation of a risk prediction model for chemotherapy-related nausea and vomiting', *Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer*, 21(10), pp. 2759–2767. doi: 10.1007/S00520-013-1843-2.

Montgomery, M. and McCrone, S. H. (2010) 'Psychological distress associated with the diagnostic phase for suspected breast cancer: systematic review', *Journal of advanced nursing*, 66(11), pp. 2372–2390. doi: 10.1111/J.1365-2648.2010.05439.X.

Muzzatti, B. *et al.* (2020) 'Quality of life and psychological distress during cancer: A prospective observational study involving young breast cancer female patients', *BMC Cancer*, 20(1), pp. 1–8. doi: 10.1186/S12885-020-07272-8/TABLES/4.

NCI Dictionary (2022) *Definition of distress*.

Nounou, M. I. *et al.* (2015) 'Breast Cancer: Conventional Diagnosis and Treatment Modalities and Recent Patents and Technologies', *Breast Cancer : Basic and Clinical Research*, 9(Suppl 2), p. 17. doi: 10.4137/BCBCR.S29420.

O´smiałowskao´smiałowska, E. *et al.* (2021) 'Clinical Medicine Coping Strategies, Pain, and Quality of Life in Patients with Breast Cancer', *J. Clin. Med*, p. 10. doi: 10.3390/jcm10194469.

‘RESEARCH AWARD’ (2022) *Cancer Nursing*, 45(6). doi: 10.1097/NCC.0000000000001179.

Sajadian, A. *et al.* (2017) ‘Breast Cancer Coping Strategies after Diagnosis: A Six-month Follow-up’, *Multidisciplinary Cancer Investigation*, 1(4), pp. 12–16. doi: 10.21859/mci-01042.

Sigurdardottir, K. R. and Haugen, D. F. (2008) ‘Prevalence of distressing symptoms in hospitalised patients on medical wards: A cross-sectional study’, *BMC Palliative Care*, 7(1), pp. 1–7. doi: 10.1186/1472-684X-7-16/FIGURES/2.

Silva, L. A. G. P. da, Lopes, V. J. and Mercês, N. N. A. das (2021) ‘Symptom management theory applied to nursing care: scoping review’, *Revista Brasileira de Enfermagem*, 74(3), p. e20201004. doi: 10.1590/0034-7167-2020-1004.

Spichiger, E. *et al.* (2011) ‘Prevalence of symptoms, with a focus on fatigue, and changes of symptoms over three months in outpatients receiving cancer chemotherapy’, *Swiss Medical Weekly 2011 :45*, 141(45). doi: 10.4414/SMW.2011.13303.

Stark, L. L. *et al.* (2012) ‘The symptom experience of patients with cancer’, *Journal of Hospice and Palliative Nursing*, 14(1), pp. 61–70. doi: 10.1097/NJH.0B013E318236DE5C.

Sung, H. *et al.* (2021) ‘Global Cancer Statistics 2020: GLOBOCAN Estimates of Incidence and Mortality Worldwide for 36 Cancers in 185 Countries’, *CA: A Cancer Journal for Clinicians*, 71(3), pp. 209–249. doi: 10.3322/CAAC.21660.

Syrowatka, A. *et al.* (2017) ‘Predictors of distress in female breast cancer survivors: a systematic review’, *Breast Cancer Research and Treatment*, 165(2), p. 229. doi: 10.1007/S10549-017-4290-9.

Takiar, R. (2018) ‘Status of breast and cervix cancer in selected registries of India’, *Ann Womens Health. 2018; 2 (1)*, 2(1), p. 1012.

Tantoy, I. Y. *et al.* (2018) ‘Changes in the Occurrence, Severity, and Distress of Symptoms in Patients With Gastrointestinal Cancers Receiving Chemotherapy’, *Journal of Pain and Symptom Management*, 55(3), pp. 808–834. doi: 10.1016/J.JPAINSYMMAN.2017.10.004.

Tarus, A. *et al.* (2021) ‘Symptom Burden in Breast Cancer Patients Seeking Hospice Care in Rural Kenya (QI718)’, *Journal of Pain and Symptom Management*, 61(3), p. 662. doi: 10.1016/J.JPAINSYMMAN.2021.01.051.

Thiagarajan, M. *et al.* (2016) ‘Symptom prevalence and related distress in cancer patients undergoing chemotherapy’, *Asian Pacific Journal of Cancer Prevention*, 17(1), pp. 171–176.

doi: 10.7314/APJCP.2016.17.1.171.

Thuné-Boyle, I. C. V *et al.* (2010) ‘Religious coping strategies in patients diagnosed with breast cancer in the UK’. doi: 10.1002/pon.1784.

Tobias, A. Z. *et al.* (2020) ‘Predictors of Patient Satisfaction and the Perceived Quality of Healthcare in an Emergency Department in Portugal’, *Western Journal of Emergency Medicine*, 21(2), p. 391. doi: 10.5811/WESTJEM.2019.9.44667.

Wambalaba, F. W. *et al.* (no date) ‘Prevalence and Capacity of Cancer Diagnostics and Treatment: A Demand and Supply Survey of Health-Care Facilities in Kenya’. doi: 10.1177/1073274819886930.

WHO (2021a) *Breast Cancer Outcomes in Sub-Saharan Africa*. Aba. Available at: https://www.iarc.who.int/wp-content/uploads/2021/03/IARC_Evidence_Summary_Brief_1.pdf (Accessed: 13 January 2022).

WHO (2021b) *Cancer*. Available at: https://www.who.int/news-room/fact-sheets/detail/cancer (Accessed: 12 January 2022).

Yamagishi, A. *et al.* (2009) ‘Symptom Prevalence and Longitudinal Follow-Up in Cancer Outpatients Receiving Chemotherapy’, *Journal of Pain and Symptom Management*, 37(5), pp. 823–830. doi: 10.1016/J.JPAINSYMMAN.2008.04.015.

APPENDICES

Appendix I: Work Plan

Time Activity	Oct-Dec 2021	Dec 2022	Jan 2022	Feb 2022	Mar 2022	Apr-Jun 2022	Jul 2022	Aug 2022	Sep 2022	Oct 2022	Nov 2022	Dec 2022
Topic identification	■											
Concept Paper development		■	■									
Proposal writing		■	■	■	■							
UON/KNH ERC review						■	■					
Study pretest and data collection								■	■			
Data analysis and presentation								■	■			
Report writing									■	■		
Defense of thesis at SONS											■	
Dissemination/ Submission /Publication											■	■

Appendix II: Budget

Activity	**Activity Description**	**Item**	**Unit Of Measurement**	**Unit Cost**	**Total In Ksh**
Literature review	Search for literature in libraries	Transport Subsistence	20 days	800	16000
	Internet services	Browsing	5GB	1000@	5000
	Stationary	A^4notebooks Biro pens Pencils Rubber Proposal printing Photocopying Questionnaire Translation	2 10 5 2 6 drafts 300 pages 2	200@ 30@ 25@ 30@ 400@ 3@ 3500@	1200 300 125 50 800 900 7000
Approval		KNH/UON REC	1	2000@	2000
Sub Total					**33,375**
Data collection and analysis	Pre- testing	Transport and subsistence	2 days	1000@	2000
		Printing and typing questionnaire	20 copies	10	200
	Questionnaire	Photocopying	400	3@	1200
	Data collection	Transport and subsistence Research assistant	15 days 15 days	1500@ 500	22500 7500
	Data processing and analysis	Statistician			50000
Sub Total					**83,400**
Reports	Draft report Final report	Printing and photocopying Printing and binding	5 copies 4 copies	400@ 500@	2000 2000
Miscellaneous					10000
Sub Total					**14,000**
Grand Total					**130,775**

Appendix III: Consent Form

Title of the study: Characterization of distressing symptoms associated with breast cancer in patients under treatment at Kenyatta national hospital

Researcher: Joystacy Kendi Mutegi (Master of Science in Nursing (Oncology) student, Year II)

Institution of Study: University of Nairobi

Introduction to the study

You are invited to participate in this research study being carried out by Joystacy Kendi Mutegi who is a student pursuing a degree of Masters of Science in Nursing (Oncology), at the University of Nairobi. The research is being carried here at cancer center targeting breast cancer patients.

This consent form has information about the study, the risks and benefits, and the process will be explained to you. Once you understand the study, and if you agree to take part, you will be asked to sign or use your thumb finger to put a mark (thumb print) on the consent form.

Purpose of the study

The purpose of this study is to characterize distressing symptoms associated with breast cancer in patients under treatment at Kenyatta National Hospital. Characterizing the symptoms will help in their prompt management and the healthcare workers will be aware what to expect and how to deal with them.

Time

The questionnaire filling will take between 15-30 minutes through guidance of the researcher or the assistant.

Study Objective

The specific objectives will be: to identify the distressing symptoms associated with breast cancer, to determine the severity of distressing symptoms expressed by patients with breast cancer at Cancer, to determine the coping strategies for addressing distressing symptoms associated breast cancer and to determine the patient satisfaction with the management of the distressing symptoms among breast cancer patients at Cancer treatment Center at Kenyatta National Hospital.

Benefits of the study

There are no direct benefits for you as an individual participant. The findings of this study can be used by the healthcare workers to know the distressing symptoms and be able to address them promptly. They will also be able to advise the patients on various coping mechanisms.

Risks

There are no directly foreseen risks for you participating in this study. If there are any questions you do not want to answer, you skip them. In addition, you have the right to decline giving information.

Confidentiality

Data, including questionnaires and file from the study will be kept in locked cabinets during the study. Your data will be labeled with your study code not your name. Your identity will be kept confidential. Any relevant additional information you will volunteer to offer to the researcher will remain confidential and will only be disclosed with your permission.

Questionnaire Procedure

The questionnaire will be self-administered and you will be required to understand before answering them. The questionnaires are numbered (coded) thus you will not be required to give any personal information like writing your name. The questionnaire will contain both open and close ended questions. The questionnaire will be divided into different sections.

Voluntary Participation and Withdrawal

Participation in this study is purely voluntary. Should you change your mind, you have the right to drop out at any time without facing any consequences. Any questions that you are not comfortable answering you can discuss with the researcher or the research assistants.

Sharing the results

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

Contact Person

If you have any further questions during or after the research, feel free to contact the investigator, the supervisor or the KNH/UON Ethics and Research Committee on the contacts given below.

1. **Investigator**

   Name: Joystacy Kendi Mutegi
   Phone No. +254 721 955 700
   Email: seashan.halonda@gmail.com
   Physical Address: School of Nursing Sciences
   University of Nairobi, College of Health Sciences
   Kenyatta National Hospital Campus

2. **Supervisors**

Name: Dr. Samuel Kimani
Phone No. +254 722 384 917
Email: tkimani@uonbi.ac.ke
Physical Address: School of Nursing Sciences
University of Nairobi, College of Health Science
Kenyatta National Hospital Campus

Name: Dr. Emmah Matheka
Phone No. +254 710 105 771
Email:ekanini@uonbi.ac.ke
Physical Address: School of Nursing Sciences
University of Nairobi, College of Health Sciences
Kenyatta National Hospital Campus

3. **Ethics Committee**

Dr. Beatrice Amugune,
The Secretary,
KNH/UON Ethics and Research Committee
Tel No. +254 726300-9
Email: uonknh_erc@uonbi.ac.ke
Physical Address: School of Pharmacy
University of Nairobi, College of Health Sciences
Kenyatta National Hospital Campus

Consent Confirmation

I thus confirm that I am fully aware of the study being conducted, that I have read and comprehended the information sheet provided above, and that the study investigator informed me of the study's nature, conduct, and advantages. The contents of the information sheet have been read and understood by me.

I understand that participation in the study is entirely optional, and that I can opt out at any time. I am also aware that the information I will provide will be kept private, and that the study's results will be handled anonymously. I've got ample time to ask questions and declare that I'm willing to take part in the study.

I agree to participate in the study. I have read and everything is clearly explained to me.

Signature …………………… Date……………………………

I Investigator/Research Assistant, hereby confirm that I have fully explained the nature of the study and the contents of this consent form to the participant, and that the participant has chosen to participate voluntarily and without coercion or undue pressure.

Signature ________________________ Date ___________________________

Appendix IV: Swahili consent form

Fomu ya Idhini

Kichwa cha utafiti: Tabia ya dalili za kuhuzunisha zinazohusiana na saratani ya matiti kwa wagonjwa wanaotibiwa katika hospitali ya kitaifa ya Kenyatta

Mtafiti: Joystacy Kendi Mutegi (Mwanafunzi wa Shahada ya Uzamili ya Sayansi katika Uuguzi (Oncology), Mwaka wa II)

Taasisi ya Utafiti: Chuo Kikuu cha Nairobi

Utangulizi wa utafiti

Umealikwa kushiriki katika utafiti huu unaofanywa na Joystacy Kendi Mutegi ambaye ni mwanafunzi anayefuata Shahada ya Uzamili ya Sayansi katika Uuguzi (Oncology), katika Chuo Kikuu cha Nairobi. Utafiti huo unafanywa hapa katika kituo cha saratani kinacholenga wagonjwa wa saratani ya matiti.

Fomu hii ya idhini ina taarifa kuhusu utafiti, hatari na manufaa, na mchakato utaelezwa kwako. Ukishaelewa utafiti, na ukikubali kushiriki, utaombwa kutia sahihi au kutumia kidole gumba kuweka alama kwenye fomu ya idhini.

Madhumuni ya utafiti

Madhumuni ya utafiti huu ni kubainisha dalili za kuhuzunisha zinazohusishwa na saratani ya matiti kwa wagonjwa wanaotibiwa katika Hospitali ya Kitaifa ya Kenyatta. Kuainisha dalili kutasaidia katika usimamizi wao wa haraka na wahudumu wa afya watafahamu nini cha kutarajia na jinsi ya kukabiliana nazo.

Wakati

Ujazaji wa dodoso utachukua kati ya dakika 15-30 kupitia mwongozo wa mtafiti au msaidizi.

Madhumuni ya Utafiti

Malengo mahususi yatakuwa: kutambua dalili za kuhuzunisha zinazohusiana na saratani ya matiti, kuamua ukali wa dalili za kusikitisha zinazoonyeshwa na wagonjwa walio na saratani ya matiti kwenye Saratani, kuamua mikakati ya kukabiliana na dalili za shida zinazohusiana na saratani ya matiti na kuamua kuridhika kwa mgonjwa. na udhibiti wa dalili za kuhuzunisha miongoni mwa wagonjwa wa saratani ya matiti katika Kituo cha matibabu ya Saratani katika Hospitali ya Kitaifa ya Kenyatta.

Faida za utafiti

Hakuna manufaa ya moja kwa moja kwako kama mshiriki binafsi. Matokeo ya utafiti huu yanaweza kutumiwa na wahudumu wa afya kujua dalili zinazosumbua na kuweza kuzishughulikia mara moja. Pia wataweza kuwashauri wagonjwa juu ya njia mbalimbali za kukabiliana nazo.

Hatari

Hakuna hatari zinazotarajiwa moja kwa moja kwako kushiriki katika utafiti huu. Ikiwa kuna maswali yoyote ambayo hutaki kujibu, unayaruka. Kwa kuongezea, una haki ya kukataa kutoa habari.

Usiri

Data, ikiwa ni pamoja na dodoso na faili kutoka kwa utafiti zitawekwa katika makabati yaliyofungwa wakati wa utafiti. Data yako itawekewa lebo ya msimbo wako wa kusoma na sio jina lako. Utambulisho wako utawekwa siri. Taarifa zozote muhimu za ziada utakazojitolea kumpa mtafiti zitabaki kuwa siri na zitafichuliwa tu kwa ruhusa yako.

Utaratibu wa Hojaji

Hojaji itajisimamia yenyewe na utahitajika kuelewa kabla ya kuyajibu. Hojaji zimeorodheshwa (zina msimbo) kwa hivyo hutahitajika kutoa taarifa zozote za kibinafsi kama vile kuandika jina lako. Hojaji itakuwa na maswali ya wazi na ya mwisho. Hojaji itagawanywa katika sehemu tofauti.

Kushiriki kwa Hiari na Kujitoa

Kushiriki katika utafiti huu ni kwa hiari tu. Ukibadilisha mawazo yako, una haki ya kuacha shule wakati wowote bila kukabiliwa na matokeo yoyote. Maswali yoyote ambayo huna raha kuyajibu unaweza kuyajadili na mtafiti au wasaidizi wa utafiti.

Kushiriki matokeo

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

Kuwasiliana na mtu

Ikiwa una maswali zaidi wakati au baada ya utafiti, jisikie huru kuwasiliana na mpelelezi, msimamizi au Kamati ya Maadili na Utafiti ya KNH/UON kuhusu anwani zilizotolewa hapa chini.

1. Mpelelezi

Jina: Joystacy Kendi Mutegi
Nambari ya simu: +254 721 955 700
Barua pepe: seashan.halonda@gmail.com
Anwani ya Kawaida: Shule ya Sayansi ya Uuguzi
Chuo Kikuu cha Nairobi, Chuo cha Sayansi ya Afya
Kampasi ya Hospitali ya Kitaifa ya Kenyatta

2. Wasimamizi

Jina: Dk Samuel Kimani
Nambari ya simu: +254 722 384 917

Barua pepe: tkimani@uonbi.ac.ke
Anwani ya Kawaida: Shule ya Sayansi ya Uuguzi
Chuo Kikuu cha Nairobi, Chuo cha Sayansi ya Afya Kampasi ya Hospitali ya Kitaifa ya Kenyatta
Jina: Dk. Emmah Matheka
Nambari ya simu +254 710 105 771
Barua pepe: ekanini@uonbi.ac.ke
Anwani ya Kawaida: Shule ya Sayansi ya Uuguzi
Chuo Kikuu cha Nairobi, Chuo cha Sayansi ya Afya
Kampasi ya Hospitali ya Kitaifa ya Kenyatta

3. Kamati ya Maadili

Dk Beatrice Amugune,
Katibu huyo,
Kamati ya Maadili na Utafiti ya KNH/UON
Nambari ya simu +254 726300-9
Barua pepe: uonknh_erc@uonbi.ac.ke
Anwani ya Kawaida: Shule ya Famasia
Chuo Kikuu cha Nairobi, Chuo cha Sayansi ya Afya
Kampasi ya Hospitali ya Kitaifa ya Kenyatta

Uthibitisho wa Idhini

Kwa hivyo ninathibitisha kwamba ninafahamu kikamilifu utafiti unaofanywa, kwamba nimesoma na kuelewa karatasi ya maelezo iliyotolewa hapo juu, na kwamba mpelelezi wa utafiti alinifahamisha kuhusu asili, mwenendo na faida za utafiti. Yaliyomo kwenye karatasi ya habari yamesomwa na nimeelewa.

Ninaelewa kuwa kushiriki katika utafiti ni hiari kabisa, na kwamba ninaweza kujiondoa wakati wowote. Pia ninafahamu kuwa maelezo nitakayotoa yatawekwa faragha, na kwamba matokeo ya utafiti yatashughulikiwa bila kujulikana. Nina muda wa kutosha wa kuuliza maswali na kutangaza kuwa niko tayari kushiriki katika utafiti.

Ninakubali kushiriki katika utafiti. Nimesoma na kila kitu kimeelezewa wazi kwangu.

Sahihi ……………………………………Tarehe ....………………………

Mimi Mchunguzi/Msaidizi wa Utafiti, ninathibitisha hapa kwamba nimeeleza kikamilifu asili ya utafiti na yaliyomo katika fomu hii ya idhini kwa mshiriki, na kwamba mshiriki amechagua kushiriki kwa hiari na bila shuruti au shinikizo lisilofaa.

Sahihi ________________________ Tarehe ___________________________________

Appendix V: Questionnaire

Serial Number………………………   Date…………………………………..

Instructions

Please follow the instructions below

- i. Do not indicate your name anywhere in the questionnaire.
- ii. Please tick in the appropriate response in the space provided.

Section A: Sociodemographic data of the patient

1. What is your Age? ____________________
2. What's your marital status?

   Single__________

   Married ___________

   Divorced ____________

   Widowed __________

   Separated___________
3. What is your religion?

   Christian ____________

   Muslim _____________

   Hindu_______________

   Others, specify ________________________________
4. Monthly House income
   a) Adequate to meet family needs
   b) Barely adequate to meet family needs
   c) Inadequateto meet family needs
5. What is your diagnosis?

   ____
6. What is the duration since diagnosis? _________________________
7. Which treatment modality have you had? (Tick all that apply)

   Chemotherapy _________

   Immunotherapy_________

   Radiotherapy___________

   Surgery ______________
8. When did you start treatment? ______________________
9. What is the aim of the current treatment?

Curative

Palliative

10. How do you take care of your medical expenses? (Tick all that apply)
    - a) Self-sponsored
    - b) Hospital waivers
    - c) Fundraisers
    - d) NHIF
    - e) Other insurances

SECTION B: Distressing Symptoms

11. Please indicate if you have experienced any of the following symptoms

S/No	**Symptom**	**Yes**	**No**
i.	Pain		
ii.	Tiredness (Lack of Energy)		
iii.	Drowsiness		
iv.	Nausea		
v.	Vomiting		
vi.	Constipation		
vii.	Diarrhea		
viii.	Lack of appetite		
ix.	Depression (Feeling sad)		
x.	Shortness of breath		
xi.	Anxiety (feeling nervous)		

12. Do you experience other symptoms apart from those stated above?

    Yes

    No

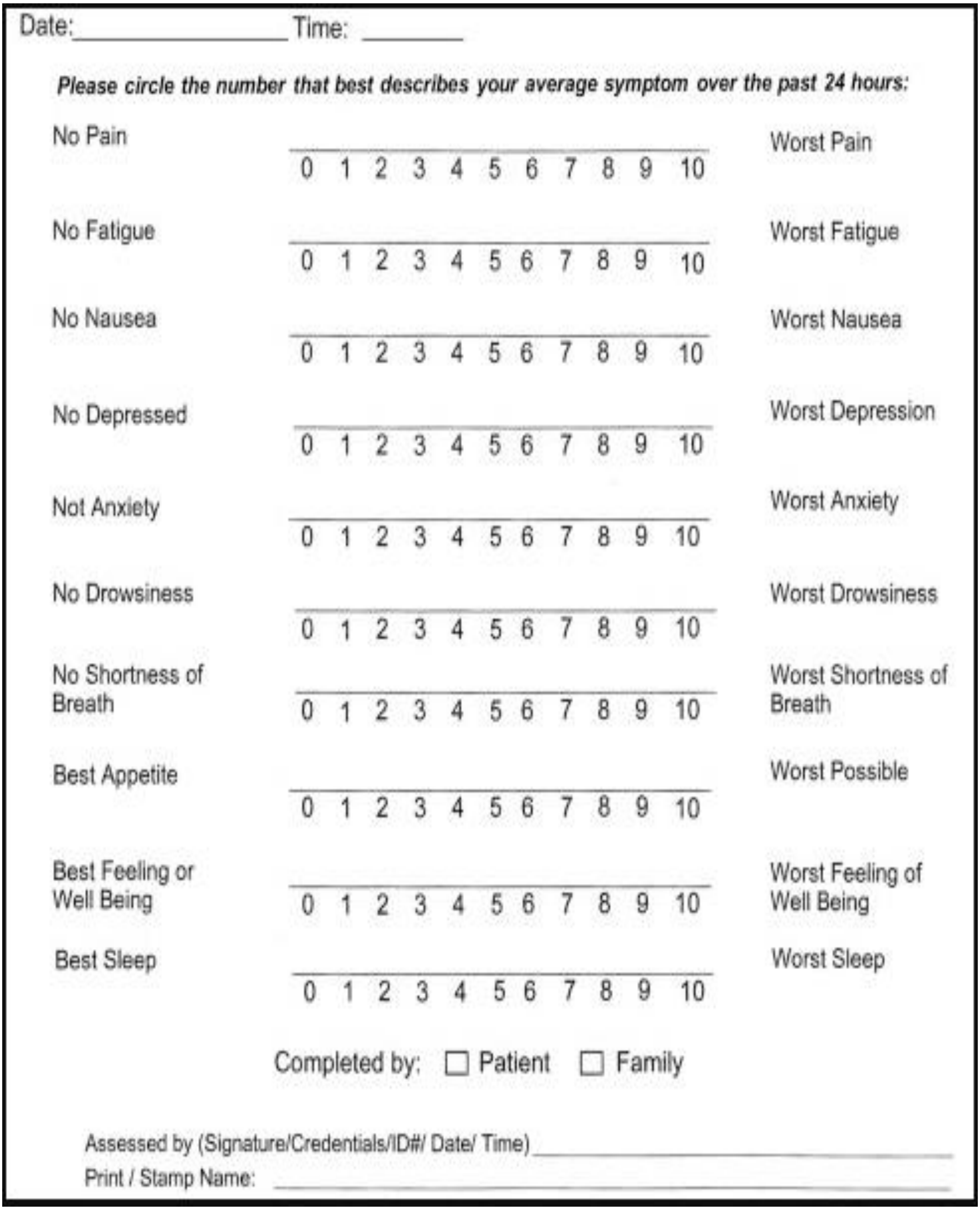
13. If ***YES*** in the above statement, state the symptoms

    ____

    ____

SECTION C: Severity of the Distressing Symptoms

14. Edmonton symptom assessment scale: Please circle the best response



Date:__________________ Time: ________

Please circle the number that best describes your average symptom over the past 24 hours:

No Pain	0 1 2 3 4 5 6 7 8 9 10	Worst Pain
No Fatigue	0 1 2 3 4 5 6 7 8 9 10	Worst Fatigue
No Nausea	0 1 2 3 4 5 6 7 8 9 10	Worst Nausea
No Depressed	0 1 2 3 4 5 6 7 8 9 10	Worst Depression
Not Anxiety	0 1 2 3 4 5 6 7 8 9 10	Worst Anxiety
No Drowsiness	0 1 2 3 4 5 6 7 8 9 10	Worst Drowsiness
No Shortness of Breath	0 1 2 3 4 5 6 7 8 9 10	Worst Shortness of Breath
Best Appetite	0 1 2 3 4 5 6 7 8 9 10	Worst Possible
Best Feeling or Well Being	0 1 2 3 4 5 6 7 8 9 10	Worst Feeling of Well Being
Best Sleep	0 1 2 3 4 5 6 7 8 9 10	Worst Sleep

Completed by: ☐ Patient ☐ Family

Assessed by (Signature/Credentials/ID#/ Date/ Time)______________________________

Print / Stamp Name: ______________________________

SECTION D: Coping mechanisms

15. When you experience any of the above distressing symptoms how do you cope with them? Please tick the coping mechanisms that you use for the symptoms.
    Facing reality

    Expressing emotions to friends

    Maintaining hope and emotions

    Reaching out for support to friends

    Seeking spiritual help

    Performing relaxation exercises

    Using positive affirmations

    Distracting yourself by use of music

    Any other, (specify)____
    ____
    ____

SECTION E: Patients’ satisfaction with management of symptoms

16. How would you rate the professionalism of our staff?

    Very Good

    Good

    Average

    Poor

    Very Poor

17. How would you rate the investigative diagnosis process that you underwent?

    Very Good

    Good

    Average

    Poor

    Very Poor

18. How often did you receive conflicting information from different medical care professionals at CTC?

    Rarely

    Often

19. How would you rate the counselling you received on the expected distressing symptoms?

    Very Good

Good

Average

Poor

Very Poor

20. How would you rate the management of the various distressing symptoms you experienced?

    Very Good

    Good

    Average

    Poor

    Very Poor

21. Did you have any issues arranging an appointment here at CTC?

    Yes

    No

22. On average, would you say that you were fully satisfied by the services offered to you here at CTC?

    Yes

    No

23. Briefly explain

    ____

    ____

24. What would you recommend to be improved or improved?

    ____

    ____

25. Any other comment

    ____

    ____

26. Based on your complete experience with CTC, how likely are you to recommend us to a friend or colleague?

    Yes

    No

    Why____

Appendix VI: Focused Group Discussion Guide

Introduction

My name is **Joystacy Kendi Mutegi,** a student at the University of Nairobi pursuing a masters' degree in oncology nursing. I am carrying out research on the characterization of the distressing symptoms among breast cancer patients at KNH CTC. You are invited to participate in this Focused Group Discussion session to highlight and share some of the coping mechanisms for the various distressing symptoms you have had in the course of treatment. You will be identified as patient number one, two, … for the purpose of this discussion so as to conceal your identity. The conversation will be taped, but the information will remain private and confidential. Feel free to take part, and keep in mind that there are no right or incorrect answers. The discussion will be guided by the moderator to keep it on track. I appreciate you taking the time to join in the discussion, which will last about 45-60 minutes.

If you agree to participate, please give your consent by giving your signature

Participant signature ____________ (initials): _______ Date: _____________________

Researcher's signature: ______________________ Date: ______________________

Guide

i. You have been on treatment modality for some time now, what are some of the distressing symptoms you have experienced?
ii. What are the worst top five distressing symptoms you have ever experienced?
iii. What actions did you take to address the distressing symptoms?
iv. How else have you been coping with the distressing symptoms? (Should cover all the symptoms as stated?
v. How different would you prefer the management/ care to be given if any was addressed clinically?

Appendix VII: Letter to Ethics Committee

Joystacy Kendi Mutegi,

H56/38256/2020,

University of Nairobi.

School of Nursing Sciences.

The Chairman,

UON-KNH ERC,

P.O. Box 20723-00202,

Nairobi.

Dear Sir/Madam

RE: ETHICAL REVIEW AND APPROVAL

This refers to the above subject matter.

I am a second year post graduate nursing student, pursuing Master of Science in Nursing (Oncology). I am writing to request permission to carry out research on **“Characterization of distressing symptoms associated with breast cancer in patients under treatment at Kenyatta national hospital.”** The study will be carried out at cancer treatment center.

Your kind consideration will go a long way in facilitating completion of my study. The research findings will be utilized both locally and internationally in improving provision of quality patient care.

I am looking forward to your comments and suggestions for improvement of the proposed study.

Yours faithfully,

____

Joystacy Kendi Mutegi,

H56/38256/2020

Appendix VIII: Letter to KNH CEO

Joystacy Kendi Mutegi,

H56/38256/2020,

University of Nairobi.

School of Nursing Sciences

The Chief Executive Officer

Kenyatta National Hospital

Nairobi.

Dear Sir / Madam,

RE: PERMISSION TO UNDERTAKE STUDY

This refers to the above subject matter.

I am a second year post graduate nursing student, pursuing Master of Science in Nursing (Oncology). I am writing to request permission to carry out research on **"Characterization of distressing symptoms associated with breast cancer in patients under treatment at Kenyatta national hospital."** The study will be carried out at cancer treatment center.

Your kind consideration to allow me carry out this research in KNH will be highly appreciated. It will go a long way in facilitating completion of my study. The research findings will be utilized both locally and internationally in improving provision of quality patient care.

Please find the attached approval letter from KNH-UON ERC

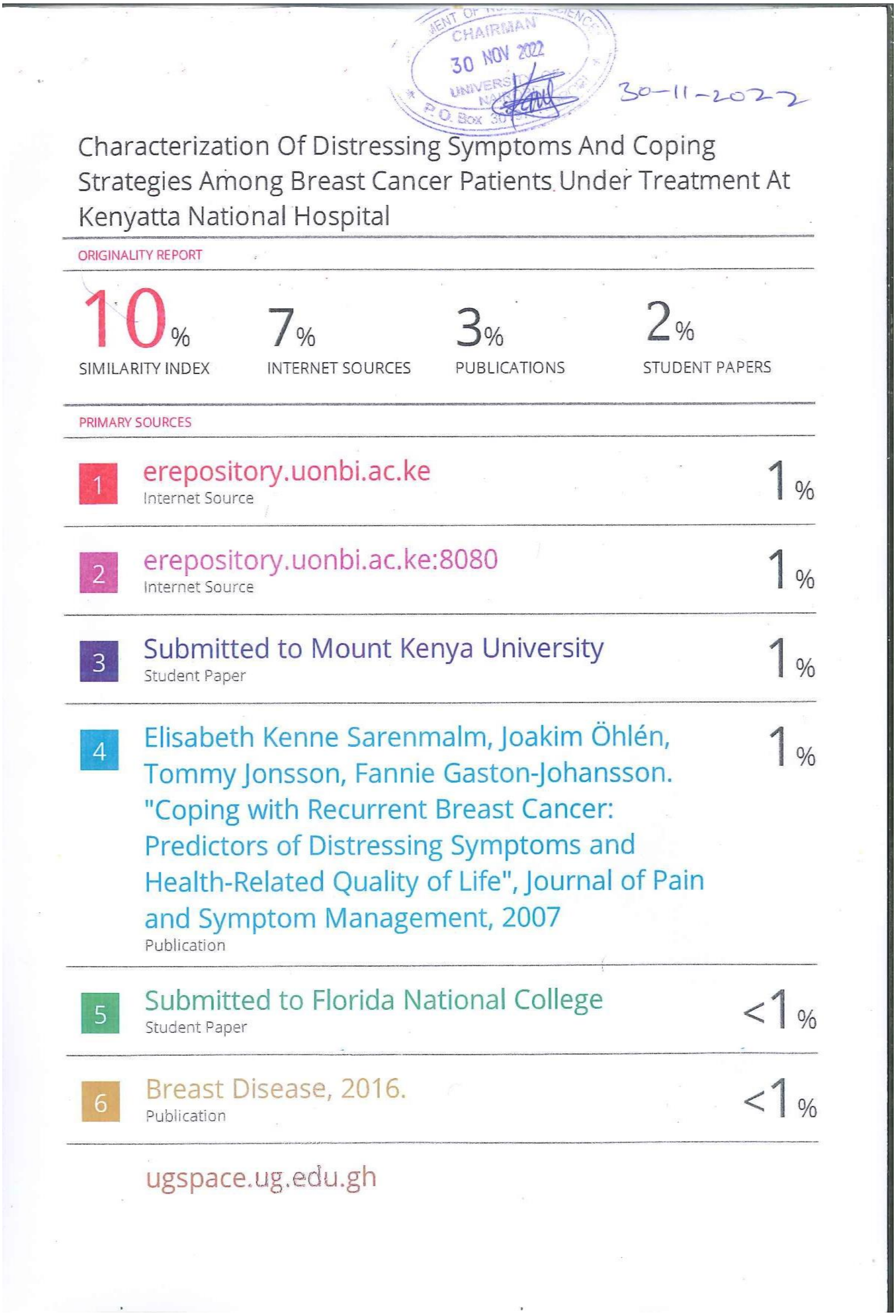
Thanks for your continuous support

Yours sincerely,

Joystacy Kendi Mutegi,

H56/38256/2020

Appendix ix: Plagiarism Report



CHAIRMAN
30 NOV 2022

30-11-2022

Characterization Of Distressing Symptoms And Coping Strategies Among Breast Cancer Patients Under Treatment At Kenyatta National Hospital

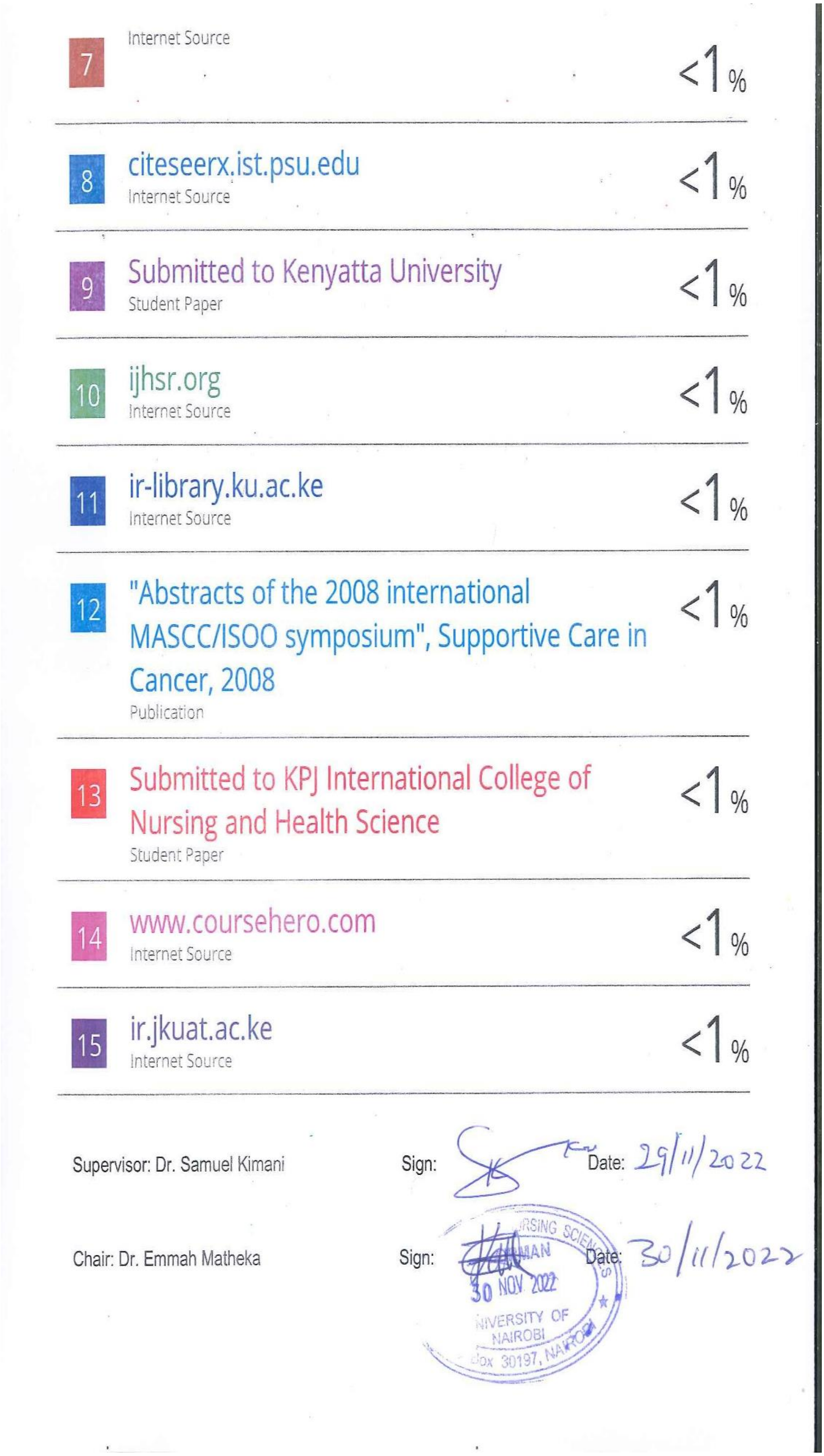
ORIGINALITY REPORT

10%	7%	3%	2%
SIMILARITY INDEX	INTERNET SOURCES	PUBLICATIONS	STUDENT PAPERS

PRIMARY SOURCES

1	erepository.uonbi.ac.ke Internet Source	1%
2	erepository.uonbi.ac.ke:8080 Internet Source	1%
3	Submitted to Mount Kenya University Student Paper	1%
4	Elisabeth Kenne Sarenmalm, Joakim Öhlén, Tommy Jonsson, Fannie Gaston-Johansson. "Coping with Recurrent Breast Cancer: Predictors of Distressing Symptoms and Health-Related Quality of Life", Journal of Pain and Symptom Management, 2007 Publication	1%
5	Submitted to Florida National College Student Paper	<1%
6	Breast Disease, 2016. Publication	<1%

ugspace.ug.edu.gh



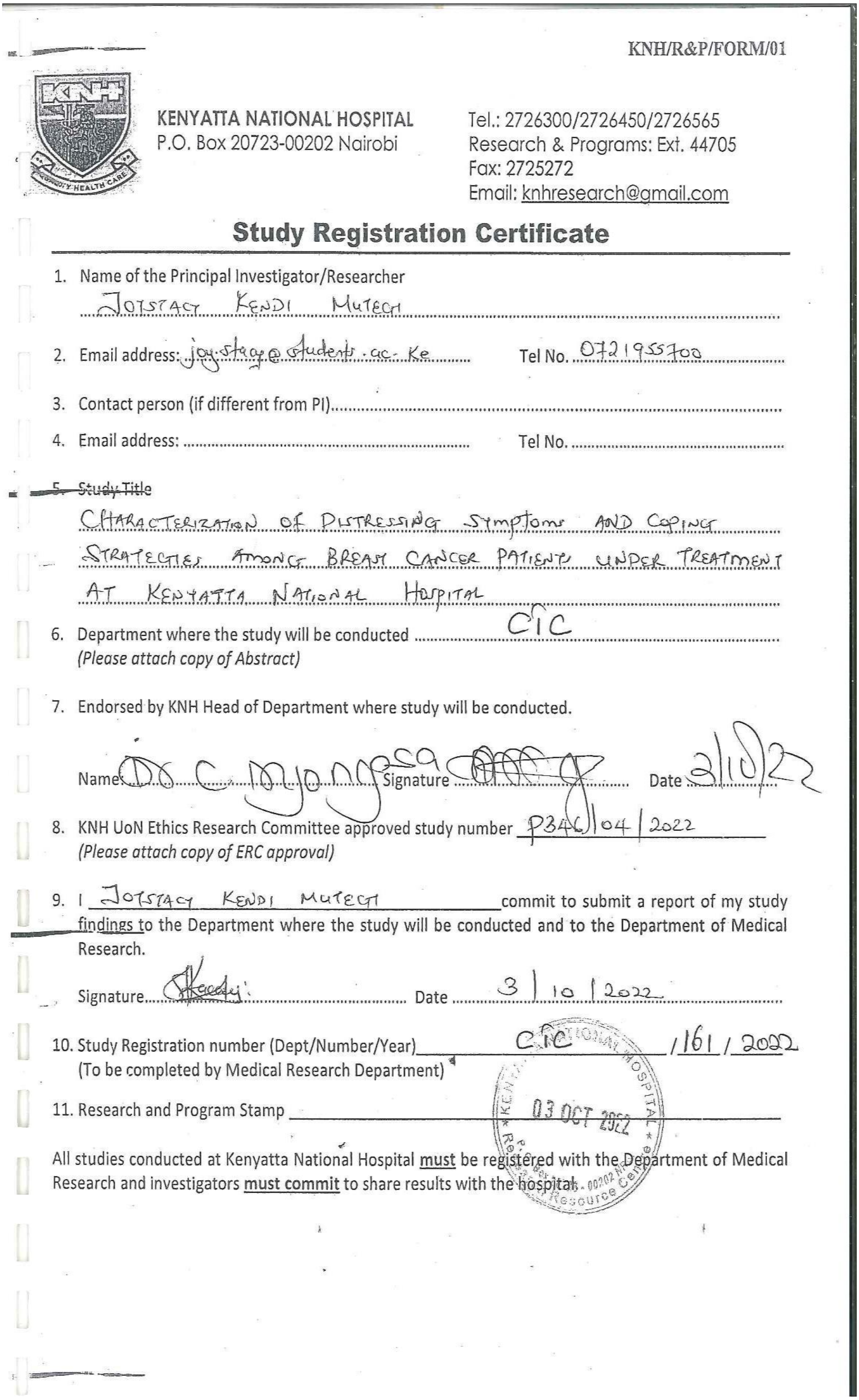
7	Internet Source	<1%
8	citeseerx.ist.psu.edu Internet Source	<1%
9	Submitted to Kenyatta University Student Paper	<1%
10	ijhsr.org Internet Source	<1%
11	ir-library.ku.ac.ke Internet Source	<1%
12	"Abstracts of the 2008 international MASCC/ISOO symposium", Supportive Care in Cancer, 2008 Publication	<1%
13	Submitted to KPJ International College of Nursing and Health Science Student Paper	<1%
14	www.coursehero.com Internet Source	<1%
15	ir.jkuat.ac.ke Internet Source	<1%

Supervisor: Dr. Samuel Kimani Sign: Date: 29/11/2022

Chair: Dr. Emmah Matheka Sign: Date: 30/11/2022

NURSING SCIENCES
CHAIRMAN
30 NOV 2022
UNIVERSITY OF NAIROBI
Box 30197, NAIROBI

Appendix x: Letter of approval from KNH



KNH/R&P/FORM/01

KENYATTA NATIONAL HOSPITAL
P.O. Box 20723-00202 Nairobi

Tel.: 2726300/2726450/2726565
Research & Programs: Ext. 44705
Fax: 2725272
Email: knhresearch@gmail.com

Study Registration Certificate

1. Name of the Principal Investigator/Researcher
JOYSTACY KENDI MUTEGI

2. Email address: joy.stacy@students.ac.ke Tel No. 0721955700

3. Contact person (if different from PI)

4. Email address: Tel No.

~~5. Study Title~~
CHARACTERIZATION OF DISTRESSING SYMPTOMS AND COPING STRATEGIES AMONG BREAST CANCER PATIENTS UNDER TREATMENT AT KENYATTA NATIONAL HOSPITAL

6. Department where the study will be conducted CIC
(Please attach copy of Abstract)

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

Name Dr C Njonge Signature Date 2/10/22

8. KNH UoN Ethics Research Committee approved study number P346/04/2022
(Please attach copy of ERC approval)

9. I JOYSTACY KENDI MUTEGI 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.

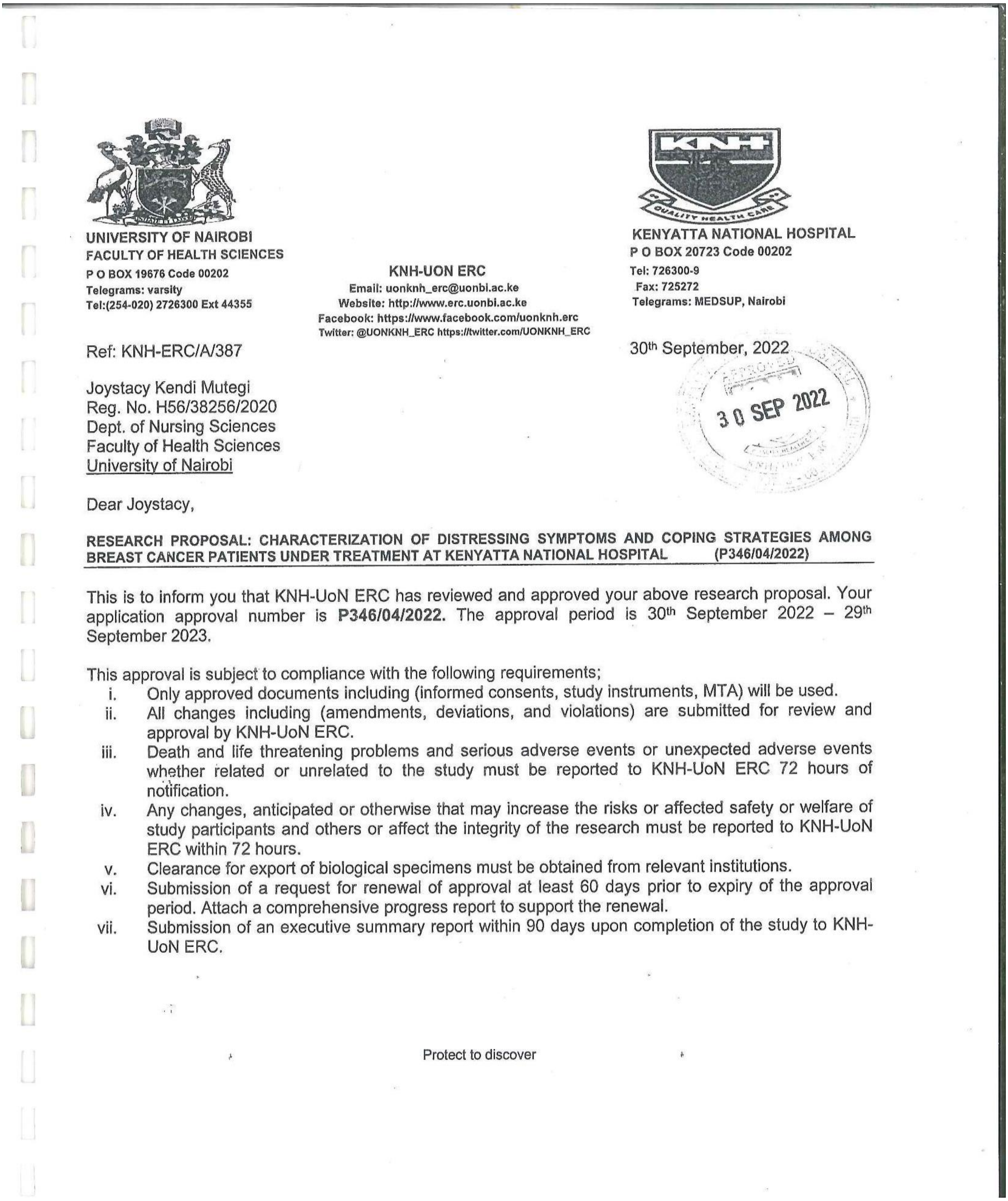
Signature Kendy Date 3/10/2022

10. Study Registration number (Dept/Number/Year) CIC /161/ 2022
(To be completed by Medical Research Department)

11. Research and Program Stamp 03 OCT 2022

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

Appendix xi: Letter of approval from uonknh/Erc



UNIVERSITY OF NAIROBI
FACULTY OF HEALTH SCIENCES
P O BOX 19676 Code 00202
Telegrams: varsity
Tel:(254-020) 2726300 Ext 44355

KNH-UON ERC
Email: uonknh_erc@uonbi.ac.ke
Website: http://www.erc.uonbi.ac.ke
Facebook: https://www.facebook.com/uonknh.erc
Twitter: @UONKNH_ERC https://twitter.com/UONKNH_ERC

KENYATTA NATIONAL HOSPITAL
P O BOX 20723 Code 00202
Tel: 726300-9
Fax: 725272
Telegrams: MEDSUP, Nairobi

Ref: KNH-ERC/A/387

30th September, 2022

APPROVED
30 SEP 2022

Joystacy Kendi Mutegi
Reg. No. H56/38256/2020
Dept. of Nursing Sciences
Faculty of Health Sciences
University of Nairobi

Dear Joystacy,

RESEARCH PROPOSAL: CHARACTERIZATION OF DISTRESSING SYMPTOMS AND COPING STRATEGIES AMONG BREAST CANCER PATIENTS UNDER TREATMENT AT KENYATTA NATIONAL HOSPITAL (P346/04/2022)

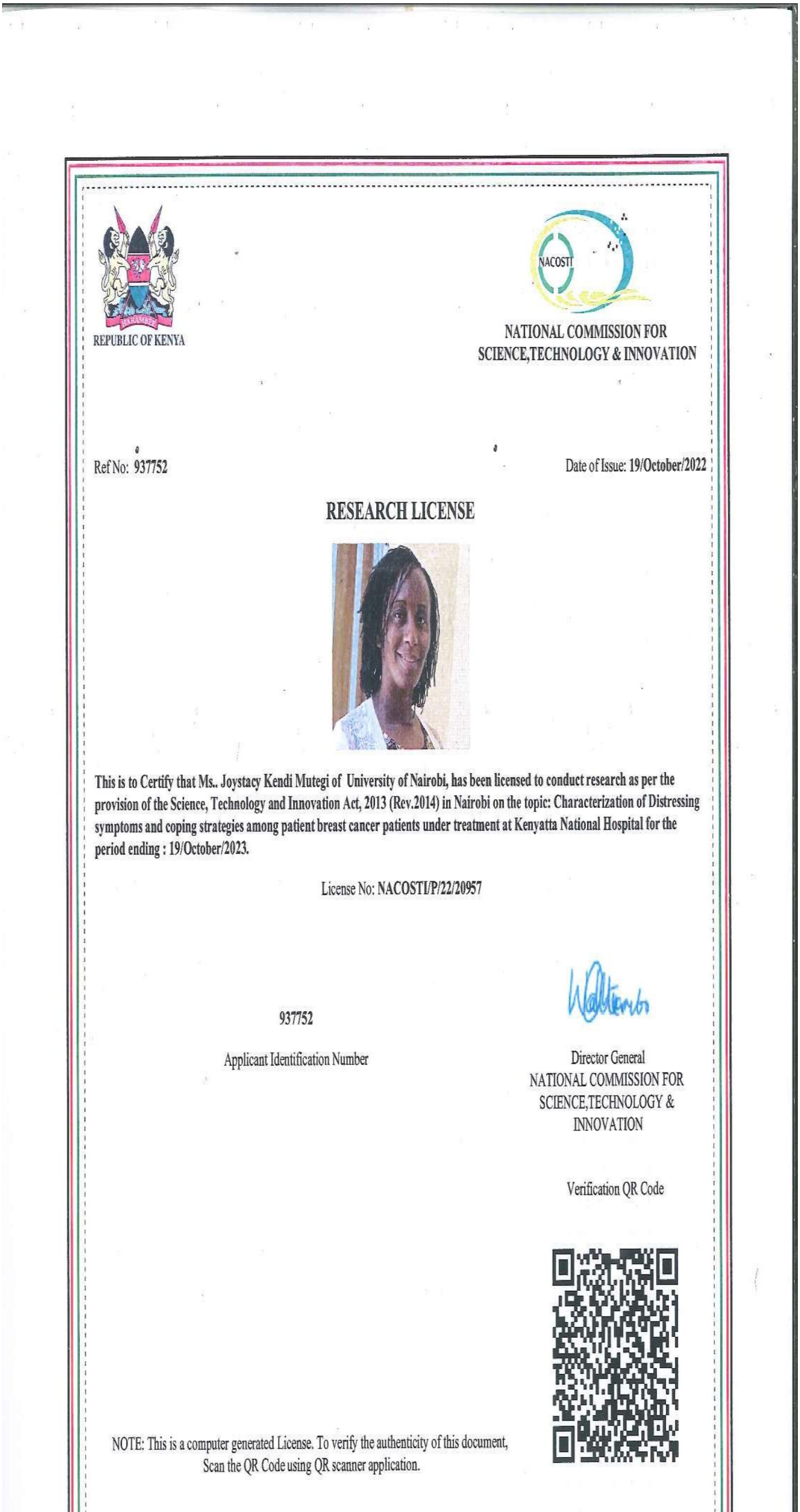
This is to inform you that KNH-UoN ERC has reviewed and approved your above research proposal. Your application approval number is **P346/04/2022.** The approval period is 30th September 2022 – 29th September 2023.

This approval is subject to compliance with the following requirements;

i. Only approved documents including (informed consents, study instruments, MTA) will be used.
ii. All changes including (amendments, deviations, and violations) are submitted for review and approval by KNH-UoN ERC.
iii. Death and life threatening problems and serious adverse events or unexpected adverse events whether related or unrelated to the study must be reported to KNH-UoN ERC 72 hours of notification.
iv. Any changes, anticipated or otherwise that may increase the risks or affected safety or welfare of study participants and others or affect the integrity of the research must be reported to KNH-UoN ERC within 72 hours.
v. Clearance for export of biological specimens must be obtained from relevant institutions.
vi. Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. Attach a comprehensive progress report to support the renewal.
vii. Submission of an executive summary report within 90 days upon completion of the study to KNH-UoN ERC.

Protect to discover

Appendix xii: Nacosti Certificate



REPUBLIC OF KENYA

NACOSTI

NATIONAL COMMISSION FOR
SCIENCE,TECHNOLOGY & INNOVATION

Ref No: 937752

Date of Issue: 19/October/2022

RESEARCH LICENSE

This is to Certify that Ms.. Joystacy Kendi Mutegi of University of Nairobi, has been licensed to conduct research as per the provision of the Science, Technology and Innovation Act, 2013 (Rev.2014) in Nairobi on the topic: Characterization of Distressing symptoms and coping strategies among patient breast cancer patients under treatment at Kenyatta National Hospital for the period ending : 19/October/2023.

License No: **NACOSTI/P/22/20957**

937752

Applicant Identification Number

Director General
NATIONAL COMMISSION FOR
SCIENCE,TECHNOLOGY &
INNOVATION

Verification QR Code

NOTE: This is a computer generated License. To verify the authenticity of this document,
Scan the QR Code using QR scanner application.