BIOPSYCHOSOCIAL EFFECTS OF CHEMOTHERAPY AMONG BREAST AND CERVICAL CANCER PATIENTS ATTENDING KENYATTA NATIONAL HOSPITAL CANCER TREATMENT CENTER.

ANASTACIA MORAA BOSIRE
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AUGUST, 2019
DECLARATION

I, Anastacia Moraa Bosire declare that this thesis is my original work and has not been presented in any other institution of higher learning or elsewhere for award of credit.

Signature: ___________________________ Date___________________________

Registration no. H56/7452/2017

SUPERVISORS’ CERTIFICATE OF APPROVAL

We the undersigned certify that this thesis was submitted for examination with our approval as supervisors:

Dr. Irene Mageto (BScN, MScN, PhD)

Lecturer School of Nursing Sciences

University of Nairobi.

Signature ___________________________ Date ____________________________

Dr. Samuel Kimani (BScN, MSc, PhD)

School of Nursing Sciences

University of Nairobi

Signature ___________________________ Date ____________________________
DEDICATION

I dedicate this work to my beloved children Terry and Longinus, who are my daily motivation.
ACKNOWLEDGEMENT

I thank God for this far He has brought me. To my husband Peter and children Terry and Longinus for the continued prayers and encouragement. You have been my pillar when it got tough.

I also wish to acknowledge Dr. Mageto and Dr. Kimani for their continued guidance and support as I carried out this study, I sincerely appreciate.

I thank Kenyatta National Hospital Management for funding my studies and allowing me time off to study. Thank you very much indeed.

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To my colleague students, we encouraged each other all the time.
# TABLE OF CONTENTS

DECLARATION .......................................................................................................................... i
SUPERVISORS’ CERTIFICATE OF APPROVAL ...................................................................... i
DEDICATION ............................................................................................................................ ii
ACKNOWLEDGEMENT ........................................................................................................ iii
LIST OF FIGURES .................................................................................................................. viii
LIST OF TABLES .................................................................................................................... ix
LIST OF ABBREVIATIONS AND ACCRONYMS ................................................................. x
OPERATIONAL DEFINITIONS ............................................................................................... xi
ABSTRACT .............................................................................................................................. xii

## CHAPTER ONE: INTRODUCTION .................................................................................. 1

1.1 Background ..................................................................................................................... 1
1.2 Problem Statement ........................................................................................................ 3
1.3 Research questions ....................................................................................................... 5
1.4 Study Objectives .......................................................................................................... 5
    1.4.1. Broad objective .................................................................................................. 5
    1.4.2. Specific objectives ........................................................................................... 5
1.5 Justification of the Study ............................................................................................. 6
1.6 Study Variables ............................................................................................................. 7
    1.6.1 Independent variables ....................................................................................... 7
    1.6.2 Dependent variable ........................................................................................... 8
    1.6.3. Intervening variables ....................................................................................... 8
    1.6.4. Outcome .......................................................................................................... 8

## CHAPTER TWO: LITERATURE REVIEW ..................................................................... 9

2.1 Introduction ................................................................................................................... 9
2.2 Cancer treatment .......................................................................................................... 10
2.3 Cancer chemotherapy .................................................................................................. 10
2.4 Chemotherapeutic agents used for breast and cervical cancer patients. .................. 11
2.5. Effects of chemotherapy on the breast and cervical cancer patients ...................... 11
    2.5.1 Biological effects of cancer chemotherapy ....................................................... 12
4.4 Sources of information on diagnosis, treatment benefits and side effects .................. 43
4.5 Characteristics and patterns of cancer diagnosis among participants ...................... 44
4.6. Chemotherapy drugs used for the treatment of breast and cervical cancer ............... 45
4.7. Effects of chemotherapy ......................................................................................... 46
  4.7.1. Biological effects of chemotherapy .................................................................... 46
  4.7.2. Psychological effects of chemotherapy .............................................................. 47
  4.7.3. Sociological effects of chemotherapy ................................................................. 49
CHAPTER 5: DISCUSSION AND LIMITATIONS .................................................................... 51
  5.1 DISCUSSION ............................................................................................................ 51
    5.1.1 Introduction ......................................................................................................... 51
    5.1.2 Socio-demographic factors ................................................................................ 51
    5.1.3 Chemotherapy agents used for the treatment of breast and cervical cancer ....... 52
    5.1.4 Biological, effects of cancer chemotherapy ........................................................ 53
    5.1.5 Psychological effects of cancer chemotherapy ..................................................... 54
    5.1.6 Sociological effects of cancer chemotherapy ....................................................... 55
    5.1.7 Relationship between socio-demographic and treatment factors and biological, psychological and sociological effects. ......................................................... 57
  5.2. LIMITATIONS OF THE STUDY ............................................................................. 58
CHAPTER 6: CONCLUSION AND RECOMMENDATIONS ................................................... 59
  6.1. CONCLUSION ........................................................................................................ 59
  6.2. RECOMMENDATIONS .......................................................................................... 60
REFERENCES ................................................................................................................. 61
APPENDICES .................................................................................................................. 73
  Appendix i: Informed consent form for patients .............................................................. 73
  Appendix ii: Ruhusa ya ridhaa kwa wagonjwa ............................................................... 77
  Appendix iii: Consent form ............................................................................................ 81
  Appendix iv: Form ya shaha .......................................................................................... 82
  Appendix v: Consent form for focus group discussion .................................................. 83
  Appendix vi: Maelezo ya shaha kwa washirika wa mjadala ........................................... 88
  Appendix vii: Questionnaire (maswali ya uchunguzi) ..................................................... 93
  Appendix viii: Clinical data checklist ........................................................................... 102
LIST OF FIGURES

FIGURE 1: THEORETICAL FRAMEWORK ........................................................................... 25

FIGURE 2: CONCEPTUAL FRAMEWORK ......................................................................... 26

FIGURE 3: REASONS FOR PARTICIPANTS CONTEMPLATING STOPPAGE OF TREATMENT .... 42

FIGURE 4: CHEMOTHERAPY AGENTS IN TREATMENT OF BREAST AND CERVICAL CANCER .... 45

FIGURE 5: PSYCHOLOGICAL EFFECTS EXPERIENCED BY PATIENTS ON CHEMOTHERAPY .... 48

FIGURE 6: SOCIOLOGICAL EFFECTS EXPERIENCED BY PATIENTS RECEIVING CHEMOTHERAPY 49
LIST OF TABLES

Table 1: Chemotherapy attendance records ................................................................. 28

Table 2: Dummy frequency table ................................................................................. 37

Table 3: Socio demographic characteristics of the participants .................................. 41

Table 4: Sociodemographic characteristics of FGD participants .................................. 43

Table 5: Source of information on diagnosis, treatment and side effects ...................... 44

Table 6: Characteristics and patterns of cancer diagnosis among participants .......... 45

Table 7: Biological effects of cancer chemotherapy ..................................................... 46
LIST OF ABBREVIATIONS AND ACRONYMS

ACS: American Community Survey

CTC: Cancer Treatment Centre

ERC: Ethics and Research Committee

FGD: Focused Group Discussion

G-CSF: Granulocyte Colony Stimulating Factor

GFD: Ground Floor wards D

GLOBOCAN: Global Cancer Incidence, Mortality and Prevalence

KEMRI: Kenya Medical Research Institute

KNH: Kenyatta National Hospital

NCCN: National Comprehensive Cancer Network

PPT: Study participant

RAM: Roy Adaptation Model

RSCL: Rotterdam Symptom Checklist

SONS: School Of Nursing Sciences

SPSS: Statistical Package for the Social Sciences

UON: University Of Nairobi

WHO: World Health Organization
OPERATIONAL DEFINITIONS

Adult: An individual who is 18 years and above.

Biological effects of chemotherapy: Physical symptoms experienced by patients who are receiving chemotherapy for the treatment of breast and cervical cancer.

Breast and cervical cancer: For purposes of this study this means patients diagnosed with either breast or cervical cancer and not the two cancers in one patient.

Cancer: It is a general term used to describe a group of diseases characterized by the abnormal growth of cells in the body with the potential to invade nearby cells and spread throughout the body.

Cancer cure: Treatment of the cancer with an aim of removing the cancer cells from the body.

Chemotherapy: A cancer treatment modality that uses one or more cytotoxic drugs.

Palliation: Control of cancer related symptoms through chemotherapy especially in advanced cancer where a cure cannot be achieved.

Psychological effects of chemotherapy: Mental health problems associated with the use of chemotherapy for the treatment of breast and cervical cancer.

Reproductive cancers: for the purpose of this study reproductive cancers refer to breast and cervical cancers.

Sociological effects of chemotherapy: The social problems experienced by patients who are receiving chemotherapy for breast and cervical cancer.
ABSTRACT

Cancer is a leading cause of mortality globally and breast and cervical cancers are two of the most common cancers among women. In Kenya, breast and cervical cancers cause the highest cancer related morbidity and mortality among women. Chemotherapy, one of the three modalities of cancer treatment, is associated with biological, psychological and sociological effects. These effects affect patients’ adherence to treatment and the overall outcome of treatment. In Kenya studies on cancer are few and none has concentrated specifically on the effects of chemotherapy on patients diagnosed with breast and cervical cancer. This study sought to determine the biopsychosocial effects of chemotherapy experienced by patients diagnosed with breast or cervical cancer. This study involved both quantitative and qualitative data collection methods to explore on the effects chemotherapy. Quantitative and qualitative data was collected for a period of 6 weeks in KNH CTC among patients diagnosed with breast or cervical cancer. A questionnaire developed from a modified Rotterdam Symptom Checklist (RSCL) was used to collect quantitative data from 157 systematically sampled participants. In addition two focus group discussions were held involving purposively selected from the study population. Quantitative data was analyzed using SPSS version 23.0. Univariate analysis was conducted and the results presented using frequency and proportions. Bivariate analysis was done using Pearson’s correlation to determine relationships between categorical variables and p-values of 0.05 or less were considered to have a significant relationship. Descriptive statistics was presented in text, frequency tables and bar graphs. Qualitative data analysis involved clustering together related narrative information then analyzed using thematic analysis. Pretesting of the study tools was done in clinic 23, questions in the questionnaire which were irrelevant were expunged. Permission to conduct the research was obtained from Kenyatta National Hospital/University of Nairobi Ethics and Research Committee (KNH/UON ERC).

The highest percentage (31.2%) of participants fell within the age group of 41-50 years. Most (66.9%) were married and depended on their husbands (45.9%) for social support. Only (22.9%) were in formal employment and majority (73.2%) earned a monthly income of below 20000kshs. Biological effects experienced by participants were anorexia (90.4%), nausea (86.5%), alopecia (79%), and peripheral neuropathy (61.8%). Psychological effects included; body image changes (65.6%), anxiety (79%), low self-esteem (63.1%), loneliness (55.4%) and sadness (51.6%). Sociological effects experienced were; inability to perform their family roles (88.5%), failure to return to work (76.3%), financial constraints (82.2%) and isolation (77.7%). Pearson’s correlation test showed that age, economic status, previous chemotherapy sessions had significant relationships with biological, psychological and sociological effects e.g. aged patients are likely to experience biological effects(r= 0.270) and as patients receive more chemotherapy they are likely to experience psychological (r= 0.510) and sociological effects(r= 0.361).

In conclusion, Cancer chemotherapy is associated with biological, psychological and sociological effects. The psychological and sociological effects are aggravated by increased chemotherapy sessions and low monthly income.
CHAPTER ONE: INTRODUCTION

1.1 Background

Cancer is among the leading causes of mortality worldwide accounting for an estimated 9.6 million deaths in 2018 (Plummer et al., 2016). Comprehensive data on cancer incidence and mortality in Africa are not readily available due to the lack of reliable cancer registries, with most of the countries relying on hospital based registries and estimates based on the demographic statistics(Jedy-Agba et al., 2012). A cancer mortality estimate shows that by 2012 over half of the cases and nearly two thirds of the cancer mortality happened in Africa and other low and middle income countries. This cancer burden is expected to rise by 60% cases and 70% deaths in the low and middle income countries by the year 2030 (Lukong, Ogunbolude and Kamdem, 2017)

Among all cancers in sub-Saharan Africa reproductive cancers have the highest morbidity and mortality and breast cancer tops the list among women while prostate cancer has the highest rate in men. Worldwide the incidence of breast cancer is estimated at 1.7million new cases annually with a mortality rate of about 60% in the developing countries(Bray et al., 2018) additionally cervical cancer is one of the most common malignancies affecting women worldwide. Globally it is the fourth most frequent cancer in women with an estimated 570000 new cases in 2018 representing an estimated 6.5% of all female cancers. There is marked improvement in the survivorship of cervical cancer patients in the developed countries but that is not the case in the developing countries with about 90% of the mortality from cervical cancer occurring in these countries.(‘WHO | Cancer’, 2017). In Kenya, data from the Nairobi registry indicates that
among women, breast cancer is the commonest accounting for 23% of all cancers while cancer of the cervix is second with 21.1% of cancers (Korir et al., 2015).

Cancer treatment has developed rapidly during the last two decades with newer treatment modalities coming into the market. However, chemotherapy has remained one of the major treatment modalities for breast and cervical cancer all over the world and is associated with better outcomes in the developed countries but the same cannot be said for the developing countries mainly due treatment adherence issues attributed to many factors (Adisa, Lawal and Adesunkanmi, 2008; O’Neil et al., 2018).

Chemotherapy like all other drugs have side effects and its use increases the chance of developing biological, psychological and social disorders which have been associated with suboptimal treatment adherence and poor health outcomes (Wampaalul et al., 2016). Physical, psychological and social stressors during cancer chemotherapy are often intertwined, resulting from and contributing to each other and a very important aspect of cancer management is to recognize these effects and determine the appropriate intervention in order to promote treatment adherence and achieve the intended outcome.

Numerous studies have been carried out on breast and cervical cancer patients’ experiences with cancer chemotherapy in the developed countries but there are very few studies documented in sub-Saharan Africa despite estimates showing that the burden of cancer including those of the cervix and breast are increasing (Stulac et al., 2015).

The drugs used for chemotherapy are very expensive and create a financial burden to the countries and individual patients and in this regard chemotherapy is moving from the inpatient to the outpatient setting as a means of reducing cost of treatment (Tachi et al., 2015). But with this shift the adverse effects associated with chemotherapy now directly influence the patients’
life at home and at work. For women suffering from breast cancer and cancer of the cervix this is compounded by the fact that most women do not make decisions even those regarding their own treatment.

Most of the patients continue to juggle with their many roles in the society, work and at home and are unable to cope with the adverse symptoms of chemotherapy. This causes them a lot of psychological stress but since these patients come from home one is likely to assume they get emotional support from their families which is not always the case (Tachi et al., 2015).

Like many of the African countries, Kenya is faced with the challenge of registries and inadequate documentation on the cancer burden and especially on the specific cancer types. Until recently (2011) chemotherapy was administered in few hospitals mainly private hospitals and the documentation was kept in those hospitals’ records. The National Cancer Institute of Kenya was given the mandate to establish a national cancer registry in 2011 which is yet to be realized. Therefore while Biopsychosocial issues among patients with breast and cervical cancer have been documented well elsewhere in the world, the same cannot be found in Kenya. This study was among the first documentation addressing the effects of chemotherapy among patients diagnosed with breast and cervical cancer receiving chemotherapy as outpatients in Kenyatta National Hospital (KNH).

1.2 Problem Statement

Chemotherapy effects are usually intertwined and it is difficult to separate them and for cervical and breast cancer treatment, it causes symptomatic biological effects resulting from the side effects of the drugs. Research has shown that most of the patients receiving chemotherapy experience multiple side effects and some of the side effects are serious necessitating immediate intervention and interruption of treatment (Pearce et al., 2017). Chemotherapy for the treatment
of these cancers interferes with the normal function of the reproductive system which is a sensitive area for the individual, partner and family as a whole. These differences that arise from the use of chemotherapy will therefore affect the patients psychologically and socially. Some of these effects are associated with stigma for example infertility and loss of sexual function which makes it difficult for the woman to discuss them freely and require careful probing in a private and trusting environment. It is therefore expected that the health care givers will evaluate patient’s needs and provide appropriate interventions, being sensitive to these patients’ unique needs because addressing these chemotherapy effects is as important as administration of the treatment itself (Kim et al., 2015) However in Kenyatta National Hospital Cancer Treatment Centre(CTC) no documentation exists to show that these needs have been identified and addressed.

These effects have been studied elsewhere in the world and shown to affect the patients’ adherence to treatment and ways of managing them have been developed and applied to improve treatment outcomes. Kenya like most African countries is faced with the challenge of cancer registries and therefore documentation on activities or studies related to cancer and its treatment especially chemotherapy are few or incomplete. At KNH CTC there is data to show that chemotherapy is actually administered but there is no documentation to show which of the side effects have been reported by patients and how they have been addressed.

This study has addressed the biopsychosocial effects of chemotherapy among patients diagnosed with breast and cervical cancer in Kenyatta hospital and compared the findings with those identified by other researchers. From the study findings recommendations have been given aimed at improving adherence to treatment and improvement on patient care.
1.3 Research questions

1. Which biological symptoms associated with cancer chemotherapy are experienced by adult patients diagnosed with breast or cervical cancer who receive treatment at KNH CTC?
2. Which psychological effects of cancer chemotherapy are experienced by adult patients diagnosed with breast or cervical cancer who receive treatment at KNH CTC?
3. What sociological effects of cancer chemotherapy are experienced by adult patients diagnosed with breast or cervical cancer attending treatment at KNH CTC?
4. Is there a relationship between the biopsychosocial effects of chemotherapy and the socio demographic characteristics of the participants?

1.4 Study Objectives

1.4.1. Broad objective

To determine the biopsychosocial effects of cancer chemotherapy among adult patients diagnosed with breast or cervical cancer attending Kenyatta National Hospital Cancer Treatment Centre

1.4.2. Specific objectives

1. To identify biological effects of cancer chemotherapy among adult patients diagnosed with breast or cervical cancer who receive chemotherapy at KNH Cancer Treatment Centre
2. To identify the psychological effects of cancer chemotherapy among adult patients diagnosed with breast and cervical cancer who receive treatment at KNH CTC.
3. To find out the sociological effects of cancer chemotherapy among adult patients diagnosed with breast and cervical cancer who receive treatment at KNH CTC.
4. To determine the relationship between socio demographic factors and biological, psychological and sociological effects of cancer chemotherapy among adult patients who receive treatment at KNH CTC.

1.5 Justification of the Study

In Kenya the burden of cancer is higher in women than it is in men with more women dying from cancer than men, an estimated 18,772 deaths in women compared to 14,215 in men yearly (GLOBOCAN 2018). Breast cancer and cervical cancer are the most common cancers affecting women in Kenya and bearing in mind that most women in the developing countries are not independent decision makers; these would be the best population for the study especially to find out psychosocial issues experienced following chemotherapy.

The effects of cancer chemotherapy are not only biological but also social and psychological and are usually interrelated and this makes it necessary to study all these effects together (Lavdaniti, 2015).

Biopsychosocial effects of chemotherapy among breast and cervical cancer patients have been studied extensively and mitigated in other parts of the world. There is limited data on the same in Sub Saharan Africa where the cancer burden continues to rise necessitating more and more chemotherapy administration. In Kenya, no known study had concentrated on the symptoms experienced by these cancer patients receiving chemotherapy. These study findings have contributed to the body of knowledge and stimulate future research on the management of cancer in Kenya. It has also identified the need for patient education and individual patient assessment during chemotherapy. The findings have identified an area of emphasis during policy development on the management of chemotherapy effects in the country.
Many patients experience chemotherapy effects throughout the treatment period and some of the symptoms are life threatening making it necessary to consider a model of care which would address the side effects, psychological and sociological challenges experienced by the patients during treatment.

1.6 Study Variables

In this study three types of variables were considered; these included the independent variables, the dependent variable and the intervening variables.

1.6.1 Independent variables

<table>
<thead>
<tr>
<th>Biological effects</th>
<th>Psychological effects</th>
<th>Sociological effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anorexia</td>
<td>Fear</td>
<td>Loss of social support</td>
</tr>
<tr>
<td>Fatigue</td>
<td>Depression</td>
<td>Financial burden</td>
</tr>
<tr>
<td>Nausea</td>
<td>Low self esteem</td>
<td>Social stigma and isolation</td>
</tr>
<tr>
<td>Alopecia</td>
<td>Anxiety</td>
<td>Loss of identity</td>
</tr>
<tr>
<td>Chemotherapy induced neuropathy</td>
<td>Cognitive impairment</td>
<td>Marital strain</td>
</tr>
<tr>
<td>Diarrhea</td>
<td>Self-projection</td>
<td>Inability to return to work</td>
</tr>
<tr>
<td>Vomiting</td>
<td>Disruption of body image</td>
<td></td>
</tr>
<tr>
<td>Low immunity</td>
<td>Sense of loneliness</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Hopelessness</td>
<td></td>
</tr>
</tbody>
</table>
1.6.2 Dependent variable

- Adherence to chemotherapy

1.6.3. Intervening variables

- Religion is used by patients with chronic illnesses like cancer as a way of coping with the stress of illness. The same is also used to cope with the effects of treatment (Kappeli, 2005; van Laarhoven et al., 2010).

- Previous chemotherapy sessions.

- Total monthly income.

1.6.4. Outcome

- Cancer Cure/Palliation
CHAPTER TWO: LITERATURE REVIEW

2.1. Introduction

Cancer is the term used for uncontrolled growth of body cells and can affect any part of the body. Cancer is a leading cause of mortality worldwide and the incidence of cancer mortality has been projected to increase with increase in population and changing lifestyles that raise the risk of cancer (Bray et al., 2018). Breast cancer affects both male and female but the incidence in males is very small accounting for only 1% of all breast cancer cases worldwide and it has been traditionally considered a female specific cancer (Ly et al., 2013). Cancers of the breast and of the cervix are common among women globally, affecting 2,088,849 and 569,847 new patients respectively in 2018 (GLOBOCAN 2018). In 2012, 522,000 and 270,000 women died of breast and cervical cancer, respectively, being responsible for the highest and fourth-highest death rates among women (Bray et al., 2018; ‘WHO | Cervical cancer’, 2018).

New cases of cancer of the breast and cervix have been increasing with most of the patients being in the 50s but younger patients in their late 20s are also being diagnosed with one of the two cancers. These younger patients are still in the reproductive age bracket and also economically vibrant members of society. The effects of chemotherapy are likely to affect them more than the older patients. Chemotherapy will be given to these patients as outpatients as they continue with their other engagements e.g. work and family (Tachi et al., 2015)

In Kenya cancer is the number three leading cause of mortality after infections and diseases of the heart and vessels and accounts for approximately 7% of the total deaths in the country. (Kenya bureau of statistics, 2012). Breast cancer accounts for 23% of all cancers registered in the Nairobi cancer Registry while cervical cancer accounts for 19% from the GLOBOCAN estimate (Korir et al., 2015)
2.2 Cancer treatment

Cancer treatment is the use of one or more of the cancer treatment modalities to cure a cancer, shrink a cancer or stop the progression of a cancer. These treatment modalities include; surgery, radiotherapy and chemotherapy which are most commonly used while immunotherapy and hormonal therapy are newer treatment modalities (‘WHO | Cancer’, 2017; Mitra et al., 2015).

2.3 Cancer chemotherapy

Chemotherapy means the use of drugs for cancer treatment. Chemotherapy targets fast growing cells, a characteristic of cancer cells and unlike the other common treatment modalities (surgery and radiotherapy), it is a systemic mode of treatment which can also affect normal fast growing cells anywhere in the body e.g. skin, hair, intestines, mucous membranes and bone marrow (Remesh, 2012)

In the treatment of breast and cervical cancer chemotherapy is used for three purposes; adjuvant, neo adjuvant and for the treatment of metastases to other parts of the body. These cancers respond well to all major classes of anticancer medications including alkylating agents, antimetabolites, mitotic inhibitors and the antitumor antibiotics either as single agents or in combination (Lai, Ching and Wong, 2017). These medications like any other medications used to treat other diseases have many side effects.

The delivery of chemotherapy that used to be done primarily as an inpatient procedure has shifted to outpatient since the 1990s. This is aimed at reducing the cost of treatment and to improve on the patient’s quality of life as well as allow the patient to remain in the home environment (Tachi et al., 2015). However this shift has come in with more challenges to the patients who now have to cope with the side effects at home and because these patients come from home it is likely to be assumed that they get sufficient physical, psychological and social
support from their families and friends and omit this necessary part of care during chemotherapy (Ahmad et al., 2016).

2.4 Chemotherapeutic agents used for breast and cervical cancer patients.

The most common drugs used for the treatment of breast cancer include: anthracycline e.g. doxorubicin, epirubicin; taxanes e.g. paclitaxel, docetaxel; 5-fluorouracil (5FU); cyclophosphamide and platinum compounds e.g. carboplatin and cisplatin. These drugs are used as single agents or most commonly in combination. For the treatment of advanced disease i.e. metastatic breast cancer the following compounds are included; Vinerolbine, capecitabine, gemcitabine and albumin bound paclitaxel. Drugs targeting HER2 are also available for use in combination with the other chemotherapy drugs for treatment of HER2 positive breast cancer such include trastuzumab. (Chemotherapy for Breast Cancer | American Cancer Society, Oct 3, 2017)

For the treatment of cervical cancer cisplatin is the most commonly used agent. Other agents used include: paclitaxel, 5fluorouracil, topotecan, carboplatin and gemcitabine. These agents are used in combination most commonly of two drugs. However cisplatin is considered the most effective agent in the treatment of advanced cervical cancer(Lorusso et al., 2014) and is frequently used as a single agent for treatment of patients undergoing radiotherapy.

2.5. Effects of chemotherapy on the breast and cervical cancer patients

Chemotherapy affects patients in different ways, some go through the treatment with minimal problems while others experience very many problems which bring a big change in their lives. Some express this experience as bearable while others feel it is great suffering(Lai, Ching and Wong, 2017).
Chemotherapy has contributed to an increase in the overall survival of patients with cancer but being a systemic therapy, it is often associated with many side effects some of which are occasionally life-threatening (Remesh, 2012). The adverse effects of chemotherapy affect the patient’s physiological function, and the inability of these patients to perform their normal daily activities destabilizes the individual’s psychological status and may lead to anxiety and depression (Nyblade et al., 2017). The inability to perform activities of daily living necessitates assistance from the family, a support which is available for the outpatient (Tachi et al., 2015). However some patients do not receive this kind of support and must perform their activities despite the side effects of the drugs. These leads to social strain where the patient feels she is being neglected or isolated (Nizamli, Anoosheh and Mohammadi, 2011).

In the recent past researchers have also concentrated on studying one symptom of chemotherapy e.g. fatigue (Charalambous and Kouta, 2016), nausea and vomiting (Iihara et al., 2016), hair loss (Trusson and Pilnick, 2017) This is important but other studies have also shown that it is very important to study all the symptoms together because most patients experience more than one symptom and this will also assist in forming a cluster of likely symptoms which can be managed together.

2.5.1 Biological effects of cancer chemotherapy

Biological effects are those effects that result from the physiological function of the body i.e. the cells, tissues, organs and body systems and they are sometimes referred to as the physical effects or side effects of treatment which are experienced by the patients as symptoms which they can identify. Chemotherapy causes frequent and severe side effects at therapeutic doses, a characteristic that distinguishes it from other drugs (Remesh, 2012). Many patients therefore tend to experience side effects of the drugs and some of them are potentially serious requiring
immediate attention and even suspension of treatment. Understanding these side effects and their management is important because they affect the treatment tolerability and adherence in the patient with breast and cervical cancer receiving chemotherapy (Degu et al., 2017).

Frequently experienced side effects by breast and cervical cancer patients on chemotherapy are anorexia, fatigue, nausea, vomiting diarrhea and alopecia (Huang et al., 2017).

**Anorexia**

Anorexia is one very significant side effect associated with drugs used for the treatment of breast and cervical cancer and has been reported to be a major concern for outpatients receiving chemotherapy. The fact that patients are unable to feed makes them conscious of their own illness. This also makes them anxious and weakens the patients will to live (Tachi et al., 2015; Huang et al., 2017).

**Nausea**

Nausea is one of the most common side effects that patients with breast and cervical cancer who are receiving chemotherapy experience. Ample nutrition is important for healing a fact that is supported by many patients but the nausea experienced during and after chemotherapy makes them unable to feed. Most patients report that the nausea is always there even after the administration of chemotherapy and interferes with their daily activities (Nies et al., 2018; Tachi et al., 2015; Günüşen, Inan and Üstün, 2013). Nausea is sometimes associated with vomiting but with the development of antiemetic given with chemotherapy drugs known to cause vomiting the incidence of vomiting has greatly reduced (Günüşen, Inan and Üstün, 2013).
Chemotherapy induced neuropathy

Many women treated for breast cancer experience sensory symptoms which they describe as numbness, tingling, cold sensation and others even describe this as pain and occasionally motor problems have been reported involving the lower limbs which can affect movement (Bao et al., 2016). Neuropathy is associated with taxanes (e.g. paclitaxel) which is one of the classes of drugs used for the treatment of cancer of the breast (Stubblefield et al., 2012). This symptom develops within three months of receiving chemotherapy for breast cancer and patients have reported that it is very stressful since it interferes with the performance of daily activities (Greenwald et al., 2019; Simon et al., 2017). But a review of literature carried out in America in 2015 described it as an unclear experience and seemed to indicate that this is not a significant symptom though it has a negative effect on the patients quality of life (Tanay, Armes and Ream, 2017).

Fatigue

This is one of the most common symptoms reported by patients receiving chemotherapy and patients have described it as an experience that is not relieved by rest or sleep and is troublesome. It was noted that the prevalence of cancer related fatigue increased from 50-75% at diagnosis to 80-96% during chemotherapy (Stasi et al., 2003) and 19-30% in patients receiving adjuvant chemotherapy for breast cancer (Andrykowski et al., 2010). It causes patients anxiety, may lead to depression and interfere with patients’ treatment adherence and the overall quality of life (Mustian et al., 2017). From a literature review on quality of life among cervical cancer patients, fatigue turned out to be one of the symptoms experienced and highly affected the quality of life of patients receiving chemotherapy (Pfaendler et al., 2015)
Alopecia

Alopecia has been identified as a common symptom of cancer chemotherapy side effect among breast and cervical cancer patients. Nies et al., (2018) indicated that hair loss was among the three most disturbing side effects of chemotherapy from their study in Malaysia on patients with cancer of the breast receiving chemotherapy and noted that even though the hair grows after the end of treatment many patients suffered distress because they associated hair loss with ‘a sign of cancer patient on chemotherapy’. Chan and Ismail, (2014) had similar findings from a Malaysian general hospital where 50% of the participants reported hair loss as a one of the symptoms they experienced. A study among breast cancer patients in South Korea indicated that hair loss was the most disturbing chemotherapy side effect and that it is associated with psychological effects like anxiety and depression as well as sociological effects including stigma and isolation. All the participants in this study stated a negative effect of hair loss on their life with some of them contemplating to discontinue the chemotherapy (Suwanthong and Liamputtong, 2018).

Chemotherapy induced neutropenia

This is a common complication during the treatment of cancer. Chemotherapy induced neutropenia is associated with platinum compounds and taxane-containing treatments both of which are used for the treatment of breast and cervical cancer (Hashiguchi et al., 2015). Chemotherapy induced neutropenia can be a problem in the management of outpatient chemotherapy; it is one of the major adverse events that necessitate dose reduction or it can lead to patients having to postpone treatment and requires the use of granulocyte colony stimulating factor (G-CSF) which adds to the expenses of cancer treatment(Vogel et al., 2005). The degree and duration of neutropenia determines the risk of life long infection. From a study among breast
cancer patients, the researcher observed that the % of patients who developed neutropenia was high (Tsuji et al., 2016)

**Mucositis**

Patients receiving chemotherapy experience mucositis as a result of the action of cytotoxic drugs on the mucous membrane of the gastrointestinal tract (Nurgali, Jagoe and Abalo, 2018). Patients stated this as moderately disturbing symptom (Kırca and Kütüürkan, 2018). Patients may restrict their food intake due to the pain experienced from the disrupted mucous membrane (Nies et al., 2018).

### 2.5.2 Psychological effects of cancer chemotherapy

Chemotherapy used to treat cancer has been associated with altered mental status in cancer patients. (Huang et al., 2017) conducted a research among patients with cancers of the breast and cervix in Taiwan and found that the psychological effects of chemotherapy were similar among the patients with the two cancers and they included decreased self-esteem, self-projection in life, impaired cognitive function, anxiety and depression. Similarly from a study in Turkey, psychological strains during chemotherapy in patients with breast cancer included uncertainty, body image changes, loneliness and disturbed emotional state, fear of cancer recurrence, anger and sadness (Günüşen, Inan and Üstün, 2013).

Ahmad et al., (2016) carried out an extensive literature review on anticancer chemotherapy side effects and noted that from most of the studies, the biological effects experienced by cancer patients during chemotherapy are associated with psychological effects to include; fear of chemotherapy, grief related to loss of self-identity, depression, low self-esteem and fear of being treated differently at the workplace.
Fear of chemotherapy side effects

Patients scheduled for chemotherapy fear the side effects especially hair loss and body image changes even before the treatment is started and this could affect their presentation for the treatment. A study in South Africa by Rayne et al., (2017) revealed fears related to chemotherapy were the most among all treatment related fears at 65.4%. Similarly in a study by Nies et al., (2018) the patients said they feared chemotherapy and actually had to gather courage to face it. This fear resulted from what they heard about chemotherapy i.e. people become weak unable to stand and others even die.

Depression

Research by Kings College in London concluded that cancer drugs affects normal brain cells hence the patients become more vulnerable to depression (Depression: 2017) and the national cancer institute estimates that about 10% of cancer patients on chemotherapy suffer from depression. Angachi, (2014) from her study on psychosocial effects of cancer on patients in Moi teaching and referral hospital in Kenya found that patients on chemotherapy suffered major depressive illness. Patients experience deep sadness mainly due to the perceived loss of self-identity due to the many body changes as a result of the treatment with chemotherapy and this affects adherence.

Low self esteem

Younger patients especially women will be very much concerned with their body image. The skin changes and loss of hair experienced during chemotherapy have been associated with low self-esteem, sadness and even depression (Suwankhong and Liamputtong, 2018; Chan and Ismail, 2014). Likewise Leite, Nogueira and Terra, (2015) from their study in Brazil among
patients receiving chemotherapy found that the body image seen in women with cancer of the breast who were receiving chemotherapy contributed to their low self-esteem

**Cognitive impairment**

Approximately 75% of patients with cancer show some degree of cognitive impairment during chemotherapy. A meta-analysis of studies on cognitive impairment among cancer patients receiving chemotherapy confirmed that many patients receiving chemotherapy indeed complained of cognitive impairment during and after treatment (Philip *et al.*, 2013) while another meta-analysis found that breast cancer patients had cognitive impairment only in the ability to speak and visuospatial ability contrary to the previous studies which found significant deficits in multiple domains (Jim *et al.*, 2012). Various other research findings also identified cognitive impairment especially memory loss as an effect of chemotherapy among breast cancer patients (Lindner *et al.*, 2014; Bijker *et al.*, 2018; Ahles, Root and Ryan, 2012). A study among Chinese patients with cervical cancer identified loss of concentration as the main cognitive impairment perceived by the patients (Zeng *et al.*, 2017).

**Anxiety**

The challenges experienced during chemotherapy and the uncertainties of the future are a source of anxiety for the cervical cancer patients (Nyblade *et al.*, 2017). However it has been noted that the level of anxiety reduces as the patients receive more information about their treatment and know what to expect but past negative experience with chemotherapy has been associated with higher levels of anxiety which can even interfere with their treatment (Baquytayan, 2012). Chemotherapy compared to other treatments is associated with higher anxiety levels and it gets worse when the patients start experiencing side effects (Charalambous *et al.*, 2017)
**Self-projection**

Breast and cervical cancer patients on chemotherapy have reported the feeling of wanting to be left alone to deal with their own problems. Others isolated themselves so that nobody gets hurt by them or wanting to bear the “punishment alone”, which is an unhealthy way of dealing with emotions (Huang *et al.*, 2017) while other patients just go through the side effects quietly without communicating to anyone because they fear asking for help from their relatives (Nies *et al.*, 2018).

**Disruption of body image.**

Women put a lot of investment in terms of time and money on their body to improve their image. Chemotherapy interferes with how the body looks despite the effort put in by the women. Most women will continue to seek body improvement procedures for treatment of alopecia, color changes and weight changes due to chemotherapy. They have a disrupted image of themselves which causes a lot of psychological stress (Campbell-Enns and Woodgate, 2015; Chan and Ismail, 2014).

**2.5.3 Sociological effects of cancer chemotherapy**

The debilitating physical symptoms of cancer and its treatment have been studied a lot, but the study on psychological and social impacts of cancer management has started receiving a lot of attention only relatively recently (Aaronson *et al.*, 2014).

**Loss of social support**

Social support as perceived by the person influences a person’s social relationships which are thought to have a major impact in buffering psychological and biological stress responses and has a link to the outcomes of treatment e. g. chemotherapy. A disruption in the patients’ social
relationship for example by the chemotherapy side effects, will therefore affect the patients response to the stresses associated with treatment. Chemotherapy has been associated with a reduction in the perception of support from caregivers leading to strained relationships (Pfaendler et al., 2015)

**Loss of identity**

Society attaches a lot of importance in one being able to perform his/her role as expected yet chemotherapy affects the patient’s ability to perform these roles. Studies have shown that during chemotherapy, patients had to give up their customary ascribed roles and duties within the family, at work or in relation to their friends because they are no longer able to cope with these demands and therefore a loss of role identity (Masika et al., 2012; Wampaalu et al., 2016; Suwankhong and Liamputtong, 2018). After treatment patients were in a dilemma on whether to resume the same roles or to adjust to life without them (Bijker et al., 2018) while other patients were not allowed back to their work due to the stigma attached to cancer and chemotherapy (Nyblade et al., 2017)

**Financial burden**

Chemotherapy is a very expensive mode of cancer treatment such that in America the per-person cost of treatment is 4 times as expensive compared to the other modes of treatment. This means that even for the patients who have health insurance they still have to top up to meet the cost of treatment (Carrera, Kantarjian and Blinder, 2018). This expense coupled with prolonged treatment puts a financial burden on the patients and their families and this is a source of social stress and some have indicated that this has lowered their average living standards and some women have experienced abandonment by their spouses (Maree, Mosalo and Wright, 2013).
In Kenya chemotherapy costs between Kshs 10,000 and 82,000 per cycle at Kenyatta National Hospital for 6 to 8 sessions. For many Kenyans this is far above what they can afford for treatment alone. Most patients are now enrolled in the NHIF which caters for their treatment but like the American patients, they still have to top up the cost of treatment. Financial burden is a reality for many Kenyan patients and a great source of social stress. (Afyasmile Kenya, 2017).

Social stigma and isolation

There is a lot of social stigma associated with a cancer diagnosis and its treatment due to misinformation and myths (Ahmad et al., 2018; Nyblade et al., 2017). Even though chemotherapy may not be directly linked to the stigma, its side effects identify the patient as a cancer patient leading to isolation due to the stigma attached to cancer (Gonzalez and Jacobsen, 2012). The link between cervical cancer and human papilloma virus which is sexually transmitted has further stigmatized this disease in some places and in other areas breast health problems are associated with poor character (Nyblade et al., 2017). The women also blame their spouses for the cancer causing a strain on their relationship.

The individual can also isolate herself from family and friends due to low self-esteem as a result of altered body image and prolonged ill health due to the chemotherapy side effects.

The ability of an individual to work defines her self-worth, identity and societal role together with providing her financial security. The effects of chemotherapy disrupt the individual’s normal working schedule because the individuals will usually have prolonged sick offs, numerous doctor’s appointments and lack of understanding from their colleagues at work (Chow, Ting and Su, 2014).
Loss of employment

Depression, cognitive impairment and fatigue as a result of Chemotherapy have been shown to interfere with ability of the patients to return to work even after treatment is completed. In the UK a study on factors that influenced cancer survivors ability to go back to work after completing treatment found that breast cancer patients who have undergone chemotherapy take 3 times longer to return to work compared to other modes of treatment and they cited the effects of the treatment as the reason why they could not go back to work early (Grunfeld, Low and Cooper, 2010). Hedayati et al., (2013) also had similar findings among patients with breast cancer and survivors who had completed chemotherapy in Scandinavia.

Marital / relationship strain

Sexuality plays an important part in the life of a human being. Love, affection and sexual intimacy contribute to healthy relationships and individual well-being. Sexual dysfunction can therefore cause a lot of stress and disrupt relationship. Chemotherapy has been associated with effects on sexual function affecting fertility, libido and sexual performance. 90% of patients on chemotherapy for breast cancer in morocco reported that they experienced sexual dysfunction a problem that did not exist before the treatment (Sbitti et al., 2011).

Cancer treatment can cause many physical and psychological changes which can affect the individual’s sexuality. Changes in body image can markedly influence the individual’s view of their own sexual identities, being attractive, and worthy leading to withdrawal and marital discordance (Ussher et al., 2015; Finocchario-Kessler et al., 2016).

A Syrian study among breast cancer patients on chemotherapy indicated that the patients were unable to perform their role and one of those roles was sexuality because the patients did not find
themselves sexuality attractive. Infertility secondary to chemotherapy was also found to be a major concern related to sexuality (Nizamli, Anoosheh and Mohammadi, 2011).

2.6 Theoretical Model: Roy’s Adaptation Model (RAM)

RAM (1991) theoretical frame work was used to guide the study. RAM focuses on individuals' adaptation to changeable environment and guides the assessment of individuals' adaptation (Ursavaş, Karayurt and İşeri, 2014)

Sr. Calista Roy views the person as a Bio-Psycho Social being who constantly interacts with the environment. Roy talks about three types of stimuli produced in the environment. These stimuli include the focal, contextual and residual stimuli. The stimuli which affect the person and the person responds by adapting through the four adaptive modes described by Roy as Physiological, Self-Concept, Role Function and Interdependence modes (Giger, Bower and Miller, 1987). According to Roy, problems arise when the individual fails to adapt in the four adaptive modes and this makes this model relevant for this study.

A summary of Roy’s model implies that a stimulus from the environment will provoke a response from the individual. The response will be assessed from the behavior exhibited by the individual from the four adaptive modes. The behaviors will then be observed during assessment and the areas that need intervention will be identified. Interventions according to Roy’s model involve manipulation of the environment in order for it to fall within the limits that the individual can use the adaptive modes (Naga and Al-Khasib, 2014). Therefore identifying the effects of chemotherapy and providing care will enable the individual to cope.
Application of Roy’s model

For this research, the focal stimulus was the cancer treatment (chemotherapy) the contextual stimulus which is known to affect the individual refers to all other stimuli of the human system’s internal and external environment that can be identified as having a negative or positive effect on the situation. In this study, age, religion and socio economic factors were those other stimuli that influence the response to treatment.

This study aimed to find out which problems had been identified due to lack of adaptation in the four adaptive modes. Lack of adaptation in the physiologic mode would exhibit the biological symptoms, while failure in the self-concept, role function and the interdependence mode would exhibit the psychological and sociological effects of chemotherapy. The adaptive modes could be positive leading to a positive outcome i.e. treatment adherence or negative leading to negative outcome i.e., treatment non adherence. RAM was used as a guide during formulation of the study questions and the questionnaire.
2.7 Theoretical Framework

**Figure 1: Theoretical Framework**

- **Stimulus**: Focal stimulus
  - **Chemotherapy**
- **Adaptive modes**
  - **Independent variables**
    - Response to the stimulus in the four adaptive modes
    - 1. Physiological mode
      - Physical symptoms e.g. Nausea, vomiting, alopecia
    - 2. Self-concept mode
      - Psychological symptoms e.g. Low self-esteem, depression, anxiety
    - 3. Role function
      - Sociological symptoms e.g. Loss of identity
    - 4. Interdependence mode
      - Sociological symptoms e.g. Social isolation
  - **Dependent variable**
    - Effective adaptation
    - Adherence to treatment
    - Ineffective adaptation
    - Non adherence to treatment

- **Outcome**
- **Residual stimulus**: Confounding factors e.g. religion and comorbidities like hypertension
2.8 Conceptual framework

This framework shows the interrelationship between the study variables

<table>
<thead>
<tr>
<th>INDEPENDENT VARIABLES</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Physical effects</strong></td>
</tr>
<tr>
<td>Anorexia, alopecia, fatigue, nausea, chemo-induced neuropathy, vomiting, diarrhea, vomiting</td>
</tr>
<tr>
<td><strong>Psychological effects</strong></td>
</tr>
<tr>
<td>Fear of chemo side effects</td>
</tr>
<tr>
<td>Depression, hopelessness</td>
</tr>
<tr>
<td>Low self-esteem, Anxiety, Self-projection,</td>
</tr>
<tr>
<td>Cognitive impairment, Sense of loneliness, Disruption of body image</td>
</tr>
<tr>
<td><strong>Sociological effects</strong></td>
</tr>
<tr>
<td>Loss of social support, Loss of identity, Financial burden, Social stigma/isolation, Loss of employment, Marital strain, Relationship tension</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>INTERVENING VARIABLES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Religion, income, chemotherapy sessions</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>DEPENDENT VARIABLE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adherence to chemotherapy</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>OUTCOME VARIABLE</th>
</tr>
</thead>
<tbody>
<tr>
<td>CANCER CURE/PALLIATION</td>
</tr>
</tbody>
</table>

*Figure 2: Conceptual framework*
CHAPTER THREE: STUDY DESIGN AND METHODS

3.1 Study Design

This study was carried out using a descriptive cross-sectional study design. Quantitative and qualitative data was collected in a period of six weeks to find out the effects of chemotherapy among patients diagnosed with breast and cervical cancer. Quantitative data was collected using questionnaires while qualitative data was collected through Focus group discussion.

3.2 Study Area

The study was carried out at KNH Cancer Treatment Center. Kenyatta National Hospital is the oldest public hospital, in Kenya and the largest referral hospital for all patients who need specialized care in the country. The hospital is located about 3 kilometers from the Nairobi city center and is accessible through both private and public transport.

KNH is the main referral hospital for cancer patients in the country and the only public hospital which offers comprehensive cancer management. The major treatment modalities given to cancer patients at the hospital include; chemotherapy, surgery, radiotherapy, brachytherapy, hormonal therapy and palliative care. This makes KNH a suitable area for the study.

The hospital has a total bed capacity of 2000 and about 6000 members of staff, 2500 of them being nurses. In 2018, 5363 cancer patients were admitted in KNH out of 67729 total number of patients admitted. Out of the cancer patient admissions, 404 were breast cancer patients and 447 were patients diagnosed with cervical cancer (source: Kenyatta hospital health information database, 2019).

Outpatient chemotherapy is offered at the CTC and clinic 23. The Cancer Treatment Centre (CTC) is located in the old hospital wing of KNH. An average of 2300 patients are attended to at
CTC those who receive chemotherapy are about 850 patients per month with an average of 150 patients diagnosed with breast cancer and 115 cervical cancer patients receiving chemotherapy at the CTC per month (source; Cancer Treatment Centre Daily patient attendance records, Oct. 2018 to Jan 2019). Patients scheduled for chemotherapy come to the clinic two days in a week (Thursdays and Fridays) from 8-5 pm. The CTC was chosen because it has the majority of patients diagnosed with cancer who receive chemotherapy as outpatients.

3.3 Study Population

For this study the population of interest was all patients diagnosed with either breast cancer or cervical cancer seeking chemotherapy treatment as outpatients at the cancer treatment center.

3.4 Sample Size Determination

3.4.1 Quantitative study

Table 3.1 below shows the number of patients with breast cancer and cervical cancer who received chemotherapy from October 2018 to January 2019.

<table>
<thead>
<tr>
<th>Cancer/Month</th>
<th>Oct 2018</th>
<th>Nov 2018</th>
<th>Dec 2018</th>
<th>Jan 2019</th>
<th>Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast cancer</td>
<td>206</td>
<td>177</td>
<td>107</td>
<td>112</td>
<td>151</td>
</tr>
<tr>
<td>Cervical cancer</td>
<td>165</td>
<td>116</td>
<td>82</td>
<td>99</td>
<td>116</td>
</tr>
<tr>
<td>Total</td>
<td>371</td>
<td>293</td>
<td>189</td>
<td>211</td>
<td>266</td>
</tr>
<tr>
<td>Average</td>
<td>186</td>
<td>147</td>
<td>94</td>
<td>106</td>
<td>133</td>
</tr>
</tbody>
</table>

Source: Cancer Treatment Centre Patients Chemotherapy Attendance Records.

Sample size determination was based on the average attendance of the patients diagnosed with breast cancer and cervical cancer who receive chemotherapy at the CTC per month, which is estimated as 266.
Sample size calculation was done using Fisher’s formula for estimating the minimum sample size that is the best representative of the population (Fisher’s et al., 1998) at 95% confidence interval

\[ n = \frac{Z^2pq}{d^2} \]

Where:

\( n \) = Sample size [where population is greater than 10,000]

\( Z \) = Standard deviation at the desired confidence interval. In this study it will be taken at 95%, \( Z \)-Value at 95\% is 1.96.

\( P \) = Proportion of the population with the desired characteristic. Put at 43.3\% based on the prevalence of breast and cervical cancer combined in Kenya (MOH-Kenya, 2012)

\( Q = 1 - p \) which will be 100\% - 43.3\% = 56.7\%

\( d \) = Degree of precision; will be taken to be 5\%

\[ n = \frac{Z^2P(1 - P)}{d^2} \]

Substituting figures in the above formula:

\[ n = \frac{(1.96)^2 (0.433) (0.567)}{(0.05)^2} = 377.24 \]

\[ n = 378 \]
Since the total number of patients with breast cancer and those with cervical cancer who receive treatment at Kenyatta hospital per year was less than 10,000 the sample size was adjusted using the Yamane formula (Yamane 1967)

\[ nf = \frac{n}{1 + \frac{n}{N}} \]

Where:

- \( nf \) = the desired sample size when population is less than 10,000
- \( n \) = the desired sample size when population is more than 10,000
- \( N \) = the study population

Hence

\[ nf = \frac{378}{1 + \frac{378}{266}} \]

\( nf = 156.13 \)

The calculated sample size was 157 participants

3.4.2 Qualitative study

The sample size was determined by data saturation which was observed after the second focus group discussion.

3.5 Sampling procedure

Systematic sampling procedure was used where every alternate participant was approached to participate. The researcher identified participants as they registered on arrival on the day of chemotherapy. The first patient to register was used as the starting point. The eligible
participants were approached and the purpose of the study was explained to them individually. Those who agreed to participate were asked to sign a consent form and a questionnaire was given to them and they were assisted to fill the questionnaires by the research assistants as they waited for their treatment to be prepared.

Purposive sampling technique was used to select participants for the qualitative data collection. This technique was used because the study population had similar experiences though they may have different characteristics. A nurse who was working in the cancer treatment center was requested to select participants for the group discussions. This is because the nurse had interacted with the participants longer and he was able to select participants with different characteristics found in the population which included breast and cervical cancer patients, age mixes, religion and those who could express themselves in Kiswahili or English.

Poor physical fitness due to cancer and its treatment might interfere with the participant attendance and over recruitment of up to 50% may be required (Tausch and Menold, 2016), therefore 20 participants were recruited with an aim of getting at least 6-8 participants on the day of the discussion. This group is small enough to allow for each participant to have 3-4 minutes to answer each question in a 90 minute session. 6 participants turned up for the first group discussion while six turned up for the second group discussion one was too sick to participate while a second one withdrew in the middle of the discussion.

The researcher used a clinical data checklist to obtain information on the specific cancer types, cancer stage, chemotherapy medication used and the number of sessions the participants had received.

### 3.6 Selection of participants

The following criteria were used to select participants for the study.
3.6.1 Inclusion criteria

All patients above 18 years diagnosed with breast or cervical cancer attending Cancer Treatment as outpatients for chemotherapy and who gave an informed consent and had received at least one previous chemotherapy session were eligible to participate.

3.6.2 Exclusion criteria

- Those patients who did not give consent
- Patients receiving the first cycle of chemotherapy because they had not experienced any effects of chemotherapy.
- Patients who were too sick to comprehend and respond to the questions

3.6.3 Focus group discussion participants.

These participants were recruited through purposive sampling method. The identified potential participants were then approached individually and informed of the purpose of the discussion. They were requested to participate in the focused group discussion and consent obtained. They were informed that the focus group discussion was to be conducted on a date when the participants were coming for their next chemotherapy session. Tausch and Menold, (2016) found that most participants for FGD prefer a date when they will be in the hospital for their normal clinic attendance. Participants attending chemotherapy session on the same day were therefore put in the same group. The participants were requested to provide their telephone contact which was used to send to them a confirmation of the date of the discussion and a reminder was sent to them a day before the scheduled date.
3.7 Data collection

3.7.1 The data collection tools

A self-administered questionnaire was used to collect quantitative data. The questionnaire consisted of open and closed ended questions. The questionnaire was organized into two sections; Section 1 consisted of the patients’ demographic data. Section 2 consisted of the symptoms experienced by the patients, using a modified Rotterdam Symptom Checklist (RSCL). RSCL was originally developed as a tool to measure symptoms experienced by cancer patients from diagnosis, through treatment and survivorship. Validity and reliability of the tool had been tested before use in many cancer related researches(Pelayo-Alvarez, Perez-Hoyos and Agra-Varela, 2013). The English version of the tool was used and translated into Kiswahili for the respondents who did not understand English and for the respondents who could not read English or Kiswahili the questionnaire were administered by the researcher and the assistants.

Qualitative data was collected during two focus group discussions during which a digital audio recorder was used. Each group discussion was recorded in one tape which was labeled. The moderator in the group discussion used a guide, which was prepared based on the study objectives, to keep the discussion on course.

A checklist was used to obtain data on patients’ cancer details including site of cancer, type of cancer, stage of cancer, specific drugs used for chemotherapy and chemotherapy sessions received.

3.7.2 Research assistants.

Two nurses working in CTC were recruited as research assistants. The assistants were trained on the content of the questionnaire and how to administer the questionnaire to the participants.
Two Masters of Science in nursing students who are familiar with qualitative research assisted the researcher during the focus group discussions.

3.7.3 Data collection procedure

3.7.3.1 Quantitative data

Quantitative data was collected for a period of four weeks during the two chemotherapy days per week. Data was collected during the working hours 8am to 5 pm on each chemotherapy day. The research assistants issued the questionnaires to the participants who consented to participate in the study and for the participants who could not read English or Kiswahili, the assistants interviewed them and filled in the questionnaires. The research assistants then collected the filled questionnaires from the participants and handed them over to the researcher for safe keeping awaiting data processing.

3.7.3.2 Qualitative data

Qualitative data was collected through two focus group discussions three weeks apart. The participants who gave consent to participate in the discussion, came on their next chemotherapy session date. The discussions were held in a room adjacent to the chemotherapy administration area which is familiar to the participants and close to the treatment area where the participants were not anxious about missing treatment. The discussions were held as the participants waited for their treatment to be prepared in the pharmacy preparation area. On the day of the discussion the researcher and the two assistants arrived early and prepared the room where the discussion was to be held. The seats were arranged in a circle where all the participants were able to see each other as they speak. The audio recorder was tested to make sure it was working before using it. A focus group discussion guide made by the principal researcher based on the objectives of
the study was used to guide the discussion. The guide focused on the three objectives of the study 1) the physical symptoms experienced by the patients. 2) Psychological effects of chemotherapy experienced by the patients and 3) how chemotherapy had affected the patients’ social life. The participants were also allowed to add any other information they felt was relevant to the discussion.

The first discussion lasted for 75 minutes and the second one lasted for 60 minutes. The moderator and one assistant took notes during the discussion while the other assistant was doing the recording. A mixture of English and Kiswahili was used during the discussion. The participants’ identities using pseudo names were placed on the table where the patients sat. The participants were welcomed as they arrived and shown to their seats. Soft drinks and snacks were provided as the participants went to take their seats. When all the participants had taken their seats the principal researcher introduced herself and the assistants and their role in the discussion. She informed them the purpose of the discussion asked the members to introduce themselves to each other. The members agreed to use pseudo names as opposed to identity numbers which had been suggested by the researcher. The ground rules were set and all participants were encouraged to participate freely. The assistant then put on the audio recorder and the participants were informed that the recording had started. The principal researcher moderated the discussion, took notes and clarified points which were not clear. All the participants were given an opportunity to answer each question before moving to the next question. Audio recording was continued until all the questions had been discussed. The participants also added some information which they thought was important to be included in the discussion. The audio recording was stopped and the participants were informed. The researcher thanked the participants and invited any of them who would like to listen to the tape played back
to be present. One participant from the second FGD listened to part of the tape as it was played back and confirmed that it reflected what was discussed. The audio recorder was replayed after each discussion to ensure that the discussion was recorded completely before keeping it together with the note books in a lockable cupboard. Data from the recorded tapes was analyzed at the end of the data collection day.

3.7.4 Pre testing

Pre testing of the study tool was done in clinic 23 where outpatients with cancer are seen and given treatment. Patients at the clinic had similar characteristics as those in the cancer treatment center. The test was administered on 16 patients which is 10% of the calculated sample size for the study. This was to test the study tool for validity and reliability. The questions which were found to be irrelevant were expunged from the questionnaire.

The FGD guide was discussed by a team of nurses (2 oncology nurses and one palliative care nurse) in the cancer treatment center before being used in the actual FGD. A pretest focus group discussion was carried out in clinic 23 to ensure reliability and validity of the tool. The room where the discussions were held was inspected beforehand on the day of the discussion and the audio recorder was tested if it was working well before the discussion. Adjustments to the study tool were done after pretesting.

3.8. Data processing

3.8.1. Quantitative data

Data cleaning and sorting was done at the end of every data collection day to ensure questionnaires were properly filled without gaps and that there were no gaps in the clinical data checklist. With the help of a statistician the data was analyzed using the SPSS software for
Descriptive statistics were presented in frequency tables, pie charts and bar graphs. Pearson’s correlation coefficient was used to test for relationships between the sociodemographic characteristics and the biological, psychological and sociological effects. P-value equal or less than 0.05 was considered significant.

Example of dummy frequency distribution table on the biologic symptoms experienced by patients

**Table 2: Dummy Frequency Table**

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Frequency (n)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nausea</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vomiting</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alopecia</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**3.8.2 Qualitative data**

Qualitative data findings were used to support the quantitative findings by providing an insight into the meanings attached to the patients experiences as expressed verbally by the participants.

Data collected was analyzed at the end of the data collection day; audio recorded data was transcribed verbatim and translated to English. Transcripts were checked for completeness and for accuracy together with the notes taken during the discussion which were used to counter check with the recorded tape whether the transcripts reflected the totality of the discussion. The transcribed data was analyzed manually and the responses identified matched with the objectives of the study. The two masters’ students who were involved in recording the discussion and the principal investigator analyzed the transcripts independently and then they discussed them at a data review meeting when they came up with a consensus on the findings.
3.8.2.1 Quality assurance

One participant listened to part of the tape as it was played back and confirmed that it reflected what was discussed in the group.

Credibility was ensured by the researcher being present during the entire discussion and taking notes in order not to miss any details of the discussion. Investigator triangulation was done by the researcher and the assistants analyzing the transcripts independently and then comparing the findings in a data review meeting where they came up with a consensus on the findings.

Transferability was ensured by describing the experiences and behaviors of the participants in context to allow for an outsider make a meaning out of it. Some expressions were quoted directly.

The process of qualitative research has been explained in detail at each step and the raw data as well as the analysis is saved for audit by anybody who may be interested in the study findings. This is to ensure dependability and confirmability.

3.9 Ethical consideration

Approval to carry out the study was obtained from KNH-UON Ethical and Research Committee (ERC). After approval the researcher obtained permission from the Chief Executive Officer KNH to carry out the study. Explanation to the participants on the purpose and the benefits of the study, confidentiality of the information obtained and the volunteer basis of the study was ensured before obtaining an informed consent from the participants. Participants were not coerced in any way and those who declined to participate did not suffer any negative consequences.
Participants were assured of confidentiality by anonymity, privacy during discussion and safe guarding of the study materials both in soft and hard copies which were kept under lock and key. Anonymity was maintained throughout the data collection process by ensuring that participants did not write their names on the questionnaire. Participants were identified using numbers during the focus group discussion.

The researcher assured the participants that the risks would be minimized and that the researcher would act promptly to assist if any form of emotional discomfort which might have been evoked by some of the questions would be experienced during the interview. No incident of emotional discomfort was observed throughout the data collection period.

Participants were also informed that there were no financial or other benefits to them for participating in the study but that the research would be used to improve on the care provided during the process of chemotherapy treatment.

3.10 Dissemination plan

An executive summary of the research report was sent to ERC. Copies of the report were sent to KNH resource center, UON School of Nursing Sciences and University of Nairobi libraries for future references. The researcher intends to publish the study findings in one of the peer reviewed nursing journals and also make presentations some relevant conferences.
CHAPTER FOUR: RESULTS.

4.1 Introduction

This section reports on the findings with regards to the study objectives. A total of 157 participants were interviewed and 100% response rate was achieved in that all the questionnaires given to the participants were returned. This achievement was possible because the questionnaires were mainly researcher administered. On the other hand 10 out the 20 participants who were purposively sampled for the focused group discussion turned up making it 50% response rate. These results are organized according to the study objectives. Descriptive statistics are presented in the form of tables, bar graphs and in narrative form. Inferential statistics are presented as narratives.

4.2. Socio Demographic characteristics of participants

Table 3 below shows the description of the socio-demographic characteristics of the participants. Many (31.2%) of the participants were aged between 41-50 years, majority (51.0%) of them were of the protestant faith, and most (66.9%) of them were married. Very few (22.9%) of the participants were in formal employment and the majority (73.2%) of the participants had a monthly income of below 20000kshs but majority (63.9) had stopped working. Many (35.8%) participants had 2-5 children and they got their social support mainly from their husbands (45.9%), with a small percentage supported by their family members (17.2%), community (1.9%) and the church supports 1.9%. Most (87.9%) of the participants had enrolled into the National Hospital Insurance Fund which pays part of their treatment expenses. Majority (75.8%) of the participants had attended at least two chemotherapy sessions and in the course of treatment 33.1% of the participants had contemplated stopping treatment.
<table>
<thead>
<tr>
<th>Variable</th>
<th>Category</th>
<th>Frequency (n)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age in years n=157</td>
<td>&lt;20</td>
<td>1</td>
<td>0.6</td>
</tr>
<tr>
<td></td>
<td>21-30</td>
<td>13</td>
<td>8.3</td>
</tr>
<tr>
<td></td>
<td>31-40</td>
<td>46</td>
<td>29.3</td>
</tr>
<tr>
<td></td>
<td>41-50</td>
<td>49</td>
<td>31.2</td>
</tr>
<tr>
<td></td>
<td>51-60</td>
<td>30</td>
<td>19.1</td>
</tr>
<tr>
<td></td>
<td>&gt;60</td>
<td>18</td>
<td>11.5</td>
</tr>
<tr>
<td>Religion n=157</td>
<td>Protestant</td>
<td>80</td>
<td>51.0</td>
</tr>
<tr>
<td></td>
<td>Catholic</td>
<td>55</td>
<td>35.0</td>
</tr>
<tr>
<td></td>
<td>Muslim</td>
<td>19</td>
<td>12.1</td>
</tr>
<tr>
<td></td>
<td>Others</td>
<td>3</td>
<td>1.9</td>
</tr>
<tr>
<td>Marital status n=157</td>
<td>Single</td>
<td>19</td>
<td>12.1</td>
</tr>
<tr>
<td></td>
<td>Married</td>
<td>105</td>
<td>66.9</td>
</tr>
<tr>
<td></td>
<td>Divorced</td>
<td>16</td>
<td>10.2</td>
</tr>
<tr>
<td></td>
<td>Widowed</td>
<td>17</td>
<td>10.8</td>
</tr>
<tr>
<td>Occupation n=157</td>
<td>Business</td>
<td>57</td>
<td>36.3</td>
</tr>
<tr>
<td></td>
<td>Farmer</td>
<td>64</td>
<td>40.8</td>
</tr>
<tr>
<td></td>
<td>Employed</td>
<td>36</td>
<td>22.9</td>
</tr>
<tr>
<td>Monthly income In kshs n=157</td>
<td>&lt;20000</td>
<td>115</td>
<td>73.2</td>
</tr>
<tr>
<td></td>
<td>20000-40000</td>
<td>32</td>
<td>20.4</td>
</tr>
<tr>
<td></td>
<td>40000-60000</td>
<td>7</td>
<td>4.5</td>
</tr>
<tr>
<td></td>
<td>&gt;60000</td>
<td>3</td>
<td>1.9</td>
</tr>
<tr>
<td>Currently working N=157</td>
<td>Yes</td>
<td>58</td>
<td>36.1</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>99</td>
<td>63.9</td>
</tr>
<tr>
<td>Number of children n=157</td>
<td>None</td>
<td>8</td>
<td>5.1</td>
</tr>
<tr>
<td></td>
<td>One child</td>
<td>53</td>
<td>33.0</td>
</tr>
<tr>
<td></td>
<td>2-5 children</td>
<td>55</td>
<td>35.8</td>
</tr>
<tr>
<td></td>
<td>&gt;5 children</td>
<td>41</td>
<td>26.1</td>
</tr>
<tr>
<td>Source of Social support n=157</td>
<td>Husband</td>
<td>72</td>
<td>45.9</td>
</tr>
<tr>
<td></td>
<td>Children</td>
<td>52</td>
<td>33.1</td>
</tr>
<tr>
<td></td>
<td>Family members</td>
<td>27</td>
<td>17.2</td>
</tr>
<tr>
<td></td>
<td>Community</td>
<td>3</td>
<td>1.9</td>
</tr>
<tr>
<td></td>
<td>Church</td>
<td>3</td>
<td>1.9</td>
</tr>
<tr>
<td>NHIF availability n=157</td>
<td>Yes</td>
<td>138</td>
<td>87.9</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>19</td>
<td>12.1</td>
</tr>
<tr>
<td>Previous chemotherapy sessions n=157</td>
<td>One</td>
<td>38</td>
<td>24.2</td>
</tr>
<tr>
<td></td>
<td>Two</td>
<td>51</td>
<td>32.5</td>
</tr>
<tr>
<td></td>
<td>Three</td>
<td>30</td>
<td>19.1</td>
</tr>
<tr>
<td></td>
<td>&gt;Three</td>
<td>38</td>
<td>24.2</td>
</tr>
<tr>
<td>Contemplated stoppage of treatment</td>
<td>Yes</td>
<td>52</td>
<td>33.1</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>105</td>
<td>66.9</td>
</tr>
</tbody>
</table>
Among the participants who had contemplated stoppage of treatment, majority (53.2%) cited lack of finance as the reason that made them think of stopping treatment. These results are presented in figure 3 below.

![Reasons for stopping treatment](image)

**Figure 3: Reasons for participants contemplating stoppage of treatment**

4.3. Socio demographic characteristics of focus group discussion participants

A total of 10 participants formed the two focus group discussions (FGD). Those participants were identified using numbers and their details are shown in table 4 below.
**Table 4: Socio-demographic characteristics of FGD participants.**

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age in years</th>
<th>Gender</th>
<th>Marital status</th>
<th>Occupation</th>
<th>Type of cancer</th>
<th>Previous chemo session</th>
</tr>
</thead>
<tbody>
<tr>
<td>PPT1</td>
<td>41</td>
<td>Female</td>
<td>Married</td>
<td>Business</td>
<td>Breast</td>
<td>2</td>
</tr>
<tr>
<td>PPT2</td>
<td>70</td>
<td>Female</td>
<td>Widow</td>
<td>Farmer</td>
<td>Breast</td>
<td>5</td>
</tr>
<tr>
<td>PPT3</td>
<td>60</td>
<td>Female</td>
<td>Married</td>
<td>Retired teacher</td>
<td>Breast</td>
<td>3</td>
</tr>
<tr>
<td>PPT4</td>
<td>54</td>
<td>Female</td>
<td>Married</td>
<td>Clerk</td>
<td>Cervical</td>
<td>3</td>
</tr>
<tr>
<td>PPT5</td>
<td>45</td>
<td>Female</td>
<td>Married</td>
<td>Business</td>
<td>Breast</td>
<td>4</td>
</tr>
<tr>
<td>PPT6</td>
<td>29</td>
<td>Female</td>
<td>Single</td>
<td>Receptionist</td>
<td>Breast</td>
<td>6</td>
</tr>
<tr>
<td>PPT7</td>
<td>39</td>
<td>Female</td>
<td>Married</td>
<td>Business</td>
<td>Cervical</td>
<td>2</td>
</tr>
<tr>
<td>PPT8</td>
<td>35</td>
<td>Female</td>
<td>Married</td>
<td>Farmer</td>
<td>Breast</td>
<td>3</td>
</tr>
<tr>
<td>PPT9</td>
<td>27</td>
<td>Female</td>
<td>Separated</td>
<td>Hairdresser</td>
<td>Cervical</td>
<td>4</td>
</tr>
<tr>
<td>PPT10</td>
<td>54</td>
<td>Female</td>
<td>Married</td>
<td>Farmer</td>
<td>Breast</td>
<td>2</td>
</tr>
</tbody>
</table>

**4.4 Sources of information on diagnosis, treatment benefits and side effects**

Participants received information about their cancer diagnosis in the last 1-6 months (46.5%), 6-12 months (24%) and only 3.8% had received the information in the last one month. The majority (45.9%) of the participants received information on their treatment from the doctor and those who received information from the nurse were 35.7%. Information on treatment included benefits of chemotherapy where slightly more than half (52.2%) of the participants said they had received this information. Regarding information on the side effects of chemotherapy 59.9% said they were given this information. These results are shown in table 5 below.
**Table 5: Source of information on diagnosis, treatment and side effects**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Category</th>
<th>Frequency (n)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time since diagnosis of cancer(months)</td>
<td>&lt;1</td>
<td>6</td>
<td>3.8</td>
</tr>
<tr>
<td></td>
<td>1-6</td>
<td>73</td>
<td>46.5</td>
</tr>
<tr>
<td></td>
<td>6-12</td>
<td>38</td>
<td>24.2</td>
</tr>
<tr>
<td></td>
<td>&gt;12</td>
<td>40</td>
<td>25.5</td>
</tr>
<tr>
<td>Information on benefits of chemotherapy</td>
<td>Yes</td>
<td>75</td>
<td>47.8</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>82</td>
<td>52.2</td>
</tr>
<tr>
<td>Information on side effects of chemotherapy</td>
<td>Yes</td>
<td>94</td>
<td>59.9</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>63</td>
<td>40.1</td>
</tr>
<tr>
<td>Informant</td>
<td>Nurse</td>
<td>56</td>
<td>35.7</td>
</tr>
<tr>
<td></td>
<td>Doctor</td>
<td>72</td>
<td>45.9</td>
</tr>
<tr>
<td></td>
<td>Trained counselor</td>
<td>18</td>
<td>11.5</td>
</tr>
<tr>
<td></td>
<td>Relative</td>
<td>7</td>
<td>4.5</td>
</tr>
<tr>
<td></td>
<td>Others</td>
<td>4</td>
<td>2.5</td>
</tr>
</tbody>
</table>

**4.5 Characteristics and patterns of cancer diagnosis among participants**

Half (50.3%) of the participants were diagnosed with cervical cancer and 49.7% had breast cancer. Of the cancers, 87.9% of those with breast cancer had invasive ductal carcinoma while for those with cervical cancer majority (82.2%) had squamous cell carcinoma. Approximately 50% of the participants presented for diagnosis at stage three as shown in table 6 below.
Table 6: Characteristics and patterns of cancer diagnosis among participants

<table>
<thead>
<tr>
<th>Variable</th>
<th>Category</th>
<th>Frequency(n)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Site of cancer</td>
<td>Breast</td>
<td>78</td>
<td>49.7</td>
</tr>
<tr>
<td></td>
<td>Cervical</td>
<td>79</td>
<td>50.3</td>
</tr>
<tr>
<td>Type of cancer</td>
<td>Breast N=78</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Invasive ductal carcinoma</td>
<td>70</td>
<td>89.7</td>
</tr>
<tr>
<td></td>
<td>Lobular carcinoma</td>
<td>8</td>
<td>10.3</td>
</tr>
<tr>
<td></td>
<td>Cervical N=79</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Squamous cell carcinoma</td>
<td>65</td>
<td>82.2</td>
</tr>
<tr>
<td></td>
<td>Adeno carcinoma</td>
<td>14</td>
<td>17.8</td>
</tr>
<tr>
<td>Stage</td>
<td>One</td>
<td>2</td>
<td>1.3</td>
</tr>
<tr>
<td></td>
<td>Two</td>
<td>43</td>
<td>27.4</td>
</tr>
<tr>
<td></td>
<td>Three</td>
<td>78</td>
<td>49.7</td>
</tr>
<tr>
<td></td>
<td>Four</td>
<td>34</td>
<td>21.7</td>
</tr>
</tbody>
</table>

4.6. Chemotherapy drugs used for the treatment of breast and cervical cancer

Cisplatin (44.6%) was the most commonly used chemotherapeutic agent for the treatment of both breast and cervical cancer followed by paclitaxel (41.8%). The aromatase inhibitor, anastrazole was the least commonly used chemotherapeutic agent and was used by 3.2% of the patients as indicated in figure 4 below.

Figure 4: Chemotherapy agents in treatment of breast and cervical cancer
4.7. Effects of chemotherapy

4.7.1. Biological effects of chemotherapy

Most of the participants with breast or cervical cancer complained of having experienced anorexia (90.4%), nausea (88.5%), alopecia (79%), vomiting (76.4%) and skin color changes (67.5%) as shown in Table 7 below.

Further analysis with Pearson’s correlation test revealed that aged patients were more likely to experience biological effects of chemotherapy ($r=0.270$). Further analysis showed that the patients who had advanced into the treatment as indicated by the chemotherapy sessions they had attended were less likely to experience biological effects ($r=-0.253$) and the longer the time since diagnosis the less likely they were to experience biological effects ($r=-0.156$).

Table 7: Biological effects of cancer chemotherapy

<table>
<thead>
<tr>
<th>Biological Effects</th>
<th>Frequency (n)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nausea</td>
<td>139</td>
<td>88.5</td>
</tr>
<tr>
<td>Vomiting</td>
<td>120</td>
<td>76.4</td>
</tr>
<tr>
<td>Fatigue</td>
<td>105</td>
<td>66.9</td>
</tr>
<tr>
<td>Anorexia</td>
<td>142</td>
<td>90.4</td>
</tr>
<tr>
<td>Alopecia</td>
<td>124</td>
<td>79</td>
</tr>
<tr>
<td>Skin color change</td>
<td>106</td>
<td>67.5</td>
</tr>
<tr>
<td>Peripheral neuropathy</td>
<td>97</td>
<td>61.8</td>
</tr>
<tr>
<td>Diarrhea</td>
<td>61</td>
<td>38.9</td>
</tr>
<tr>
<td>Weight loss</td>
<td>90</td>
<td>57.3</td>
</tr>
<tr>
<td>Mucositis</td>
<td>69</td>
<td>43.9</td>
</tr>
<tr>
<td>Neutropenia</td>
<td>77</td>
<td>49</td>
</tr>
</tbody>
</table>

These results on the effects of chemotherapy were supported by messages shared during FGD as quoted below,

“When I was given chemo I felt very bad. I started vomiting a lot and even when the chemo is finished I continue vomiting. Chemo is very bad for me, I cannot eat anything because of nausea and vomiting. The vomiting stops after three days but not completely.”
When I think about chemo I just start vomiting so I do not talk about it. But when I reach almost going back for chemo I start having the nausea again. When I enter the chemo room I start vomiting even before I have the branula put…” (PPT6)

“I have lost a lot of weight and I do not like the way I look at all. I have changed a lot since I started being given the medicine. I have become black yet I used to be brown. These medicines have very bad side effects. I know if I had stayed with my illness without medicine I would not have reached where I am I would have been better. I don’t have hair now, I cannot eat well, I cannot enjoy my food even chicken which I liked to eat. Nausea all the time. No appetite. Food smells very bad. I don’t even want to talk about it. Without eating you even have no energy to do things. You are tired all the time. I keep sending my children to do for me things and I feel very bad about it…” (PPT7)

4.7.2. Psychological effects of chemotherapy

The most common psychological effect experienced by the participants was anxiety (79%) followed by dissatisfaction with body image (65.6%) and low self-esteem (63.1%). Loss of hope was the least experienced psychological symptom. These findings are shown in figure 5 below

Further analysis with Pearson’s correlation test showed that married women were likely to suffer fewer psychological effects(r= -0.389). The same test also showed that as the patients advanced into the treatment trajectory they were more likely to experience psychological effects(r= 0.51). Additionally aged patients were less likely to suffer psychological effects(r= -0.300)
Figure 5: Psychological effects experienced by patients on chemotherapy

These results are supported by findings from the FGD where anxiety, fear of death and low self-esteem were identified as the most disturbing psychological effects of chemotherapy as stated in participants expressions quoted below,

“When you hear a person with cancer has died you start getting worried that you are also going to die...” (PPT2)

“...I do not like the way I look. I cannot wear any dress or trouser and look good. My face is thin and ugly. My hands, nails oooh! ... I feel very sad because of the way I look. I cannot even go in front of people I have no confidence to stand before them. My friends do not want to associate with me because I am no longer presentable...” (PPT6)

All the participants said they derive their strength from believing in God and they have hope of getting better.
4.7.3. Sociological effects of chemotherapy

Majority (85.5%) of the participants were not able to perform their roles in the family. Of the respondents 82.2% experienced financial constraints and were not able to pay for their hospital bills while 76.4% experienced loss of libido. Marital tension was reported as the least (21%) experienced sociological effect as shown in figure 6 below.

Further analysis showed that participants with low monthly income were very likely to suffer sociological effects ($r = -0.480$). As the patients receive more treatment they are more likely to experience sociological effects ($r = 0.361$).

![Figure 6: Sociological effects experienced by patients receiving chemotherapy](image)

These findings were supported by messages from focus group discussion as stated below

“…In the family you are isolated because everyone sees that you are spending so much. You will see the husband start pulling away and the rest feel that you are tiring them. You feel you are being isolated because you are spending a lot of the family income. Other family needs are not being met because you are using so much (PPT 5)
“...For me I lost my friends since they knew I have this disease. Up to now I do not have friends. My friends are my children and those who help me are my siblings and my husband. (PPT3) Even no neighbor who would come to check on me even when they have not seen me out for a week to find out how I am doing there is nothing like that. Only when they see me outside is when they greet me and finish like that.” (PPT2)
CHAPTER 5: DISCUSSION AND LIMITATIONS

5.1 DISCUSSION

5.1.1 Introduction

Chemotherapy as one of the major treatment modalities for cancer is associated with many side effects which affect the patients psychologically and also leads to many social challenges. This study was looking for the biological, psychological and sociological effects of chemotherapy which are experienced by the patients who are treated as outpatient in KNH CTC. It also sought to find out if there is a relationship between the patients’ social demographic characteristics and the biological, psychological as well as sociological effects.

5.1.2 Socio-demographic factors

Majority (31.2%) of the participants recruited for this study were middle aged with the highest percentage ranging between 41-50 years. This age distribution is attributed to the fact that the two cancers are commonest in the reproductive age group when the female hormones are most active. This finding is similar to a study in India where the highest incidence of the two cancers was found to be among middle aged patients (Takiar, 2018). Similar findings were also observed by Huang et al., (2017) who found that the average age at diagnosis for breast cancer was 48.89+/8.53 while that of cervical cancer was 49.0+/10.30 years.

Married patients derive their social support from their spouses (45.9%) as shown in the study findings and this reduces the likelihood of them experiencing psychological symptoms during treatment with chemotherapy. Social support assists the patient to choose positive coping mechanisms and reduces the likelihood of experiencing emotional stress. This findings are similar to those of Kim et al., (2010) who found that the more and better social support one has,
the higher the chance the patient has for improving her psychological well-being by having a higher likelihood of selecting active coping strategies, having more confidence, and more control over her situation.

Majority (98%) of the participants subscribed to a religion and expressed that they believed in God and had faith and hope that they would get better and this could also be seen from the low percentage of responses about loss of hope. This findings are similar to those of a Latin American study by Mesquita et al., (2010) on religious and spiritual coping among patients receiving chemotherapy who found that religion/spirituality was an important way of coping with cancer and its treatment. This belief they hold on a Supreme Being makes them to continue taking the treatment despite the many side effects and other chemotherapy associated challenges.

5.1.3 Chemotherapy agents used for the treatment of breast and cervical cancer

In this study, the most commonly used agent for the treatment of cancer of the breast and that of the cervix was cisplatin (44.6%). Cisplatin is a platinum compound used as a combination with paclitaxel for the treatment of cervical cancer. It has also been found to be effective as a single agent for the treatment of advanced cervical cancer when radiation is used simultaneously (Gupta, 2019). Carboplatin and paclitaxel were also very frequently used for the treatment of the two cancers. Carboplatin was used with paclitaxel for the treatment of cervical cancer in a Japanese study where they found that the efficacy of combining carboplatin and paclitaxel was high (Gupta, 2019). Kenyatta hospital could have adopted this combination based on its efficacy in order to provide maximum benefit for the patients who are also financially constrained.
5.1.4 Biological, effects of cancer chemotherapy

The most common side effects experienced by the study participants included anorexia (90.4%), nausea (88.5%) and vomiting (76.4%) in that order. This is despite the patients having been given antiemetic medicines before the administration of the chemotherapeutic agents. Participants felt that these symptoms were very distressing because they interfered with their feeding. These findings concur with those of a study in Gifu by Tachi et al., (2015) who found that inability to feed due to anorexia made patients conscious of their own illness. Similarly, Huang et al., (2017) in Taiwan found that patients receiving chemotherapy experienced anorexia, nausea and vomiting despite prior administration of anti-emetic medication.

Most (79%) participants reported that they had experienced Alopecia which is a common side effect of cytotoxic agents as these target destruction of fast growing body cells of which hair is among them. Similar to Chan and Ismail, (2014) findings from a Malaysian general hospital which showed that 50% of the participants reported alopecia as one of the symptoms they had experienced. Another study among breast cancer patients in South Korea also reported that hair loss was the most disturbing chemotherapy side effect and that it was associated with psychological effects like anxiety and depression as well as sociological effects including stigma and isolation (Suwankhong and Liamputtong, 2018).

Peripheral neuropathy which was described by women as numbness of the hands and feet was expressed as a disturbing side effect which also interferes with the activities of daily living. Similar findings were expressed by participants in two studies (Greenwald et al., 2019; Simon et al., 2017) but Tanay et al., (2017) thought it was not a significant symptom. But any symptom which affects the daily living of a patient is significant and clinicians should be aware of these
side effect associated with paclitaxel, a commonly used taxane in the management of breast and cervical cancer in KNH.

Older patients were more likely to experience biological effects as indicated by \( r=0.270 \), most probably due to the reduction in the physiological function associated with aging. This reduces the clearance of the drugs from the body and the body cells are exposed to drug toxicity for a longer time. Older patients may also be having other comorbidities and resultant polypharmacy which affects the pharmacological function of the chemotherapy. Similar findings were observed from a study in USA which found that older patients experienced chemotherapy side effects due to reduced physiological function and they were noted to have comorbidities like cardiovascular diseases. (Muss, 2010)

### 5.1.5 Psychological effects of cancer chemotherapy

The findings of this study showed that chemotherapy side effects can lead to psychological problems which affect the patient’s activities of daily living. Loss of hair together with skin color changes and loss of weight experienced by participants led to a disturbed body image and low self-esteem especially among the younger participants as described in the FGD. This is because the younger participants were more concerned with body image and a sense of femininity which was reduced by alopecia and loss of weight. Participants in the focus group discussion also stated that they had experienced anxiety and fear of dying from the cancer or from the treatment. Ahmad et al., (2016) also noted that the biological effects experienced by cancer patients during chemotherapy were associated with psychological effects to include; fear of chemotherapy, grief related to loss of self-identity, depression, low self-esteem and fear of dying from the disease or its treatment.
In this study, self-projection was expressed by participants in the FGD where they said they did not tell people about their disease because they thought it was a “devil” in their life while others thought God had purposed for them to suffer like that. Self-projection is a negative way of coping with stress which will require for the nurses and other health care staffs to be aware and develop ways of helping the patients cope with stress positively. These findings concur with the findings of Huang et al., (2017) who reported that patients isolated themselves so that nobody gets hurt by them or wanting to bear the “punishment alone”, which is an unhealthy way of dealing with emotions. Similarly a study in South Africa reported that other patients just go through the side effects quietly without communicating to anyone because they thought it was their destiny and feared asking for help from their relatives (Nies et al., 2018)

Loss of concentration (42%) and loss of memory (45.9%) were cognitive side effects associated with chemotherapy for breast cancer and cervical cancer observed in this study. These side effects were reported during the FGD by participants who had received more than three chemotherapy sessions implying that these effects could be as a result of a cumulative effect of the cytotoxic drugs over time. This is consistent with findings of Philip et al., (2013) in their meta-analysis of studies which confirmed that many patients who were receiving chemotherapy complained of cognitive impairment approximately three months into their treatment and after treatment.

5.1.6 Sociological effects of cancer chemotherapy

Owing to the many challenges which patients receiving treatment for breast and cervical cancer go through, they need social support from family and friends. Findings from this study show that the women received support from their husbands (45.9%), their children (33.1%) and from other family members (17.2%). Social support especially from close family members is essential for
the patient’s psychological adaptation to physical illness and a higher perception of social support encourages the patients to have a fighting spirit which reduces hopelessness. A longitudinal study in Australia among breast cancer patients reported similar findings (Leung, Pachana and McLaughlin, 2014). Therefore it is important for those patients without support to be identified and guided to the available social support resources in the community.

Chemotherapy treatment for breast and cervical cancer is expensive and despite the participants having enrolled and actively using NHIF they were still required to pay part of their treatment expenses. The participants were mainly from the low income group earning below 20000kshs (73.2%) from their business or farming. Even those who were employed were in jobs where they earned less than 20000kshs. Most (63.9%) of the participants had also stopped working reducing the family total monthly income and financial constraint was a reality for them. The problem of cost of treatment is not unique to Kenyan patients only, in America the per-person cost of treatment is 4 times as expensive compared to the other modes of treatment. This means that even for the patients who have health insurance they still have to top up to meet the cost of treatment as stated by Carrera, Kantarjian and Blinder, (2018) from their study in America.

In the Kenyan society women are expected to take care of their families i.e. husband, children and the elderly parents. Most (88.5%) of the participants said they were not able to perform these roles due to the treatment and they had lost this identity. The society now perceives them as “incomplete women”. Some of the women were working to contribute to the family’s income but due to the treatment they were not able to cope with that role anymore and they had acquired a new “dependent” role as stated by participants in the FGD. This findings are similar to those of previous studies which showed that during chemotherapy, patients had to give up their customary ascribed roles and duties within the family, at work or in relation to their friends.
because they were no longer able to cope with those demands and therefore had a loss of role identity (Masika et al., 2012; Wampaalu et al., 2016; Suwankhong and Liamputtong, 2018).

Cytotoxic agents lead to decreased sexual interest in women on treatment for breast and cervical cancer as indicated by Ussher in their study in Australia (Ussher et al., 2015) and a study at a university hospital in Turkey, whose findings indicated that younger patients less than 45 years old had problems with sexual desire and activity (Kırca and Kutlutürkan, 2018). In the current study, discussion showed that sexuality was a concern especially among the young participants but the older ones did not want to discuss this issue probably because in the African culture, women do not discuss sexual issues in public. This also translates into the hospital setting where patients will not disclose their sexuality problems even though they exist unless provided with privacy. Similar findings were reported in Morocco where women with breast cancer who were receiving treatment disclosed through anonymous questionnaires that they had not disclosed their sexuality related problems to the physician though the problems actually existed (Sbitti et al., 2011). Therefore Health care providers should be sensitive and provide privacy where the patients can share their private information.

5.1.7 Relationship between socio-demographic and treatment factors and biological, psychological and sociological effects.

In this study statistical analysis showed that as the participants advanced into the treatment trajectory they were likely to experience more psychological \((r=0.510)\) and sociological \((r=0.361)\) challenges than biological \((r=-0.253)\) challenges. Similar findings were observed by Patricia from her study among breast cancer patients (Patricia A. Ganz, 2008). This may not necessarily mean that the biological effects become nonexistent but it could mean that the patients could have learnt to cope with some of the biological effects and that the effects are also more
responsive to some of the other drugs used to reduce their occurrence. On the other hand as the patients advance into treatment they start experiencing more psychological effects like anxiety about the effects of their illness on their family, fear of treatment outcomes, body image changes and low self-esteem. They also experience financial constrains from the expensive treatment and they are unable to work to contribute to the family income. They then experience isolation from their family and friends. These findings are an important insight to consider possible improvements to the accompanying therapies as well as providing stronger psychological and social support to the patients as they advance into the treatment.

5.2. LIMITATIONS OF THE STUDY

The study was conducted in one public institution and the results cannot be generalized for all Kenyan patients diagnosed with breast and cervical cancer who receive chemotherapy.

There were no tests which were carried out to determine some of the biological effects but the study relied on symptoms expressed by the patients.
CHAPTER 6: CONCLUSION AND RECOMMENDATIONS

6.1. CONCLUSION

Based on the findings of this study the researcher draws the following conclusions:

1. Patients diagnosed with breast and cervical cancer who receive chemotherapy at KNH experience biological effects which include anorexia, nausea and vomiting which are distressing at the beginning of treatment. Alopecia, fatigue and peripheral neuropathy appear latter in the treatment period.

2. The patients also experience psychological effects some of which are as a result of the biological effects experienced by the patients. Some of the psychological effects include anxiety, low self-esteem, amnesia and dissatisfaction with body image.

3. Patients diagnosed with breast and cervical cancer receiving chemotherapy at KNH CTC experience various biological, psychological and sociological effects which are intertwined and influence each other making it necessary for them to be treated together.

4. Sociological effects are experienced by the patients most of which develop latter as the patients receive more chemotherapy sessions. The most distressing sociological effects are financial constraint and loss of role identity as well as social isolation.

5. Biological effects are more distressing at the beginning of treatment, while psychological and sociological effects become more important as treatment advances.
6.2. RECOMMENDATIONS

1. The health care personnel at KNH CTC should use the results of this study to teach the patients on what to expect during chemotherapy.

2. Doctors and nurses should use the findings of this study as a guide during patient assessment before every chemotherapy session.

3. Kenyatta Hospital should develop and implement a biopsychosocial model of care which will involve multidisciplinary teams in order to address the biological, psychological and sociological effects of chemotherapy experienced by the patients.

4. The results of this study should be available at the national cancer registry for reference by the policy makers as well as future researchers.

5. This research was carried out in the country’s referral hospital which is a public institution. It is recommended that further research to be carried out on the topic involving more institutions, both public and private.
REFERENCES


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Philip, E. J. *et al.* (2013) ‘Depression and cancer survivorship: importance of coping self-


APPENDICES

Appendix i: Informed consent form for patients

Title of the study: Biopsychosocial effects of cancer chemotherapy among adult female patients diagnosed with breast and cervical cancer attending Kenyatta National Hospital Cancer Treatment Centre.

Researcher: Anastacia Moraa Bosire, Master of Science in oncology nursing student year two.

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

Introduction

I am a student at the School of Nursing Sciences, University of Nairobi pursuing a Master of Science Degree in Nursing- oncology specialty. I am conducting a study titled: Biopsychosocial effects of cancer chemotherapy among adult female patients diagnosed with breast and cervical cancer attending Kenyatta National Hospital Cancer Treatment Centre.

This study will be conducted at Kenyatta National Hospital Cancer Treatment Center.

This study will be looking to determine the biopsychosocial effects of cancer chemotherapy among patients diagnosed with breast and cervical cancer. To achieve this, the study will look at the, chemotherapy side effects, psychological effects and social effects associated with chemotherapy in cancer patients. This research will ultimately help in improving management of outpatients receiving chemotherapy.

The purpose of this information is to give you details pertaining to the study that will enable you make an informed decision regarding participation. You are free to ask questions to clarify any of the aspects we will discuss in this information and consent form. I will also ask you questions
regarding the study before you sign the consent form to ascertain your understanding of the information provided.

**Purpose of the study**

This study will determine the effects of chemotherapy among patients diagnosed with breast and cervical cancer. Identifying the side effects and the psychological and social effects of chemotherapy among patients is very important as it will contribute to improvement in care for patients receiving chemotherapy as outpatients.

**Risks**

There will be no economic or physical risks to participating in the study. However, you will take some time off your schedule to respond to questions from the self-administered questionnaire. Some questions will require you to disclose some personal information that might trigger some negative feelings and possibly anxiety. If this happens, the researcher will refer you to the hospital counselor for you to have counseling from the hospital counselor on duty without any extra cost. This will not affect your subsequent clinic visits.

**Benefits:**

There is no direct monetary benefit in participating in this study. However, the results of the study will be useful in facilitating the understanding of the various effects of cancer chemotherapy and the results will also be used by stakeholders in preventing and improving the patients’ experience of the effects and the management of the effects when they occur.

**Confidentiality:**

Confidentiality will be maintained and the information you provide will only be used for the intended purpose of the study. In addition, your name will not be required on any forms or used
during publication of the final report thus ensuring your anonymity. All materials used during this study will be kept in a locked cupboard and only the personnel involved in this study will have access to them. Electronic files will be saved on password and fire-wall protected computers.

Voluntary participation:

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

Compensation:

There is no compensation, monetary or otherwise, for participating in the study.

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

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: Anastacia Moraa Bosire
   Phone No. +254722616169
   Email: annebosi2015@gmail.com
   Physical Address: School of Nursing Sciences
   University of Nairobi, College of Health Sciences
   Kenyatta National Hospital Campus

2. **Supervisors**
   1. Name: Dr. Irene Mageto (BScN, MScN, PhD)
      Phone No. +254 724205419
      Email: igmageto@gmail.com
      Physical Address: School of Nursing Sciences
      University of Nairobi, College of Health Sciences
      Kenyatta National Hospital Campus
   2. Name: Dr. Samuel Kimani (BScN, MScN, PhD)
      Phone No. +254722384917
      Email: tkimani@uonbi.ac.ke
      Physical Address: School of Nursing Sciences
      University of Nairobi, College of Health Sciences
      Kenyatta National Hospital Campus

3. **Ethics Committee**
   Prof. M.L. Chindia,
   The Secretary,
   KNH/UON Ethics and Research Committee
   Tel No. +254 726300-9
   Email: uonknh_erc@uonbi.ac.ke
Appendix ii: Ruhusa ya ridhaa kwa wagonjwa

Mada ya utafiti: Utafiti juu ya matokeo/dalili ya mwili, kiakili na kimaisha yanayohusishwa na dawa ya Kansa miongoni mwa wagonjwa wa saratani ya matiti na ya kizazi wanaohudhuria matibabu ya saratani katika hospitali Kuu ya Taifa ya Kenyatta

Mtafiti: Anastacia Moraa Bosire, mwanafunzi wa mwaka wa pili, shahada ya uzamili katika uuguzi wa saratani

Taasisi ya utafiti: Chuo kikuu cha Nairobi P.O Box 30197-00400 Nairobi.

Utangulizi

Mimi ni mwanafunzi katika chuo kikuu cha Nairobi. Nasomea shahada ya uzamili katika uuguzi wa ugonjwa wa saratani. Ninafanya utafiti kuhusu matokeo ya dawa za kutibu saratani kwa mwili wa mgonjwa anayezitumia na pia kama kuna madhara ya kiakili na kimaisha. Utafiti huu unafanyika katika hospitali kuu ya Kenyatta kati ya wagonjwa wa saratani ya matiti naya kizazi ambao wanakuja kwa matibabu na kurudi nyumbani baada ya matibabu. Lengo kuu la utafiti huu ni kutafuta jinsi ya kuboresha huduma wanayoipata wagonjwa wa saratani wakati wanatumia dawa hizo za saratani.

Kusudi la habari hii ni kukupa maelezo kuhusu utafiti ambayo itakuwezesha kufanya uamuzi sahihi juu ya kushiriki. Wewe una uhuru kuuliza maswali ili kufafanua mambo yoyote tutakayojadili katika habari hii na fomu ya ridhaa. Mimi pia nitakuuliza maswali kuhusu utafiti kabla ya kutia sahihi fomu ya ridhaa ili kuhakikisha kama umeelewa habari iliyotolewa.
Kusudi la utafiti

Utafiti huu utaamua athari ya dawa katika wagonjwa wa saratani. Kutambua athari hizo na masuala ya kisaikolojia na kijamii ya dawa za saratani kati ya wagonjwa ni muhimu sana kwani itasaidia kuboresha huduma wanaopata wagonjwa.

Hatari

Hakutakuwa na hatari ya kiuchumi au kimwili ya kushiriki katika utafiti. Hata hivyo, utachukua muda kidogo mbali na ratiba yako ili kujibu maswali kutoka kwa dodoso iliyosimamiwa. Maswali mengine yatakuhitaji kufichua taarifa za kibinafsi ambazo zinaweza kusababisha hisisazenye hasi wa uwezekano wa wasiwasi. Ikiwa hii itatokea, mtafiti atakupeleka kwa mshauri wa hospitali ambaye anahusika na wagonjwa wenye kansa ambaye anapatikana katika wodi ya GFD. Msaidizi wa mtafiti atakuelekeza kwa mshauri. Ushauri hautakuwa na malipo na hautatatiza matibabu yako kwa njia yeyote.

Faida:

Hakuna faida ya moja kwa moja ya fedha katika kushiriki katika utafiti huu. Hata hivyo, matokeo ya utafiti huu yatakuwa na manufaa katika kuwezesha kuelewa athari mbalimbali ya kisaikolojia ya saratani na matokeo pia yatatumiwa na wadau katika kuzuia na kuboresha huduma kwa wagonjwa kuzuia au kutibu athari wakati zinatokea

Usiri:

Usiri utadhibiwa na maelezo ambayo utatoa yatatumiwa tu kwa madhumuni yaliyotarajiwa ya utafiti huu. Kwa kuongeza, jina lako halitakiwa kwa fomu yoyote au kutumika wahatari wa kuchapishwa kwa ripoti ya mwisho hivyo kuhakikisha kutumika kwa mwisho. Vifaa vyote vilivyotumiwa wakati wa utafiti huu vitawekwa kwenye kikombeli kilichofungiwa na
wafanyakazi tu wanaohusika katika utafiti huu ndio watakaovifikia. Faili za elektroniki zitahifadhiwa kwenye kompyuta.

Kushiriki wa hiari:


Fidia: Hakuna fidia, fedha au vinginevyo, kwa kushiriki katika utafiti huu. Ikiwa utafiti huu utasababisha mawazo au hisia sumbufu basi mtafiti atakusaidia kupata ushauri kutoka kwa mshauri mkuu mwaajiriwa wa hospitali bila wewe kugharamia malipo.

Dodoso ya maswali


Kuasambaza matooke ya utafiti

Matokeo yanaweza kujadiliwa katika hafla mbali mbali na pia kachapishwa kwenye majarida ya kisayansi mbali mbali bila kukutambulisha kama mhusika.

Mawasiliano

Ukiwa na swali lolote wakati wa utafiti huu au hata baadaye unaweza kuwasiliana na wafuatao

1. Mtafiti

Jina: Anastacia Moraa Bosire
Simu: +254722616169
barua pepe: anebosi2015@gmail.com
2. **Wasimamizi**

1. **Jina:** Dr. Irene Mageto (BScN, MScN, PhD)
   
   Simu: +254 724205419
   
   Barua pepe: igmugato@gmail.com
   
   Eneo la ofisi: School of Nursing Sciences
   
   University of Nairobi, Kenyatta National Hospital Campus

2. **Dr. Samuel Kimani (BScN, MScN, PhD)**
   
   Simu:+254722384917
   
   Barua pepe: tkimani@uonbi.ac.ke
   
   Eneo la ofisi: School of Nursing Sciences
   
   University of Nairobi, Kenyatta National Hospital Campus

3. **Ethics Committee**

   Prof. M.L. Chindia,

   Katibu,

   KNH/UON Ethics and Research Committee

   Tel No. +254 726300-9

   Barua pepe: uonknh_erc@uonbi.ac.ke

   Eneo la ofisi: School of Pharmacy, University of Nairobi, College of Health Sciences

   Kenyatta National Hospital Campus
Appendix iii: Consent form

If you Consent to Participate in the study please sign below:

I hereby consent to participate in this study. I have been informed of the nature of the study being undertaken and potential risks explained to me. I also understand that my participation in the study is voluntary and the decision to participate or not to participate will not affect my treatment at this facility in any way whatsoever. I may also choose to discontinue my involvement in the study at any stage without any explanation or consequences. I have also been reassured that my personal details and the information I will relay will be kept confidential. I confirm that all my concerns about my participation in the study have been adequately addressed by the investigator and the investigator has asked me questions to ascertain my understanding of the information provided.

Participant’s Signature (or thumbprint) ___________________ Date _________________

I confirm that I have clearly explained to the participant the nature of the study and the contents of this consent form in detail and the participant has decided to participate voluntarily without any coercion or undue pressure.

Investigator Signature __________________________ Date _____________________
Appendix iv: Form ya shaha

Ikiwa Unakubali Kushiriki katika utafiti tafadhali weka ishara hapa chini:


Sahihi ya Mshiriki (au alama ya kidole) ___________________ Tarehe ___________________

Ninathabitisha kwamba nimeelezea wazi kwa mshiriki hali ya utafiti na maudhui ya fomu hii ya ridhaa kwa undani na mshiriki ameamua kushiriki kwa hiari bila shinikizo lolote au shinikizo la kutosha.

Sahihi ya msaidizi ______________________________ Tarehe ___________________________


Appendix v: Consent form for focus group discussion

Title of the study: Biopsychosocial effects of cancer chemotherapy among adult patients diagnosed with breast and cervical cancer attending treatment at Kenyatta National Hospital cancer treatment center.

Researcher: Anastacia Moraa Bosire (Master of Science in Oncology Nursing student, Year II)

Institution of Study: University of Nairobi

Introduction to the study

You are invited to participate in focused group discussion as a part of a research study, carried out by Anastacia Bosire who is a student pursuing Master of Science in Oncology Nursing at the University of Nairobi. The research is being carried out at cancer treatment center. You have been selected to participate because you are one of those patients receiving treatment for breast/cervical cancer at the cancer treatment center. This discussion is being held between patients receiving treatment at the cancer treatment center only.

This consent form gives you 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 find the effects of chemotherapy experienced by patients during the period of their treatment at Kenyatta National Hospital cancer treatment center. The study will help KNH to know the areas of improvement towards the care given to support patients during the period of treatment.
Time

The group discussion will take about 60-90 minutes and will be guided by the researcher who will be assisted by 2 research assistants.

Study Objective

The specific objectives will be:

1. To find out which physical symptoms of cancer chemotherapy among adult patients diagnosed with breast and cervical cancer attending treatment at KNH CTC experience.
2. To determine the psychological effects of cancer chemotherapy experienced by adult patients diagnosed with breast and cervical cancer attending treatment at KNH CTC.
3. To determine the sociological effects of cancer chemotherapy among adult patients diagnosed with breast and cervical cancer.
4. To determine the relationship between sociodemographic factors and the biological, psychological and sociological effects of chemotherapy

Benefits of the study

There are no direct benefits for you as an individual participant. However, the findings of this study can be used by KNH and other institutions where patients diagnosed with breast and cervical cancer receive treatment, to plan and give improved care during the period of chemotherapy treatment

Risks

There are no directly foreseen risks for you participating in this study. If there are any discussion questions you do not want to answer, you are free to skip them. In addition, you have the right to
decline giving information. Any part of the recording you would like not to be included in the study will be expunged.

**Confidentiality**

The discussion will involve other members like you. Members will be identified by numbers to ensure anonymity. It will be held in a closed room to ensure privacy and though it will be recorded via tape recorder and through notes taken by the researcher and assistants, the information will be kept in locked cabinets during the study. Your identity will be kept confidential.

**Discussion Procedure**

The group discussion will be carried out during your next clinic visit before your next chemotherapy session. The researcher will assist you to be attended at the clinic before the group discussion. The discussion will be held in the CTC computer room which is quiet and private. You will be required to answer questions as guided by the researcher. The discussion will be audio taped and the researcher will also take notes during the discussion in order to ensure that important participant points are not missed out during analysis.

**Voluntary Participation and Withdrawal**

Remember, your participation is entirely voluntary. Should you change your mind, you have the right to drop out at any time without facing any consequences. You may skip questions or stop participating at any time.

**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.
Compensation

There is no compensation monetary or otherwise for participation in the focus group discussion. Soft drinks and snacks will be offered on the day of the discussion as refreshments.

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: Anastacia Bosire
   Phone No. +254 722616169 Email: annebosi2015@gmail.com
   Physical Address: School of Nursing Sciences, College of Health Sciences, University of Nairobi, Kenyatta National Hospital Campus

2. Supervisors
   Name: Dr. Irene Mageto
   Phone No. +254 724205419 Email: igmageto@gmail.com
   Physical Address: School of Nursing Sciences, College of Health Sciences, University of Nairobi, Kenyatta National Hospital Campus
   Name: Dr. Samwel Kimani
   Phone No. +254 722 384917 Email: tkimani@uonbi.ac.ke
   Physical Address: School of Nursing, College of Health Sciences, University of Nairobi.

3. Ethics Committee
   Prof. M.L. Chindia,
   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

Participants’ Statement

I hereby confirm that I have full knowledge of the study being undertaken, that I have read and understood the information sheet supplied above and that the study investigator informed me about the nature, conduct and benefits of this study. I have read and understood the contents of the information sheet.

I am aware that participation is voluntary and that I can withdraw from the study should I wish to do so. I am also aware that the information that I will be giving will be confidential and that the results of the study will be anonymously processed. I have had sufficient opportunity to ask questions and declare myself prepared to participate 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 confirm that I have clearly explained to the participant the nature of the study and the contents of this consent form in detail and the participant has decided to voluntarily participate without any coercion or undue pressure.

Signature ______________________ Date ______________________
Appendix vi: Maelezo ya shaha kwa washirika wa mjadala

Mada ya utafiti: Madhara ya biopsychosocial ya tiba ya kansa kati ya wagonjwa watu wazima walio na kansa ya matiti na ya kizazi wanahudhuria matibabu katika Kituo cha matibabu cha kansa cha Kenyatta National Hospital.

Mtafiti: Anastacia Moraa Bosire (Mwanafunzi wa Sayansi katika Uuguzi (Oncology) mwanafunzi wa Mwaka wa II)

Taasisi ya Utafiti: Chuo Kikuu cha Nairobi

Utangulizi wa utafiti

Unakaribishwa kushiriki katika mjadala wa kikundi cha makini kama sehemu ya utafiti, unaofanywa na Anastacia Bosire ambaye ni mwanafunzi wa uuguzi wa Chuo Kikuu cha Nairobi.

Utafiti huo unafanyika katika kituo cha matibabu ya saratanikatika hospitali kuu ya Kenyatta. Umechaguliwa kushiriki kwa sababu wewe ni mmojawapo wa wagonjwa hao wanaopata matibabu ya saratani ya matiti / kizazi katika kituo cha matibabu ya saratani. Mjadala huu unafanyika kati ya wagonjwa wanaopata matibabu katika kituo cha matibabu cha saratani tu.

Fomu hii ya idhini inakupa taarifa kuhusu utafiti, hatari na faida, na mchakato utaelezewa kwako. Mara baada ya kuelewa masomo, na ikiwa unakubali kushiriki, utaombwa kusaini au kutumia kidole kutia alama (kuchapa kidole) kwenye fomu ya kibali.

Kusudi la utafiti:

Madhumuni ya utafiti huu ni kupata adhari ya chemotherapy kwa wagonjwa wakati wa matibabu yao katika kituo cha matibabu ya kansa ya Kenyatta National Hospital. Utafiti huo utasaidia KNH kujua maeneo ya kuboresha kuelekea huduma inayopewa wagonjwa wakati wa matibabu
Muda

Mjadala wa kikundi utachukua muda wa dakika 60-90 na utaongozwa na mtafiti ambaye atasaidiwa na wasaidizi wa utafiti 2.

Lengo la mjadala

Malengo maalum yatakuwa:

1. Ili kujua dalili za kimwili za kisaikolojia ya kansa ya wagonjwa watu wazima walioambukizwa na saratani ya matiti na ya kizazi wanahudhuria matibabu katika uzoefu wa KNH CTC.

2. Kuamua athari za kisaikolojia za kisaikolojia za kansa ambazo huwa na wagonjwa watu wazima ambao huwa na saratani ya matiti na ya kizazi wanaohudhuria matibabu katika KNH CTC.


Faida za utafiti

Hakuna faida ya moja kwa moja kwako kama mshiriki mmoja. Hata hivyo, matokeo ya utafiti huu yanaweza kutumiwa na KNH na taasisi nyingine ambapo wagonjwa wanaopatikana na saratani ya matiti na kizazi wanapata matibabu, kupanga na kutoa huduma bora wakati wa matibabu ya saratani.

Hatari

Hakuna hatari moja kwa moja inayoonekana kwa kushiriki katika somo hili. Ikiwa kuna maswali yoyote ya majadiliano hutaki kujibu, wewe ni huru kukosa kujibu. Kwa kuongeza, una haki ya
kupunguzu kutoa maelezo. Sehemu yoyote ya kurekodi ungependa ionderelewe katika utafiti itaondolewa.

Usiri

Mzungumzo yatahusisha washiriki wengine kama wewe. Washiriki watatambuliwa kwa namba ili kuhakikisha kutokujulikana. Itafanyika katika chumba kilichofungwa ili kuhakikisha faragha na ingawa itaandikwa kupitia rekodi ya mkanda na kupitia maelezo yaliyochukuliwa na mtafiti na wasaidizi, habari itahifadhiwa katika makabati yaliyofungwa wakati wa utafiti. Utambulisho wako utahifadhiwa siri.

Utaratibu wa Majadiliano


Kushiriki kwa hiari na Kujiondoa

Kumbuka, ushiriki wako ni kwa hiari. Unaweza kubadilisha mawazo yako, una haki ya kuacha wakati wowote bila kukabiliana na matookeo yoyote. Unaweza kukosa kujibu maswali au kuacha kushiriki wakati wowote.

Kusambaza matookeo

Matokeo ya utafiti huu yanaweza kutolewa wakati wa vikao vya kisayansi na vya kitaaluma na inaweza kuchapishwa katika majarida ya kisayansi na karatasi za kitaaluma. Usiri utadumishwa.


**Fidia**

Hakuna fidia kifedha au kwa njia nyingine yeyote. Vinywaji na vitafunio vinaweza kutolewa siku ya mazungumzo kama rafu.

**Mawasiliana au maswali**

Ikiwa una maswali zaidi wakati au baada ya utafiti, ujisikie huru kawasiliana na mchunguzi, msimamizi au Kamati ya Maadili na Utafiti ya KNH / UON kwenye anwani ulizopewa hapa chini.

1. **Mchunguzi**

Jina: Anastacia Bosire

Nambari ya simu +254 722616169 Barua pepe: annebosi2015@gmail.com

Anwani: Shule ya Sayansi ya Uuguzi, Chuo Kikuu cha Nairobi,

Kinacho patikana Katika Hospitali ya Kenyatta

2. **Wasimamizi**

Jina: Dr Irene Mgeto

Nambari ya simu +254 724205419 Barua pepe: igmageto@gmail.com

Anwani: Shule ya Sayansi ya Uuguzi, Chuo Kikuu cha Nairobi, kinachopatikana katika Hospitali Kuu ya Kenyatta

Jina: Dr. Samwel Kimani

Nambari ya simu +254 722 384917 Barua pepe: tkimani@uonbi.ac.ke

Anwani: Shule ya Uuguzi, Chuo Kikuu cha Nairobi, Chuo cha Sayansi za Afya.

Katika Hospitali ya Kenyatta

3. **Kamati ya Maadili**
Jina: Prof. M.L. Chindia,
Katibu,

KNH / UON Kamati ya Maadili na Utafiti
Nambari ya simu +254 726300-9

Barua pepe: uonknh_erc@uonbi.ac.ke

Anwani : Shule ya Pharmacy, Chuo Kikuu cha Nairobi, Chuo cha Sayansi za Afya
Katika Hospitali ya Kenyatta

**Taarifa ya Washiriki**

Nawahakikishia kuwa nina ujuzi kamili juu ya utafiti unaofanywa, kwamba nimesoma na kuelewa karatasi ya habari iliyothelewa hapa juu na kwamba mfuatiliazi wa utafiti alinieleza kuhusu hali, mwenendo na faida za utafiti huu. Nimesoma na kuelewa yaliyomo ya karatasi ya habari.

Ninafahamu kuwa ushiriki ni wa hiari na kwamba ninawe kujiondoa kwenye utafiti ikiwa napenda kufanya hivyo. Pia ninajua kwamba habari nitakaytoa itakuwa siri na kwamba matokeo ya utafiti yanaweza kujadiliwa bila kutambulishwa. Ninaweza na fursa ya kutosha ya kuuliza maswali na nimeamua mwenyewe kushiriki katika utafiti.

Nakubali kushiriki katika utafiti. Nimeisoma na kila kitu kinaelezea wazi kwangu.

Saini_____________________________tarehe________________________

Mimi ___________________ Mtafiti / Msaidizi wa Utafiti anathibitisha kwamba nimeelezea wazi kwa mshiriki hali ya utafiti na maudhui ya fomu hii ya ridhaa kwa undani na mshiriki ameamua kushiriki kwa hiari bila kulazimishwa au shinikizo isiyofaa.

Saini ___________________ Tarehe __________________________

92
Appendix vii: Questionnaire (maswali ya uchunguzi)

Questionnaire for the research on biopsychosocial effects of cancer chemotherapy among patients diagnosed with breast and cervical cancer, attending cancer treatment Centre at Kenyatta National Hospital (Swala la utafiti juu ya madhara ya kibiologia, kisaikolojia na kijamii yanayohusiana na dawa za tiba ya kansa kati ya wagonjwa walio na kansa ya matiti na ya kizazi wanaohudhuria matibabu ya kansa katika Kituo cha Hospitali ya Taifa ya Kenyatta).

Instructions (Maelekezo)

- The purpose of this questionnaire is to obtain information for the study purpose only. The information obtained will go a long way in improving the clinical experience of patients receiving chemotherapy at the cancer treatment Centre in Kenyatta National Hospital. All your responses will be treated with total confidence (Kusudi la maswali haya ni kupata habari kwa ajili ya kujifunza tu. Taarifa zilizopatikana zitasaidia pakubwa katika kuboresha matibabu wanopata wagonjwa katika kituo cha matibabu ya kansa katika Hospitali ya Taifa ya Kenyatta. Majibu yako yote yatathibitiwa kwa usiri).
- Please respond to all questions (Tafadhali jibu maswali yote).
- Do not write your name or any other identification anywhere on the questionnaire (Usiandike jina lako au kitambulisho kingine chochote mahali popote kwenye dodoso).
- The questionnaire has two sections, kindly complete all the sections (Daftari ina sehemu mbili, tafadhali kamilisha sehemu zote).
- Please respond according to the instruction given in each section (Tafadhali jibu maswali kulingana na maagizo yaliyotolewa katika kila sehemu).
SECTION I: SOCIO DEMOGRAPHIC DATA

1. What is your age in years? (*umri wako ni miaka mingapi*)? ________________

2. What is your citizenship? (*je uraia wako ni upi*)? ______________________

3. Which is your county of residence? (*je unaishi katika jimbo gani*)?
_________________________________________________________________

4. Which is your religion? (*je dini yako ni gani*)?

<table>
<thead>
<tr>
<th>Protestant (protestanti)</th>
<th>Catholic (katoliki)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Muslim (muslamu)</td>
</tr>
<tr>
<td></td>
<td>Other (specify)</td>
</tr>
</tbody>
</table>

5. What is your marital status? (*Je hali yako ya ndoa ni gani*)?

<table>
<thead>
<tr>
<th>Single (sijaolewa)</th>
<th>Married (nimeolewa)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Divorced (tumetengana)</td>
</tr>
<tr>
<td></td>
<td>Widow (mjane)</td>
</tr>
</tbody>
</table>

6. When was your last monthly period? (*damu yako ya mwezi ya mwisho iliku linii*)? ______________________________

7. How many children do you have? (*una watoto wangapi*)? ______________________

8. At what age did you get your first pregnancy? (*mimba yako ya kwanza ulipata ukiwa na umri wa miaka mingapi*)? __________________________________________
9. Who provides you with social support? *(ni nani hukusaidia kumudu mahitaji yako ya kijamii)*

10. Do you have National Hospital Insurance Fund (NHIF) card? *(Je una kadi ya bima ya NHIF?)*

<table>
<thead>
<tr>
<th>Yes (ndio)</th>
<th>No (la)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

If yes is it activated? *(Je inatumika?)*

<table>
<thead>
<tr>
<th>Yes (ndio)</th>
<th>No (la)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

11. What is your career? *(unafanya kazi gani)*

12. Are you currently working? *(unafanya kazi kwa wakati huu?)*

<table>
<thead>
<tr>
<th>Yes (Ndio)</th>
<th>No (La)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

If no why? *(Ikiwa haufanyi ni kwa nini?)*

13. What is your average monthly income in ksh? *(Mapato yako Kwa mwezi ni kiasi gani?)*

<table>
<thead>
<tr>
<th>less than <em>(chini ya)</em> 20000</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>20000-40000</td>
<td></td>
</tr>
<tr>
<td>40000-60000</td>
<td></td>
</tr>
<tr>
<td>above <em>(Zaidi ya)</em> 60000</td>
<td></td>
</tr>
</tbody>
</table>

14. When did you know that you have cancer? *(je ulijua lini kuwa unaugua saratani?)*

<table>
<thead>
<tr>
<th>Less than 1months ago <em>(chini ya mwezi)</em></th>
<th></th>
</tr>
</thead>
</table>
15. Who informed you about your diagnosis? (ni nani aliyekulisha kuhusu saratani ambayo unaugua?)

- Nurse (muuguzi)
- Doctor (daktari)
- Relative (jaama yako)
- Others specify (wengine wataje hapa)

16. Has anyone discussed with you about the treatment you are getting for the cancer you have? (je kuna mtu yeyote amejadiliana na wewe kuhusu dawa unazopokea?)

- Yes (Ndio)
- No (La)

If yes who (kama ndio, nani alijejadili)

- Doctor (daktari)
- Nurse (muuguzi)
- Trained counselor (mshauri)
- Relative (jamaa yako)
- Friend (rafiki)
17. Were you told of the possible benefits of the treatment you are receiving?

(je umeelezwa faida ya dawa unazopewa)

| Yes (Ndio) |  |
| No (La) |  |

18. Were you told of the possible side effects of the treatment you are receiving?

(je umaambiwa uwezekano wa Athari zinazotokana na matibabu unayopokea)

| Yes (Ndio) |  |
| No (La) |  |

19. How many sessions of cancer drugs have you received before today?

(umepewa vipimo vingapi vya dawa hadi sasa?)

| One (kimoja) |  |
| Two (viwili) |  |
| Three (vitatu) |  |
| More than three (Zaidi ya vitatu) |  |

20. Have you ever thought of stopping the treatment you are receiving for cancer?

(je umewahi kufikiria kuacha matibabu ya saratani?)

| Yes (Ndio) |  |
| No (La) |  |

If yes why (ikiwa ndivyo, kwa nini?) _______________________

97
SECTION II: EFFECTS OF CHEMOTHERAPY

A. BIOLOGICAL EFFECTS (ATHARI ZA KIBIOLOGIA)

Have you experienced any of the following symptoms since you started taking the drugs for cancer treatment? (Please tick all that apply to you in the spaces provided)

(Je! Umewahi kupata dalili yoyote kati ya zifuatazo tangu ulianza kutumia madawa kwa ajili ya matibabu ya saratani? (Tafadhali weka alama kando ya yote yanayokuhusu katika nafasi zinazotolewa)

<table>
<thead>
<tr>
<th>SYMPTOM (DALILI)</th>
<th>YES (NDIO)</th>
<th>NO (LA)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Nausea (kichefuchefu)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Vomiting (kutapika)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Feeling tired (kuhisi uchovu)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Loss of appetite (kukosa hamu ya kula)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Loss of hair (kung`oka nywele)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Skin colour changes (kubadilika kwa rangi ya ngozi)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Tingling sensation and numbness of hands and feet (kufa ganzi au kuhisi kuganda mikono na miguuu)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Diarhoea (kuhara)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Loss of weight (kupunguza uzito)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Mouth ulcers (vidonda kwa mdomo)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
12. Since you started receiving medication have you been informed that from your lab results that your immunity cells are low and you could not be given your due treatment?

(Je tangu uanze kutumia dawa za saratani umwahi kuelezwa kuwa kuambatana na vipimo vya damu chembechembe za mwili za kuzuia magonjwa mwilini ziko chini ya kiwango cha kawaida na haungeweza kupokea dawa yako ya saratani)?

<table>
<thead>
<tr>
<th>Yes (ndivyo)</th>
<th>No (la)</th>
</tr>
</thead>
</table>

**B. PSYCHOLOGICAL EFFECTS (ATHARI ZA HISIA)**

Have you experienced any of the following feelings since you started taking medicine for cancer? (Tick all that apply to you)

(Je! Umekua na hisia yoyote kati ya hisia zifuatazo tangu ulianza kutumia dawa za kansa (weka alama kando ya zote zinazokuhusu)

<table>
<thead>
<tr>
<th>FEELING(HISIA)</th>
<th>YES(NDIO)</th>
<th>NO(LA)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Sense of loneliness(kuhiśi kuwa na upweke)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Low self-esteem/loss of confidence in yourself(kujishusha hadhi/kukosa kujiamini wewe mwenyewe)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Feeling sad(kuwa na huzuni)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Inability to concentrate or remain attentive during activities e.g. reading(Ukosefu wa kuzingatia au kubaki makini wakati wa shughuli k.m. kusoma)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Inability to remember things (kukosa kumbukumbu)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Feeling that you are the reason other people in the family are</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Getting hurt (<strong>Kuhisi kwamba wewe ndio sababu watu wengine katika familia wanapata madhara</strong>)</td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>7.</td>
<td>Feeling anxious most of the time (<strong>Kuhisi kuwa na wasiwasi zaidi wakati mwingi</strong>)</td>
<td></td>
</tr>
<tr>
<td>8.</td>
<td>Feeling dissatisfied with the way your body looks (feeling less feminine) (<strong>Kuhisi hujaridhika na jinsi mwili wako unavyoonekana (hisia yake wewe si mwanamke kamili)</strong></td>
<td></td>
</tr>
<tr>
<td>9.</td>
<td>Feeling depressed (<strong>Kuhisi kuzongwa na mawazo</strong>)</td>
<td></td>
</tr>
<tr>
<td>10.</td>
<td>Losing hope of getting better from taking the treatment (<strong>Kukosa matumaini ya dawa kuweza kukuponyesha</strong>)</td>
<td></td>
</tr>
</tbody>
</table>

### C. SOCIOLOGICAL EFFECTS (**ATHARI ZA KIJAMII**)

Since you started taking cancer medication, have you found yourself in any of the following circumstances? (Tick all that apply to you)

(Tangu ulipoanza kutumia dawa za Kansa, umewehai kujikuta katika hali yoyote kati ya hali zifuatazo? (weka alama kando ya yote yanayokuhusu)

<table>
<thead>
<tr>
<th></th>
<th>SOCIAL EFFECT (<strong>ATHARI ZA KIJAMII</strong>)</th>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Friends and family members avoid being with you because you are taking medicine for cancer treatment (<strong>Marafiki na familia huepuka kwana wewe kwa sababu unatumia dawa za matibabu ya saratani</strong>)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>You have no interest in activities you liked before, social events and socializing and prefer to stay alone (<strong>Huna nia ya shughulikia vitu ambavyo</strong>)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.</td>
<td>ulipenda mbeleni, matukio ya kijamii au kujihusisha na watu wengine na unapendelea kukaa peke yako</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td>You have no sexual interest or sexual performance has reduced(Hauna hamu ya kijinsia au utendaji wa ngono umepungua)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td>You are not able to go back to work because of your treatment(Huwezi kurudi kufanya kazi kwa sababu ya matibabu yako)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td>There is tension in your marriage because of your treatment(Kuna mvutano katika ndoa yako kwa sababu ya matibabu yako)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.</td>
<td>You cannot perform your roles in the family e.g. mother, breadwinner(Huwezi kufanya majukumu yako katika familia k.m. mama, msimamizi wa nyumba)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.</td>
<td>You cannot perform your role in the community e.g. church elder, chairlady due to the treatment(Huwezi kufanya jukumu lako katika jumuiya k.m. mzee wa kanisa, mwenyekiti wa chama, kutokana na matibabu yako)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.</td>
<td>Experienced episodes of inability to pay hospital bills or to buy prescription medication(wakati mwingine unakosa uwezo wa kulipa bili ya hospitali au kununua dawa za kansa)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9.</td>
<td>Friends and family have become closer and provide emotional support(Marafiki na familia wamekuwa karibu na kutoa msaada wa kihisia)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix viii: Clinical data checklist

1. Site/organ involved______________________________________________________

2. Histology report confirmation (cells involved) ____________________________

3. Stage of cancer:

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td></td>
</tr>
<tr>
<td>II</td>
<td></td>
</tr>
<tr>
<td>III</td>
<td></td>
</tr>
<tr>
<td>IV</td>
<td></td>
</tr>
</tbody>
</table>

4. Current treatment being given:

<table>
<thead>
<tr>
<th>Treatment</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Chemotherapy</td>
<td></td>
</tr>
<tr>
<td>Surgery</td>
<td></td>
</tr>
<tr>
<td>Radiotherapy</td>
<td></td>
</tr>
<tr>
<td>Palliative care</td>
<td></td>
</tr>
<tr>
<td>Combination (specify)</td>
<td></td>
</tr>
</tbody>
</table>

5. Chemotherapy drugs being given(treatment sheet)___________________________

6. Chemotherapy cycle____________________________________________________
Appendix ix: Focus group discussion guide (Maswali ya Mahojiano)

Introduction

My name is Anastacia Bosire. I am a student at the University of Nairobi studying for a masters’ degree in oncology nursing. I am carrying a research to find out the effects of chemotherapy among breast and cervical cancer patients in KNH CTC. You are invited to participate in this Focused Group Discussion session to discuss the effects which you may have experienced since you started chemotherapy. You will be given Identity numbers which will be used for the purpose of this discussion for your identification otherwise do not give any information that is likely to identify you. The discussion is going to be tape recorded but the information will be kept private and confidential. Feel free to participate and remember there is no right or wrong answer. The moderator will guide the discussion in order to keep it on course. The discussion will take about 60-90 minutes and I greatly appreciate you for taking your time to participate.

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

Participant signature ____________________ (initials):_______ Date: ______________________

Researcher’s signature:______________________ Date: ______________________
PART A: GENERAL INFORMATION

<table>
<thead>
<tr>
<th>Date of discussion:</th>
<th>Moderator:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Venue:</td>
<td>Note-taker:</td>
</tr>
<tr>
<td>Time start:</td>
<td>No. Participants at start:</td>
</tr>
<tr>
<td>Time stop:</td>
<td>No. Participants at stop:</td>
</tr>
<tr>
<td>Script code:</td>
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PART B: PARTICIPANT DEMOGRAPHIC DATA

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<th>Gender</th>
<th>Marital status</th>
<th>Occupation</th>
<th>Cancer type</th>
<th>Religion</th>
<th>Previous chemo session</th>
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PART C: DISCUSSION.

1. Please explain some of the physical changes you have experienced in your body since you started receiving chemotherapy. (Tafadhali eleza baadhi ya mabadilika ambayo umeshuhudia kwa mwili wako tangu ulipoanza kupata matibabu.)

2. What have you done about them? (Umfanya nini juu ya mabadiliko hayo?)

3. How has chemotherapy affected you psychologically? (Matibabu ya Kansa yamekuathiri vipi kisaikolojia?)

GUIDE (muongozo): -

a. Depression (Huzuni)

b. Anxiety (Wasiwasi)

c. Fear of dying, fear of chemotherapy side effects, (Hofu ya kufa, hofu ya madhara ya chemotherapy)

d. Cognitive impairment, memory loss, lack of concentration (Ukosefu wa utambuzi, kupoteza kumbukumbu, ukosefu wa ukolezi au utulivu)

4. Please explain how chemotherapy has affected your social life in the following aspects (Tafadhali eleza jinsi chemotherapy imeathiri maisha yako ya kijamii katika nyanja zifuatazo)

a. Your usual job (Kazi yako ya kawaida)

b. Social role (Jukumu la kijamii)

c. Relationship with family and friends. (Uhusiano na familia na marafiki).

d. Sexual relationship (uhusiano wa kijinsia)

5. Any other important point to be included in the discussion (hoja ya ziada)
Appendix x: Letter of approval from KNH-UON ERC

Dear Anastacia

RESEARCH PROPOSAL: BIOPSychosocial EFFEcts of CANcer CHEMOTHERAPY AMONG ADULT FEMALE PATIENTS DIAGNOSED WITH BREAST AND CERVICAL CANcer ATTENDING KENYATTA NATIONAL HOSPITAL CANcer TREATMENT CENTER (P88/02/2019)

This is to inform you that the KNH-UoN Ethics & Research Committee (KNH-UoN ERC) has reviewed and approved your above research proposal. The approval period is 22nd May 2019 – 21st May 2020.

This approval is subject to compliance with the following requirements:

a. Only approved documents (informed consents, study instruments, advertising materials etc) will be used.

b. All changes (amendments, deviations, violations etc.) are submitted for review and approval by KNH-UoN ERC before implementation.

c. Death and life threatening problems and serious adverse events (SAEs) or unexpected adverse events whether related or unrelated to the study must be reported to the KNH-UoN ERC within 72 hours of notification.

d. Any changes, anticipated or otherwise that may increase the risks or affect safety or welfare of study participants and others or affect the integrity of the research must be reported to KNH-UoN ERC within 72 hours.

e. Clearance for export of biological specimens must be obtained from KNH-UoN ERC for each batch of shipment.

f. 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).

g. Submission of an executive summary report within 90 days upon completion of the study. This information will form part of the data base that will be consulted in future when processing related research studies so as to minimize chances of study duplication and/or plagiarism.
Appendix xi: Letter of approval from KNH.