

**QUALITY OF PATIENT-CENTERED CANCER CARE IN THE
GYNAECOLOGICAL WARDS AT KENYATTA NATIONAL
HOSPITAL**

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DECLARATION

I, JULIE MUTHONI MATIBA, certify that this report is my original work and it does not incorporate without acknowledgement any material previously submitted in any institution of higher learning or contain any material previously published or written by another person except where due reference is made in the text.

Signature

Date

CERTIFICATE OF APPROVAL

This research dissertation has been submitted in partial fulfilment of the requirements for the award of Master of Science in Nursing (Oncology) degree of the University of Nairobi, with our approval as supervisors.

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DEDICATION

I dedicate this work to my loving husband Stephen, my daughters Ashley and June for their continued love and support.

My extended family for their continued prayers and encouragement

To all who have suffered in one way or another because of cancer, may you find peace and comfort from the Almighty God.

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LIST OF ABBREVIATIONS AND ACRONYMS

COVID:	Corona Virus Disease
ERC:	Ethics Review Committee
FGD:	Focused Group Discussion
HIV:	Human Immunodeficiency Virus
IARC:	International Agency for Research on Cancer
IOM:	Institute of Medicine
KNH:	Kenyatta National Hospital
NICCQ:	National Initiative for Cancer Care Quality
PCC:	Patient-centered care
PCCC:	Patient-centered cancer care
QI:	Quality Indicators
UHC:	Universal Health Coverage
UK:	United Kingdom
USA:	United States of America
WHO:	World Health Organization

OPERATIONAL DEFINITIONS

Autonomy: the ability of the patient to make his or her own decisions.

Cancer: a term that describes a malignant growth in any part of the body.

Cancer care: care given to a person with cancer.

Communication: imparting or exchanging of information and education by speaking, writing, or using some other medium.

Educate: enable or facilitate learning, or the acquisition of knowledge and skills.

Expressed need: desires the patient has conveyed in words or gestures.

Family involvement: involving first degree relatives, caregivers, or close friends in the care of the patient by giving information, educating them and involving them in decision making.

Gynaecological cancer: refers to cancers that affect a woman's reproductive system. Vulval, vaginal, cervical, endometrial or ovarian cancer.

Preferences: liking for one alternative over another or others.

Psychological: all that relates to the mental and emotional state of a person.

Sharing information: the voluntary act of making ideas, new data possessed by one entity available to another.

Holistic care: total patient care that considers the physical, psychological, social, and spiritual needs of the person.

Listening: take notice of and act on what someone says

Patient-centered care: providing care that is respectful of, and responsive to, individual patient preferences, needs and values and ensuring that patient values guide all clinical decisions.

Physical Comfort: care that involves promoting rest and minimizing discomfort and pain.

Psychological care: care related to the ability to cope with the illness experience and its consequences.

Quality of care: care that must be holistic, respectful to patient's values, preferences and expressed needs, provides good communication, and involves family and friends.

Respect: due regard for the patient's feelings, wishes and rights.

Respect for patient's values, preferences and expressed needs: Treat patients with dignity, respect and sensitivity to his/her cultural values, preferences and needs.

Significant other: A person with whom someone has an established relationship.

Social: relates to the ability to participate in various activities and be involved with others.

Social support: emotional and practical or financial support give to help patients better understanding of their condition, life situation and problems.

Spiritual: relating to religion or a religious belief to find meaning in life.

Spiritual care: care that recognises patient's religion and /or spirituality and attends to their spiritual needs.

Stage of Disease: where the tumour is located and where it has spread to.

Values: one's judgement of what is important in life.

ABSTRACT

Background: Patient-centered cancer care (PCCC) is a health care practice that treats cancer patients with high regard by listening and educating them, and considering the patient and their significant others in all decisions about their management. It is a health care approach that provides a partnership between the health care providers, the patient and their relatives. Examining the patient's perspective on the care offered is one of the best ways to evaluate patient-centered care.

Purpose of the Study: To determine patient's perceptions on the quality of patient-centered cancer care in the gynaecological wards at Kenyatta National Hospital (KNH).

Methodology: This was a qualitative study where 19 patients gave their lived experiences through in-depth interviews (IDIs). Purposive sampling was utilized, the audio recordings were transcribed verbatim and thematic analysis was used to identify the common themes. Data was presented as narratives from the interviews and ethical approval and clearance was sort from KNH-UoN Ethics Review Committee and the KNH management.

Results: Four major themes emerged: Holistic care, communication, respect for patient's values, preferences and expressed needs, and family involvement. Patients' positive experiences with holistic cancer care was closely coupled with improved overall health and quality of life. Participants felt pain was adequately managed, the environment was clean but assistance with toileting and bathing was not satisfactorily addressed neither was psychosocial and spiritual care provided. Several barriers to good communication were identified. Respect for patient's values, preferences and expressed needs were perceived as present or absent by how the healthcare providers communicated with and treated them. Finally, there was no family involvement in the patient care.

Conclusion: From the findings, the quality of PCCC provided in the gynaecological wards at KNH, as per the perceptions of the patient was below average.

Recommendations: To safeguard quality patient-centered cancer care, all healthcare stakeholders need to be involved, and a tool to assess the quality of PCCC needs to be developed.

CHAPTER ONE: INTRODUCTION

1.1 Background Information

Worldwide one of the leading causes of mortality is Cancer which caused about 9.6 million deaths in 2018 (WHO, 2018). It is estimated 43.8 million are alive within the first 5 years after cancer diagnosis in the world. (IARC, 2018). The rise is attributed to factors that include population growth, ageing and factors related to social and economic development (GLOBOCAN, 2018). In low income countries, cancer deaths, are higher than the incidence rates because they are associated with poorer outcomes and high morbidity rates, with limited access to timely diagnosis and treatment (Bray et al., 2018).

The management of cancer patients is complicated because, cancer has a great impact on the patient's physical, emotional and social well-being. Various professionals are involved in prevention, diagnosis, treatment and follow-up while toxic therapies are administered and this can lead to sub-optimal care. There are constant problems in the health care systems that hamper provision of standard health care which may lead to discontinuity of care. Not to forget the system is already over stretched due to the increasing patient numbers, limited resources and a lack of coordination. Therefore, there is a need to organise health care systems to be more patient-centred and not disease or provider centered.

Patient-centered care is a practice that treats patients with high regard by listening and educating them, and considering the patient and their significant others in all decisions about their management. (Relman, 2001). Previously, patients were seen as a passive recipients of health care, with the health care provider targeting the patient's needs instead of their concerns. Patient-centered care on the contrary, allows the health care provider to include the patient and their relatives in making a joint decision on the treatment plans and general care, with an overall perspective of considering the life situation of the patient. People-centered health services is an approach to health care that acknowledges the perspectives of individual patients, their

families and communities and sees them as key stakeholders in health care management (WHO, 2019).

With the upsurge of cancer cases, there's increasing demand for quality cancer care. To ascertain that quality patient-centered cancer care is provided, a monitoring system must be in place to assist in measuring the quality of cancer care. It also helps to eliminate any barriers to quality cancer care and increases awareness and understanding of patient-centered cancer care.

1.2 Problem Statement

Patient-centered cancer care is a health care approach that has been accepted worldwide by health care systems so as to boost the quality of cancer care and improve patient outcomes. Monitoring cancer care has become widely accepted in the first world countries with surveys indicating a percentage of patients lack appropriate care nor do they benefit from current cancer management.

In America for example, the National Initiative for Cancer Care Quality (NICCQ), developed a system for measuring and reporting the quality of cancer care (Hewitt et al., 2006). The system measured breast & colorectal cancer in five metropolitan areas. Patients with breast cancer in the five areas received about 86 percent of the recommended care and patients with colorectal cancer received about 78 percent of recommended care.

Japan also established a program that measured the quality of cancer care (Iwamoto, et al, 2016), for breast, prostate, colorectal, stomach, lung, liver and cervical cancer patients in 2011. The results showed the scores on pre-treatment testing was high at 80%, but scores for chemo and radiation therapies was low at 20-37 percent. Some of the benefits of effective patient-centered care include, improved clinical outcomes, staff satisfaction and high morale and there is cost-effectiveness (NEJM Catalyst, 2017). These act as quality indicators when assessing and monitoring quality patient cancer care.

In Africa the only documented evidence on cancer care so far, is a study carried out to review the data on existing cancer control resources in Africa. The results indicated that in Africa, the resources allocated for cancer control are not adequate. (Stefan, 2015). However, the African Cancer Coalition (ACC) and the National Comprehensive Cancer Network (NCCN) in November 2017, developed guidelines for cancer care which offered recommendations for management of breast, prostate and cervical cancer, B-cell lymphoma, and Kaposi sarcoma.

Kenya has not yet established a monitoring system for quality cancer care although, the government launched the National Cancer Control Strategy 2017-2022 which was designed to guide the country on cancer prevention and control interventions. The incidence rate in 2018 was 47,887 with 32,987 number of deaths. Of the new cases 40% were male while 60% were female (The Global Cancer Observatory, 2019).

Kenyatta National Hospital (KNH) under the guidance of the Ministry of health working with the National Comprehensive Cancer Network and the American Society of Clinical Oncology, formulated patient-centered care guidelines in June 2016. But there is no evidence of monitoring and evaluation of cancer care even though it has an overwhelming number of patients requiring cancer care.

The demand for quality cancer care is clearly very high in this institution given that it is the main referral hospital in Sub-Saharan Africa. This implies that the available resources are over stretched and the health care personnel are overworked. Therefore, there was a need to find out whether patients are getting quality cancer care, centered on their individual needs and preferences.

1.3 Justification

Establishing the patient's perspectives on the care they are receiving while in the gynaecological wards, has enabled the researcher to identify gaps in patient-centered cancer

care. This has led to recognition of improvement areas which if resolved will enhance the quality of health services provided. In the long term, there will be improved quality of life and better clinical outcomes.

Gynaecological cancers are the leading cause of morbidity and mortality among women. In 2014, gynaecologic cancers accounted for approximately 12% (94,990 out of 810,320) of all new cancer diagnoses in women in the United States (Siegel et al., 2014). At the Kenyatta National Hospital, the leading cause of hospitalization and the leading cause death in the period between 2015-2016 was cancer (KNH CANCER REGISTRY, 2017).

In the gynaecological wards (1B & 1D) 70% of all patients hospitalized have cancer (Health Information Department, KNH., 2019). Involving patients in assessment of their care will help ensure there is respect for them as unique human beings with an intention to care for them on their terms. Therefore, patients on treatment in the gynaecological wards at KNH are a suitable population to provide their views on patient-centered cancer care.

There is no documented evidence, of studies that have evaluated the quality of patient-centered cancer care after diagnosis or during treatment, within the Kenyan context. This indicates lack of strong and persuasive evidence that may influence a change in clinical practice or that may improve patient outcomes. Patient-centered cancer care (PCCC) can be perceived either positively or negatively depending on the outcome of the illness. By establishing their views, the researcher is able to identify the gaps or barriers in service provision which if resolved will improve clinical outcomes. The findings may also provide a background for development of a cancer care monitoring tool.

1.4 Research Questions

1. What are patient's experiences on holistic care, in the gynaecological wards at KNH?

2. What are the patient's perceptions on communication with healthcare providers, in the gynaecological wards at KNH?
3. What are the patient's perceptions on respect for their values, preferences and expressed needs while in the gynaecological wards at KNH?
4. What are the patient's perceptions on family involvement while in the gynaecological wards at KNH?

1.5 Study Objectives

1.5.1 Broad Objective

To determine patient's perception on the quality of patient-centered cancer care in the gynaecological wards at KNH.

1.5.2 Specific Objectives

1. To determine patients' experiences with holistic cancer care during their stay in the gynaecological wards at KNH.
2. To explore patient's perceptions on facilitators and barriers to healthcare provider-patient communication, during their stay in the gynaecological wards at KNH.
3. To determine patient's perception on respect of their values, preferences and expressed needs during their stay in the gynaecological wards at KNH.
4. To explore patient's perceptions on quality of family involvement during their stay in the gynaecological wards at KNH.

1.6 Expected Benefits

This study enabled the researcher establish the aspects of patient-centered care that were well delivered and those that needed improvement. Addressing the issues, could help improve the quality of cancer care, and consequently improve clinical outcomes, patient survival and quality of life.

1.7 Significance of the Study

The study established the quality of patient-centered cancer care as per the views of the patients in the gynaecological wards at KNH. The findings provided a background which may help develop a cancer care monitoring tool that would, in the long-term, help improve health care services, health outcomes and reduce costs for both the individual patient and the community as a whole. The study may also inspire further research on patient-centered cancer care within KNH and the country as a whole.

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

This chapter gives an in-depth review of assorted books, studies, reports and also internet searches on the specific areas of importance in patient-centered cancer care.

In the world today many people are seeking quality health services, because they want the best value for their money. However, unless the health services provided are monitored and evaluated, on regular basis, the efficiency of the services cannot be established. There are various ways of monitoring services provided to patients, and in this study, focus will be on the opinion of the patient, concerning their cancer care.

There are eight recognised Principles of Patient-Centered Care (Tzelepis et al, 2015). This study will focus on four i.e. information and education (communication), respect for patient's values, preferences and expressed needs, holistic care and involvement of family and friends. This literature review highlights the concept of Patient-centered cancer care in the context of this study.

2.2 Patient-centered care

Patient-centered care is a health care approach that considers the patient's specific needs and their desired health outcomes, with patients and health care providers working as partners. The individuals and their families are considered independent and capable in their own ways of making informed decisions concerning their health. PCC includes informing, listening and involving patients in their care.

The primary goal of PCC is to improve client experiences and provide better health outcomes. This develops health systems that benefit both the patient and health care provider and improves confidence in the health system by the client's family and community. It in return increases morale and productivity among the health providers. Patients are better placed to

determine whether the care they are receiving is patient-centered and if their values, preferences and expressed needs are respected (Tzelepis et al., 2015a).

A study on health care professionals working in a New York City hospital showed that they did not perceive all dimensions of PCC as important for improvement of care. The patient preferences, information and education and coordination of care dimensions were considered most important (Berghout et al., 2015). Several studies have shown that PCC is key to ensuring provision of quality care and promotes positive health outcomes, but knowledge about patient experiences in PCC is limited.

2.3 Holistic Approach to Care

Providing holistic care means focusing on the whole person. It includes social, spiritual, psychological, as well as the physical comfort and clinical care. In a study by Raja et al. (2015), participant brought the issue of holistic care in PCC. Indicating the importance of medical, psychological and environmental concerns during care. Provision of holistic care leads to prevention of depression, enhanced physical wellness and decreased hospitalization (Valizadeh et al., 2017).

The term holistic care has been used interchangeably in the medical and nursing field. However, both specialities agree that, in order to provide quality holistic care, there should be a positive work environment for staff, continuous in-service education, good and professional leadership and collaborative team work. Patients in a study by Edvardsson et al. (2017), cited the following as indicators for quality care knowledgeable staff who communicate effectively, appropriateness of assistance and good environmental support. Having good follow-up skills and effectively monitoring treatment was noted to be of concern (Nyarko et al., 2015)

2.3.1 Physical Comfort

Physical comfort involves promoting rest and minimizing discomfort and pain, by providing care needed during fatigue, mucositis, bowel changes, weight changes, sexual dysfunction, disturbed sleep, inability to move, co-morbidities or injuries, and neurological symptoms. (Okediji et al., 2018)

However, comfort is personal and depends on the circumstances therefore, understanding the patient's perspective will help improve practice and quality improvement decisions. (Wensley et al., 2017)

2.3.2 Psychosocial care

This is the care associated with the ability to deal with the illness experience and its consequences. It starts with assessment and identification of a patient's individual needs, any psychosocial conditions and psychiatric comorbidities (Andersen et al., 2014). Psychosocial pain may include emotional, cognitive, social and functional problems (Weis, 2015).

The commonly reported psychosocial needs include dealing with anxiety, depression and fear of recurrence or progression of the disease and in addition, improving communication and support for families or significant others is imperative (Sanson-Fisher et al., 2008).

In order to reduce anxiety and depression and to boost quality of life, interventions like relaxation techniques, counselling, psychoeducation, individual or group psychotherapy and psychotherapeutic interventions with families are proven to be effective (Faller et al., 2013).

Psychological care improves quality of life during and after treatment and also increases survival (Bultz et al., 2014). Providing good physical care by effectively communicating with the cancer patients can help reduce psychosocial needs of cancer patients (Chan et al., 2018). Therefore, psychosocial care experiences should be assessed to ensure continuous, coordinated and comprehensive care is offered to individuals with cancer.

2.3.3 Social support

In order to improve quality of life in patients with cancer, social support, hope and resilience are crucial factors in PCC (Li et al., 2016). Social support is the physical and emotional comfort given by family, friends, co-workers, and others. It also includes practical help such as providing finances, transport and accommodation, and sharing information and experiences with people with similar problems. For improvement of social support; counselling of the spouse, members of the family and friends can be done together with the patient (Shrestha et al, 2017).

Sharing of experiences is an important aspect of social support, therefore health care providers should proactively seek the lived experiences of patients on their social support in order to enhance the quality of care.

2.3.4 Spiritual care

Spiritual care is the care that recognises patient's religion and /or spirituality and attends to their spiritual needs. Providing spiritual care means being sensitive and accommodating the various religious, cultural and traditional beliefs of the patient, their families and friends. Provision of spiritual care by health care professionals to terminally ill patients is related to improved quality of life, greater hospice utilization and fewer end of life interventions (Balboni et al, 2010). However, a large number of patients with cancer did not receive the spiritual care they wanted while in hospital (Pearce et al., 2011).

Establishing patient's spiritual needs by health workers goes a long way in determining the kind of spiritual care they will require. Although nurses may have a little confidence to meet their patient's spiritual needs due to lack of know-how (Zakaria Kiaei et al., 2015), effort can be made to involve the spiritual leaders as per the patient's preference.

2.4 Communication

Informing and education (communication) of patients with cancer is a dimension of PCC that is very crucial. Patients need to be informed on all aspects of their management as information helps to facilitate autonomy, self-care and health promotion. Communication barriers and lack of trust in the healthcare system leads to poor adherence to management choices and plans (Ahmed et al., 2017).

Documented researches have provided a lot of insight on how patient's culture influences communication with physicians (Schouten et al., 2006 & Chaturvedi et al., 2014), and others have dealt with patient's expectations on a clinician's behaviour in regards to communication taking into account their preferences and desires (Deledda et al., 2013).

Most of the studies on patient-provider communication are quantitative with very few giving a qualitative view. Although quantitative studies allow for association of variables, it is important to get a detailed understanding of a patient's lived experience. Physicians however, need to be aware of the specific factors that hinder or promote effective communication with patients (Rocque and Leanza, 2015).

Patients with cancer have special communication needs including: information on clinical status, progress and prognosis, as well as the processes of care. In order to improve on quality of care it is important for providers to develop positive relationships with their clients by practicing good communication skills to better understand patient's experiences.

2.5 Respect for patient's values, preference and expressed needs

This means treating patients with dignity, respect and sensitivity to their cultural or religious values. This could be achieved by giving informing about their medical condition, involving them in decision making, recognizing and treating them as individuals with unique values and preferences and providing an atmosphere that is respectful of the patient's quality of life issues (Van Leijen-Zeelenberg et al, 2016).

Recent studies have shown potential areas of improving PCC through patient's preference which are non-time consuming and inexpensive (Aumann et al., 2015), with many patient's preferences mainly requiring information and education either during or after treatment (Cherven et al., 2015) while others showed preference for open, collaborative communication with health care professionals on areas such as sexuality, future fertility among other concerns (Reese et al., 2017).

Rapid diagnosis and treatment, high professional standards, and providing information about treatment, (side)effects and consequences was rated as having the highest priority in cancer care (Petersen et al., 2015). Another key preference and need realised was involvement in treatment decision making. A study in Australia indicated that a large number of migrant cancer patients underwent passive involvement during treatment consultations and stated a desire for more involvement despite the challenges in language difficulties (Sinclair et al., 2016). It is therefore, important to recognize patient's perspectives and more so the gynaecological cancer patients as it can influence practice, policy improvement and future studies.

2.6 Involvement of Family and Significant others

Informal care giving by first-degree relatives takes away lots of burden from the formal health care workforce (Bhalla et al., 2014). Timely involvement of family members at different stages of the decision-making process may help them to adjust to patients' illness, and prepares them for any eventuality as well as reduces their psychological distress ((Maltoni et al., 2016).

Researches on family caregivers have brought out several factors which need to be considered before engaging them. These include: when and how to involve the family caregivers, their availability, and attitude towards the treatment decision making process and their overall contribution towards the care of the patient. However, it is critical that the health care

professionals make certain the patient's preferences and the various ways of involving the family in decision making (Laidsaar-Powell et al., 2016).

Health care providers are sometimes reluctant to involve family members because the patient has the capacity to make decisions and only involve them when the patient is incapacitated (Laryionava et al., 2018). Sometimes there are barriers such as language, and socio-cultural processes that may hinder family caregiver's engagement (Hetland et al., 2018). Involving the family can help decrease stress and may encourage patients to participate in self-care activities (Bellou & Gerogianni, 2019).

Establishing the patient's preference should be the priority before involving relatives or friends, then coming to an agreement in regard to who should make the final treatment decision, the patient or the family. From the studies reviewed it is clear that health care professionals should involve the family and friends during the continuum of care, recognizing and supporting them as caregivers in order to improve patient adherence and ensure quality care.

2.7 Gaps in Literature Review

This literature review has established that patient-centered care is now accepted globally as a way to ensure quality health care. Unfortunately, there is no documented evidence of standards or guidelines on its implementation. Several studies have been done on one of the eight principles of PCC but none has been done on all or any two at the same time. There's none on patients with gynaecologic cancer specifically. It is important to note that all the dimensions of PCC are interrelated rather than independent. Therefore, determining the patient's perception of PCC should not involve one principle but all principles. Many studies have tried to establish the views of health care workers, family care givers but very few have explored the patient's lived experiences on PCC.

The Picker Institute developed a tool for assessing the quality of PCC which was to provide a picture of in-patient experiences of health care. The use of this tool has enabled clinicians to monitor the quality of health care to a great extent especially in countries with established health systems. However, in the Kenyan context, there's need for more qualitative research to establish a baseline on PCC and eventually how to monitor health care. There's also a gap in patient-centered cancer care (PCCC) where individual cancer care specialists e.g. haemato-oncology, gynae-oncology, paediatric oncology, have not yet set out guidelines on PCCC as per the cohort. This therefore, means cancer care cannot be monitored and no one knows whether they are providing quality care.

With the limited documentation of patient's experiences on PCC as a whole in the Kenyan context, this study among other things provided background information that may help to develop a PCC monitoring tool in the country. In future, studies may need to be done on knowledge, attitude and practice of health workers on PCCC before putting together a monitoring tool.

2.8 Theoretical Framework

This study adopted the Donabedian model developed by Avedis Donabedian, in 1966. It provides a structure for exploring and assessing the quality of health care services and this can be drawn from three categories i.e. the structure, process and outcome.

Structure includes the physical facilities, equipment and supplies, human resource and organizational characteristics, e.g. staff training and payment methods. These factors control how providers and patients in a health care system act. Structural measures enable the consumers to analyse the ability of the health care providers, the available systems, and how the processes function.

Process includes patient education, preventive care, diagnosis and treatment. The actions of the patient and their families are also included here. Process measures point out the interventions of health care providers which are both preventive and curative.

Outcome includes clinical outcomes which can include changes in behaviour, attitude, and satisfaction with the care or improved quality of life. They reflect the impact of the health interventions on the patient's health.

Donabedian believed that the health system structure affects the processes, which then affect the health outcome. This study aims at measuring the process in patient-centered cancer care, as perceived by the patient, in terms of, holistic care, communication, respect for patients' values, preferences and expressed needs as well as family involvement. This will determine whether the outcome is either high or low quality of patient-centered cancer care.

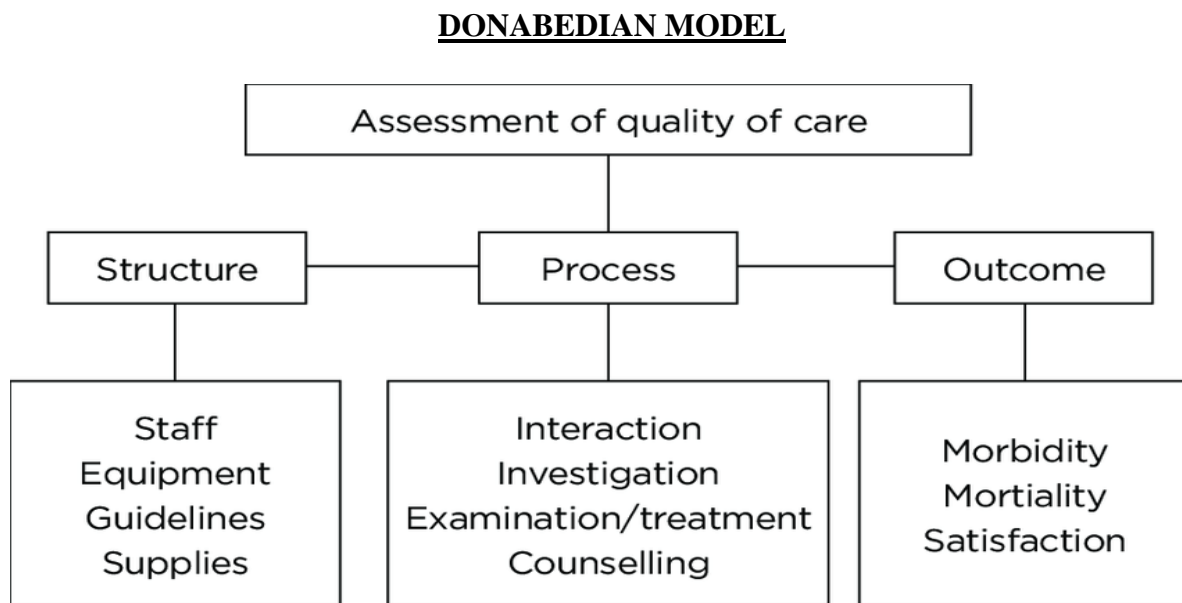


Figure 2: Theoretical Framework
Source: Donabedian (1988)

2.9 Conceptual Framework

Definition of variables. This study assessed the patient's perception on how the provision of holistic care, communication with health care providers, respect for patient's preferences and values as well and family involvement (independent variables) is impacting on the quality of patient-centered cancer care (dependent variable) that they are receiving. It also took into consideration the institutional factors and health care provider's characteristics (confounding factors) that could influence both the independent and dependent variables.

CONCEPTUAL FRAMEWORK

Independent variables

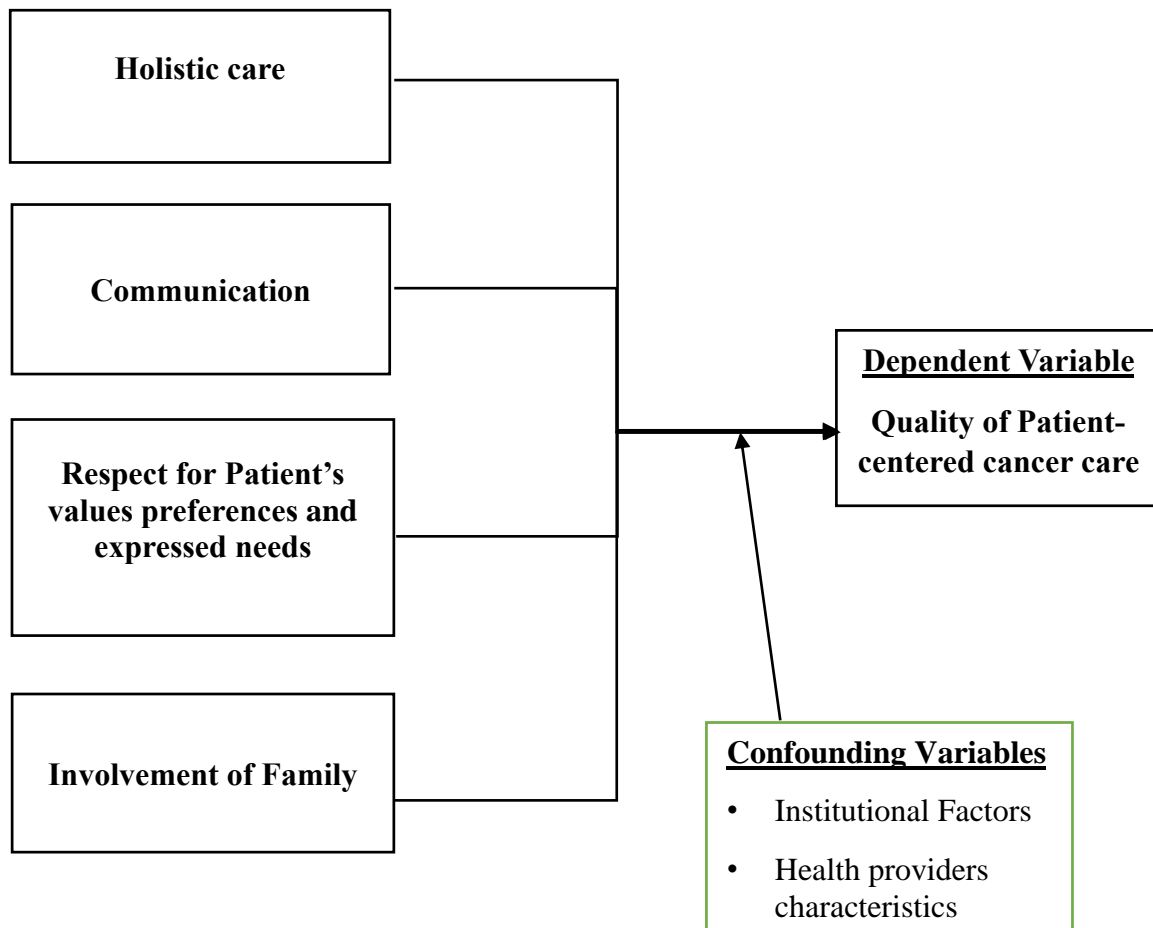


Figure 2.2: Conceptual Framework

2.11 Operational Framework

Independent Variables

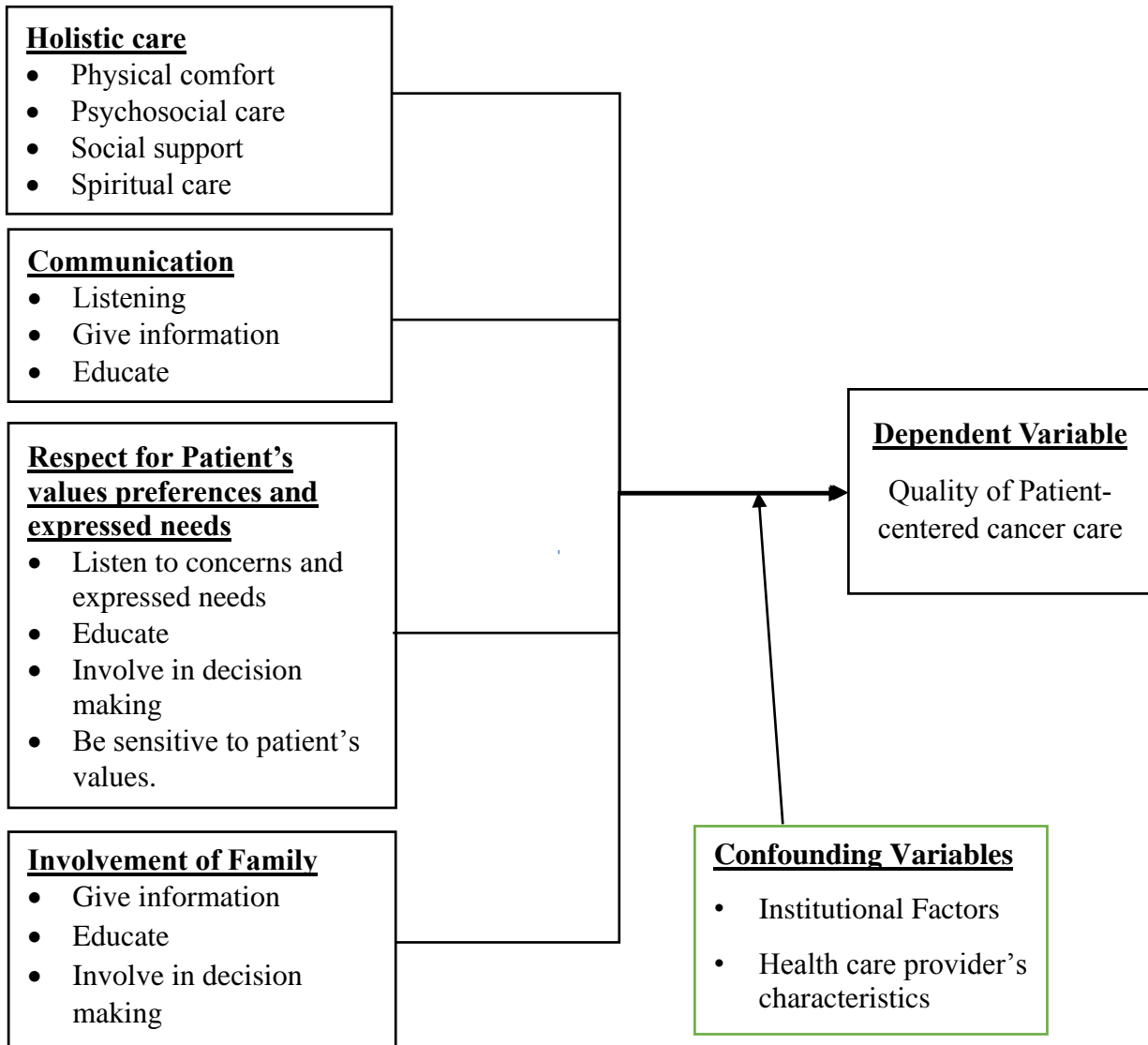


Figure 2.3: Operational Framework

CHAPTER THREE: MATERIALS AND METHODS

3.1 Study Design

This was a qualitative study with an interpretive phenomenological approach seeking the patient's opinions, subjective accounts and individual interpretations through in-depth interviews (IDIs). Interpretive phenomenological approach provided a better understanding of the individual patients lived experiences and took advantage of their unique perspectives. Taking into account what they underwent and how they felt about it.

3.2 Study Area

This study was conducted in the gynaecological wards at Kenyatta National Hospital (KNH) in Nairobi, Kenya. KNH is a level six facility of the Ministry of Health, with a bed capacity of about 2000. A multi-specialty complex that offers universally accredited standards and is ISO 9001:2015 certified. It is located in the Upper Hill section of Nairobi, about 3.5 kilometres west of the Central Business District and is found along Hospital Road. It serves as a teaching hospital for the University of Nairobi's College of Health Sciences, the Kenya Medical Training College and other public and private institutions and is currently the largest teaching and referral hospital in the country.

The gynaecological wards are part of the Obstetrics and Gynaecology (OBS/GYN) Department, one of the largest and busiest departments in the institution. The OBS/GYN department has several units, including: The Labour Ward, three postnatal and antenatal wards (Ward GFA, GFB and 1A), two gynaecological wards (Ward 1B & 1D). Three out-patient units namely: Clinic 18, Clinic 66 and the Youth Centre.

Of the two gynaecology wards, ward 1D takes care of the acute gynaecology patients i.e. patients with threatened abortions, puerperal sepsis/psychosis, ectopic pregnancies, and acute gynaecological cancer cases among others. This ward also has patients who are mainly in stage III and IV of their illness, on palliative care and not many are ambulant. Ward 1B on the other

hand admits patients with less acute gynaecology cases like patients with ovarian cysts, vesicle vaginal fistula (VVF), recto-vaginal fistulas (RVF), those for bilateral tubal ligation (BTL), hysterectomy, fibroids excision and cancer patients on chemotherapy or radiotherapy. Ward 1B has patients who are ambulant and in stage I, II and a few in stage IIIa of the illness. The common gynaecologic cancer here are cervical, endometrial, choriocarcinomas and ovarian.

3.3 Study Population

The study population comprised of patients with gynaecological cancers who were undergoing either surgery, chemotherapy, hormonal therapy or radiotherapy for ovarian, endometrial/uterine, vulval, vaginal, fallopian and cervical cancer in wards 1B & 1D at Kenyatta National Hospital.

3.4 Recruitment Criteria

3.4.1 Inclusion Criteria

The intended participants were women on treatment for gynaecological cancer, at Kenyatta National Hospital, were above 18 years of age and were of sound psychological and cognitive health having received at least one session of either chemotherapy, hormonal therapy or radiation therapy for their illness and having given a written informed consent.

3.4.2 Exclusion Criteria

Those who were not enrolled in the study were women with gynaecological cancers, but were newly diagnosed and had not yet been initiated on any kind of treatment. Patients who had dementia or any form of cognitive disorder, were very sick, and those who were eligible but declined to give a written consent were also excluded. Any patient who had signs and symptoms or highly suspected to have COVID 19 were also be excluded.

3.5 Sample Size Determination

Participants were identified from the two gynaecological wards at KNH. The study participants were objectively selected (purposive sampling) by the principal investigator and a minimum of 6 participants were identified from ward 1D. Taking into account the various types of gynaecologic cancers and ensuring each type was represented as much as possible. The principle of data saturation determined the sample size, where data was collected until redundancy was achieved.

3.6 Sampling Technique

Participants were selected using purposive sampling. From the nursing registers and patient's files in the wards, the researcher used her judgement to choose patients. This included ensuring the patients could understand and speak either English or Kiswahili, were ambulant and in fair general condition. The researcher chose patients who were available in each of the wards at the time and only those who met the inclusion criteria were selected as study participants.

3.7 Recruitment and Consent Procedure

The eligible participants were taken through the content of the information sheet including why the study was being carried out, the benefits, potential risks and what was expected of them during the interview. The information sheet and the consent were translated into Kiswahili for better understanding by the participants and they were made to appreciate that their participation in the study was voluntary and that they were free to withdraw from the study at any time without any negative implications. The participants were also allowed to ask questions, any concerns were cleared and clarifications were made on the aspects of the study that may not have been clear.

An endorsed signature or thumbprint was then obtained before the participant was accompanied into the room where the interview was conducted. Participants were taken to a quiet, spacious, well ventilated and confided area within the wards from where the interviews

were carried out. The interviews took place mostly in the afternoons after visiting hours when there were not too many procedures going on and the patients were relatively free.

3.8 Trustworthiness

The Lincoln and Guba criteria was used to ensure trustworthiness. It comprises credibility, dependability, transferability and confirmability.

Credibility was ensured by spending time in the units so as to familiarise with the environment, build a trusting relationship with the participants and develop a rapport with them. The interviews were also undertaken at different times of the day and in two wards with fairly different kind of patients so as to give a divergent view of their experiences. Respondents were also given a chance to listen to their recordings in-order to ensure accuracy of their responses. To further ensure credibility, the researcher personally collected all the data to avoid misconceptions. Dependability involves showing that the findings were consistent and could be repeated. An independent researcher's views were sort on the process and the findings of the study. This enabled better evaluation of the preliminary results and sufficiency of data. Transferability was achieved by accurately interpreting the respondents' detailed experiences while paying attention to their cultural and social backgrounds. Confirmability was established by audio recording the interviews and then transcribing verbatim as soon as possible. Making sure the experiences were correctly described and all non-verbal communication was recorded in a notebook. All records had dates and time of the recordings. The views of another analyst were also sort and a code book was formulated to guide in theme formulation.

3.9 Research Tool

An interview guide was used to guide the moderator during the interview. The guide outlined how the interview was set up including structured probe questions, follow-up questions and finally exit questions. The questions were simple, short and clear to avoid any biases and ensure quality.

3.10 Pre-Testing

Pre-testing was done to recognise any issues such as unclear wording or to check if the guidelines were well understood. It also helped to determine the strengths and weaknesses of the study tool for example the order and format of questions. (Charlotte, 2015). An undeclared pre-testing design was used whereby the respondents were not told that it was a pre-test. It was done at the gynaecological outpatient clinic (Clinic 18), which offers various services among them, the review and follow-up care for women with gynaecological cancer. Only women who gave a written consent were recruited for the pre-testing. Any adjustments to the tool was done accordingly after the pretesting.

3.11 Data Collection Procedure

The identified participants who gave a written consent were taken into a confined area within the ward, where the interview took place. Because of the larger number of stable patients in this ward, more in-depth interviews were carried out in ward 1B. The principle investigator and the study participant were the only people who were in the room to ensure confidentiality. An interview guide was used to coordinate the discussions and ensure relevant information was captured. All the sessions were audio recorded and the recordings transcribed as soon as possible to avoid forgetting the important dialogues. Short notes were also taken during the discussions and after the dialogue for reflective purposes and also to ensure quality. Emotional issues were addressed by giving the respondent time to express their feelings, allowing them to cry and/or involving a counsellor when necessary.

3.12 Data Management Plan

The data management plan describes the data entry and cleaning, data analysis and data storage.

3.12.1 Data entry and cleaning

The audio recorded data was transcribed daily after the interviews. All print outs of the transcripts, any field notes or documents and the patient's demographic data were collected and marked accordingly.

3.12.2 Data analysis

The study population was described by summarizing the socio-demographic data and clinical characteristics using measures of central tendency and dispersion.

The transcribed data and documented notes were arranged and filed immediately, as per the study objectives. This was to ensure no mix up during the analysis. i.e. for the responses on holistic care a separate folder, while communication responses were in another one. Thematic analysis was used to make sense of the data as per each objective.

During the interviews the researcher noted non-verbal cues on a note book that served as the research log. Each participant was given a unique code depending on the position and the date of the interview and the interview recordings were saved in a password protected file in the researcher's computer to avoid any unintentional loss. Transcription of the original recordings was done verbatim, then the researcher read through the transcripts several times to familiarize herself with the data before making potential codes. Different categories were identified and assigned codes so as to describe the content. Constant comparisons were made to create patterns or themes from the codes either from the words used, or phrases most commonly presented while taking note of the language, beliefs and opinions of participant during the interviews. Eventually, the themes were defined, and linked to the study objectives to find meaning and interpretation.

3.12.3 Data Storage

All interview notes, transcript print outs and audio recordings were anonymised by allocating continuous numbers to each participant. They were then locked away in a filing cabinet

immediately. The keys to the filing cabinet were only handled by the principle researcher to ensure confidentiality. Any soft data entered in the computer was password protected and only accessed by the principle researcher.

3.13 Ethical Considerations

Ethical approval and clearance was sought from Kenyatta National Hospital-University of Nairobi, Ethics and Research Committee, the hospital management and in particular the Head of Department, Obstetrics & Gynaecology.

The researcher explained the purpose, benefits, and risks to each participant before obtaining an informed consent from them. Participation was voluntary and they were free to pull out of the study at any stage without any penalty what so ever. They were also informed that there were no financial benefits for taking part in the study. Confidentiality was assured by maintaining the anonymity of every participant and the information given stored in password protected files.

COVID 19 Prevention/Safety Measures

To safeguard the participants from corona virus disease (COVID-19), the researcher ensured that the space where the interviews were held was well ventilated and spacious enough for participants to be able to keep the recommended social/physical distance of one and half metres from one another to prevent interpersonal transmission. Environmental cleaning and disinfection were ensured by regularly cleaning of the surfaces and floors within the ward with a disinfectant solution.

Before the participants were ushered into the room, they were assessed for any symptoms of acute respiratory illness such as fever, nasal congestion, rhinorrhoea, sore throat or cough. A brief history was also taken to rule out any recent travel outside the country, any contact with a COVID-positive patient or any signs and symptoms of COVID-19.

The researcher also ensured all the participants were wearing disposable surgeon's face masks at all times and were provided a place with soap and running water for washing hands or alcohol hand-rubs with at least 70% alcohol, and encourage frequent hand hygiene to limit or prevent person to person transmission. A health talk was also given to all patients on respiratory hygiene/cough etiquette, restricting movement within the institution and restricting visitors to the hospital as well as the proper way to wear face masks to prevent cross infection.

Proper personal protective equipment was worn as per the situation. The researcher also went for screening for SARS COV2 to rule out infection while working within the hospital.

3.14 Limitations and Delimitations

Study population: the population of in-patients on treatment for gynaecological cancers in KNH is low and the researcher involved almost all the patients who met the inclusion criteria in order to get a representative sample.

Responder bias: the subjects may have responded to questions untruthfully or misleadingly. They may have felt the pressure to provide socially acceptable answers on their health status and hospital environment may have had an influence on their answers. To avoid this the researcher explained to the participants the importance of honesty during the interview and tried as much as possible to ask simple and well understood questions depending on the patient's cognitive level.

Interviewer bias: how the interviewer asked questions and how the participants responded to the questions may have influenced how the participants responded. This was mitigated by ensuring the questions were as simple as possible and the researcher minimized responses to the participants' answers.

Recall bias: some participants may not have remembered some details in their treatment. To mitigate this the information was collected from the patient's personal file.

Language Barrier: differences in languages may have caused difficulty in communication. This was mitigated by looking for a person who understands the patient's language to act as a translator.

Lack of Triangulation: This study focused on the patient only. In future other studies could look at the perceptions of the health care providers. Comparing information from patients and healthcare providers would have strengthened the findings.

3.15 Data Dissemination plan

The study findings will be shared with the KNH-UON ERC, the School of Nursing Sciences (SONS) of The University of Nairobi, where a copy of the study and results will be made available in the repository of the Library, and the staff and management of KNH through the KNH Research Unit. The study and its findings will also be presented in professional conferences, and be published in peer reviewed journals.

CHAPTER FOUR: RESULTS

4.1 Introduction

This chapter presents the qualitative findings from the study's analysis of information obtained from in-depth interviews (IDIs) with patients seeking their opinions, subjective accounts and individual interpretations. The overall goal was to get an in-depth understanding of the individual patient's experience and take advantage of their unique perspectives on their experience while seeking gynaecological care at Kenyatta National Hospital. The results presented outline the themes that emerged from the interviews, illustrated with exemplar quotes from interviewees and organized into key themes and subthemes focussing on aspects of patient centered cancer care. To identify the interviewees, a unique number was allocated. Themes aligned to the study objectives and emergent ones were identified and organized into themes and sub-themes as appropriate. Five main themes were identified: patients' experiences with holistic cancer care, healthcare provider-patient communication; respect for patients' values, preferences and expressed needs; involvement of family and significant others in patient's care.

4.2 Respondents socio-demographic characteristics.

Majority of the respondents 52%, (n=10) were aged between 31 and 40 years with a median age of 37yrs and with 48% (n=9) having had secondary education and 42% (n=8) having primary education. Sixty eight percent (68%) n=13, were married and most of them 63% (n=12) were unemployed. All respondents had children with most of them having less than 5 children each.

Table 1: Respondents socio-demographic characteristics

VARIABLE	FREQUENCY (n)	PERCENTAGE (%)
Age group		
20 – 30	3	16
31 – 40	10	52
41 – 50	6	32

Education level		
None	1	5
Primary	8	42
Secondary	9	48
College	1	5
Occupation		
Employed	2	11
Self-employed	5	26
Unemployed	12	63
Marital status		
Single	6	32
Married	13	68
Type of house		
Semi-permanent	9	47
Permanent	10	53
Number of children		
0 – 5	16	84
6 – 10	3	16

4.3 Respondents Disease Characteristics

During the period of data collection 47% (n=9) of the eligible participants had cancer of the cervix 42% (n=8) of whom had received chemotherapy. Fifty-eight percent (n=11) of the respondents had been diagnosed within the last 6 months.

Table 2: Respondents disease characteristics

CHARACTERISTIC	FREQUENCY (n)	PERCENTAGE (%)
Diagnosis		
Cervical cancer	9	47
Ovarian cancer	3	16
Vulval cancer	1	5
Gestational trophoblastic disease (GTD)	6	32
Treatment		
Chemotherapy	8	42
Radiotherapy	5	26
Surgery/chemotherapy	5	26
Radiotherapy/chemotherapy	1	6

Time since diagnosis		
0 – 6months	11	58
7 – 12months	5	26
12months and over	3	16

4.4 Theme 1: Patients’ experiences with holistic cancer care

Experiences of patients seeking cancer care was explored to elicit the holistic nature of care received. Aspects of general care, spiritual care, psychosocial care and physical comfort were explored.

4.4.1 Sub-theme 1: Improved general health

Patients’ experiences with holistic cancer care was nearly similar among interviewees with a majority narrating a positive overall experience. Positive experiences with general care were tied to improvements in their general state after receiving care at the facility.

“I have been taken care of well because when I came here, I was very ill, my blood was 7.8 and I was transfused 2 pints of blood in 1D then I came here. I was very happy because now I’m okay.”. [Respondent 19]

“I was treated well not badly, if I would have been treated badly, I think I would not have been alive. Compared to when I came here, the condition I was in was not good now I am in good condition. I feel I’m healthy. the problem I was having I see is over. and even if I am continuing with treatment, I feel at least it is not as before”
[Respondent 5]

Her sentiments further indicating that improvements in general condition was tied to a positive experience while receiving care. Similarly, respondent 17 said:

“... since I came, they have taken care of my chest. I wasn’t breathing well; I was breathing very fast. They have been taking care of my chest, at least now I’m feeling

better, I sleep without oxygen. Right now, I'm using this chemo. I see it has helped me".

[Respondent 17]

There were four sub-themes analysed under physical comfort care namely: pain management, assistance with bathing/toileting and environment. Majority of the respondents felt their pain was well managed.

4.4.2 Sub- theme 2: Pain well managed

Pain management is central in ensuring physical comfort. Interviewees were asked about how they managed their pain or how the hospital staff helped them manage their pain.

Almost all the interviewees reported that their pain was managed effectively by the healthcare providers, a few reported having no pain at all at the time of the interview. Often nurses went round enquiring if any of the patients was in pain. One interviewee reported:

"When in pain especially due to my problem, the nurses give me painkillers. They come round asking how we are feeling and if we say we are in pain, then we are given medicine. This medicine has helped me remain pain free... If they pain is too much, they give me morphine which is really helpful. They also give us drugs when they are due" [Respondent 4]

Pain management medication was also delivered via an IV line, via an injection or orally. One interviewee said:

"They have attended to me; they have been putting some medicine through my hand. Whenever I told them I'm feeling pain somewhere, they would give me an injection. I have not seen them treat me badly" [Respondent 17]

In some instances, interviewees reported that they initiated pain care by requesting nurses for pain medication:

When you are in pain you ask for a drug, they give you. After theatre they always give me drugs, TDS, three times a day... when I was in pain, when I came from the theatre,

I was in pain they injected me tramadol and just left me there comfortable. In fact, we were two of us, they did to both of us [Respondent 18]

Assistance with toileting and bathing is a major part of physical comfort care, this aspect of care, alongside maintenance of privacy while providing care, were explored.

4.4.3 Sub-theme 3: Assistance with bathing offered

Nearly all the interviewees who needed assistance with bathing and toileting were assisted.

“... after surgery on the first day because I could not immediately leave the bed, the nurse brought me warm water and I bathed myself while in bed. On the 2nd day I was able to walk to the bathroom and now I am able to bath without a problem”
[Respondent 12]

“For me I am happy with the care, whenever I need something, they give me. for example, if my clothes are soiled, they change for me or if I need pampers, they also give me without any problem. Except of course when they are not available which I understand”

“To say the truth, I could hardly leave the bed. The nurses would bring me water so I could bath myself while in bed. They also gave me pampers to help with toileting”
[Respondent 4]

“They always provided hot water in the morning for bathing. For those who could not get out of bed because of illness, they were assisted to bath in bed” [Respondent 3]

4.4.4 Sub-theme 4: No assistance with bathing offered

However, there are those who received minimal or no assistance with bathing or toileting.

Respondent 15 narrated here ordeal regarding assistance with bathing and toileting:

“How can I bath? They give me warm water and I wipe myself in bed. I don't have a choice. I will wait until I'm discharged so when I get to my son's house, I can bath properly... If someone is not able, I would like them to have pity on them and help them. Because God

called them to do this kind of work. They do it but they complain. Very few don't complain...Sometimes, they can let a patient who has messed herself stay for a long time. Such that the room is smelling until other patients are not able to eat. Not to mention there is no social distancing...even though I have not mentioned"

4.4.5 Sub-theme 5: No privacy

One interviewee reported that there were instances when there was no privacy offered when being assisted with bathing:

"When he is going on to review patients the nurse doesn't care. She continues to tell the patients to remove their clothes and bathe them. Instead of letting the doctor first finish the round then the patients can continue bathing" [Respondent 4]

4.4.6 Sub-theme 6: Clean environment

To explore their perceptions and feelings about their environment, interviewees were asked how they felt about the hospital environment. For most of the interviewees, the environment was clean with fresh air and adequate space enhancing physical comfort.

"The environment is clean, there is fresh air" said Respondent 1.

"Everything is fantastic, anyway everything is good. You see, the other side the wards are big, you have spaces, not a space like here, you have space. You have no issue with anyone" [Respondent 18]

Psychosocial care was targeted towards addressing, emotional, cognitive, social and functional problems often through counselling and other social interactions. The most commonly reported psychosocial issues that were a source of stress and anxiety ranged from family and work-related concerns to meeting costs of care. Under this theme, two categories were identified namely; sources of psychosocial distress and dealing with psychosocial issues. Among the sources of psychosocial distress, the following sub-themes were identified:

4.4.7 Sub-theme 7: Family/children

Most of the respondents were worried about their families while they were admitted and receiving care at the hospital.

“... my concern is that my children are young and I have left them alone for a long time” [Respondent 1]

The extended periods of time that the patients take in the facility while undergoing treatment was a major concern to them in terms of being separated from their families for long periods of time. Especially those with babies, they were likely to miss their major developmental milestones. Respondent 5 voiced her concern over this:

“I left a one-year old baby at home who was breastfeeding when I came for hospitalization. Now she is talking. Whenever I am talking to someone on the cell phone, she is eager to talk as well. So, if I would continuously think about her, I would not be alive today. Stress would have overwhelmed me”

4.4.8 Sub-theme 8: Job security

The extended period of stay at the hospital also caused anxiety about job security.

“I’m not worried. What I’m worried about is where I go to work, maybe they’ll see that I’ve extended for so long. Then maybe...in fact they took somebody for locum, so they may say that ‘now that Jane (pseudonym) has gone for long, let’s take Joy(pseudonym) for good’, you see” [Respondent 18]

4.4.9 Sub-theme 9: Financial cost of care

Another psychosocial issue with most of the interviewees was financial-related stress and the additional strain the cost of care places on their already constrained income.

“The NHIF does not cover all my medical expenses for example, it only covers 20 sessions of radiotherapy, the rest I am to pay cash which I do not have. The hospital administration should find a way to help us because we delay our treatment due to lack

of money... My eldest daughter is at the university and sometimes I wonder whether she will complete school. This starts to cause some stress” [Respondent 13]

4.4.10 Sub-theme 10: Inability to care for self

Another major source of stress for most patients was the inability to engage in self-care and be self-dependent. This could be due to the lack of respect for their values, preferences and needs that they constantly face while receiving care at the facility. A 50-year-old widowed woman receiving treatment for her cervical cancer said:

“There is a lot of stress. For me I would like to get healed and be able to walk. Or at least I would like my feet to heal to be able to bath, only to bath or to wash even a plate. Or even to be able to walk around and not depend on anyone. Like right now I am alone my only child is away working.” [Respondent 15]

When dealing with psychosocial issues the following sub-themes were identified:

4.4.11 Sub-theme 11: No psychotherapeutic interventions.

“I really don’t know. I have not seen any counsellor. Or maybe it is because I have not stayed long”. [Respondent 16]

Patients therefore invented ways of dealing with their psychosocial issues. Self-care and keeping to self, were the two ways identified in which they dealt with their psychosocial issues.

4.4.12 Sub-theme 12: Sharing with others

Given the lack of facility-initiated psychotherapeutic interventions, patients resorted to other means of dealing with their psychosocial issues. When asked how they dealt with stress and other related psychosocial issues, most of the interviewees said that they open up to the other patients in the ward.

“We usually share with other patients who are in the ward. This helps us a lot. I also talk to my family and friends through the phone”. [Respondent 12]

Respondent 2 said that she deals with her stress through socialization:

“I like socializing and talking to people to reduce my stress or anxiety. I share with other patients or even the health care provider. I am free with everyone. Even the new patients I usually introduce myself to them and create friendships easily. So, I rarely get stressed or worried “

4.4.13 Sub-theme 13: Keeping to self

There are other interviewees who preferred to keep to themselves and not share their psychosocial issues with any one:

“I just keep quiet and keep to myself I don’t talk to anyone because I prefer to stay silent as I am not comfortable sharing with anyone” [Respondent 3]

With regard to spiritual care, Balboni et al., (2010) stipulated that health workers should be sensitive and accommodating to the varied religious, cultural and traditional beliefs of their patients and families. Under this category, three sub-themes were identified: insensitivity to spiritual needs, lack of in-hospital spiritual care and effects of COVID-19 on spiritual care

4.4.14 Sub-theme 14: Insensitivity to spiritual needs

When asked about spiritual care, reports from some respondents revealed that there were instances when health workers were very insensitive to the spiritual needs:

“... there are nurses who do not want us to pray loudly. They say we pray silently in our heart. For me I prefer to pray loudly. Others don’t want us to listen to gospel music even with low volume, yet most of the patients want to listen” [Respondent 5]

4.4.15 Sub-theme 15: Lack of in-hospital spiritual care

Most of those interviewed said that no spiritual care was offered by the hospital.

“No one from the hospital chaplaincy comes but I am in touch with people from my church. We talk and they encourage me through the phone” [Respondent 13].

Her sentiments were also echoed by another patient

“No one from the hospital church has ever come to encourage or pray with me.”

[Respondent 3]

4.4.16 Sub-theme 16: Effect of COVID-19 on spiritual care

Due to the ongoing COVID-19 pandemic, the hospital introduced measures to reduce contact with patients and curb the spread of the disease. A number of the patients recognized this:

“during this time of corona, the preachers do not come.” [Respondent 1].

For most of the interviewees, spiritual care and support came from their pastors, fellow church members and their families.

4.5 Theme 2: Patients’ perceptions on facilitators and barriers to healthcare provider - patient communication

Patient-provider interaction with a focus on communication was explored. Barriers and facilitators to effective communication were identified as the two main categories. When interviewees were asked about their experience when communicating with healthcare providers, the following sub-themes were identified:

4.5.1 Sub-theme 1: Response to inquiries from patients

Often times the interviewees had questions and concerns lingering in their minds. Whenever they would seek further information on the concerns they had, healthcare workers provided the information necessary and the interviewees got responses to questions they posed to healthcare providers. This created a conducive environment for inquisition and encouraged future communications thus facilitating communication in general.

“Most of the doctors who come for the ward rounds are always ready to answer my questions when I ask. The senior doctors do not tell us much during the ward round but the other doctors and nurses do explain and make us understand what is going on.”

For example, I like knowing how my blood test is. Whenever I ask some doctors, they tell me it is okay. Others will say it is 10 or less than 10 which is not good, and I know when it is 10, I am okay “. [Respondent 2]

Another patient reiterated:

“When I have a question the doctors or nurses always answer. For example, I ask about the lab tests done and they always tell me what it was for and if the result is good or bad. They even tell you how much your blood (Hb) was if you ask” [Respondent 6].

Respondent 1 also shared the same sentiments concerning how the healthcare providers addressed any of the concerns they had about the care they were receiving; she said:

“I have seen them speak well; they serve us well. when you ask a question you are answered, they will always answer you there is another doctor I asked him a question, I just called him and asked him and he answered me very well.”. [Respondent 1]

On the other hand, six barriers to healthcare provider-patient communication were identified by the respondents.

4.5.2 Sub-theme 2: Busy schedules of healthcare providers

There are times when the healthcare providers were often too busy and the patients felt that they could not ask questions at such times. This was seen as a barrier to communication since patients would end up not getting any information on any concerns or issues about their care.

“...if I have a question, they have an answer. But sometimes when they are busy, it’s difficult to ask”. “... For the nurses I always saw they were busy and I didn’t want to disturb them when they were taking care of the other patients”. [Respondent 2]

4.5.3 Sub-theme 3: Preconceived notions about patient’s understanding on care

A number of the interviewees noted that sometimes communication could be impeded by preconceived notions about their ability to understand the information shared. One interviewee said:

“...but some will not tell you anything because they assume you do not understand.

There are those who think your questions are not important” [Respondent 2]

4.5.4 Sub-theme 4: Lack of involvement in care planning and shared decision making on care

Five out of the 19 respondents expressed their outrage on lack of involvement in the planning and decision making regarding their care. This showed that involvement of patients in planning and decision making can facilitate communication and when this is not done, communication is negatively impacted. Interviewees said that they often felt ambushed by decisions made regarding their treatment by the healthcare providers.

“I came for chemo, then the doctor decided maybe he saw the wound was shrinking too fast then he decided let’s do surgery. So that Wednesday I was to go for surgery. They asked me to bring people to donate blood. Now where was I to get blood” [Respondent 18]

4.5.5 Sub-theme 5: Provision of incomplete information concerning care

Respondent 14 reported;

“Yesterday during the ward round the doctors asked me where I reside. They didn’t tell me whether I will continue coming for daily wound cleaning or I will be coming to the clinic, after discharge. They just left without explaining”.

This further showed involuntarily hoarding information impedes effective communication.

Another interviewee also reported that at the onset of treatment, she was not aware that she had already been started on chemotherapy, she said:

“You know we usually come and we are put on drugs, even that day I came I didn’t even know I was put on chemo. I didn’t know. Because I was added blood like today and we were starting chemo the next day, so I didn’t know that I would be started on

chemo, so the doctors who usually come round came and said 'put her on chemo'. So, you know I don't know." [Respondent 3]

Another interviewee noted that she was not told about the side effects of the treatment she was about to start and recounted her previous thoughts when she first started treatment:

"When I first came into the ward, I asked myself "did all the patients look for someone to come and shave off their hair?" everyone was bald. A few days later I realised that the chemotherapy is what was causing the baldness. I later went home after chemotherapy and my hair fell off. No one had informed me that chemotherapy cause hair to fall off. I was informed the chemo would make my nails would turn black, and cause a lot of nausea and vomiting. Nothing about my hair" [Respondent 11]

4.5.6 Sub-theme 6: Assumptions made by healthcare workers

Often times the healthcare providers assume that they always give the patients what is best for the patients even without consulting the recipients of the said care. Decisions regarding admissions and length of stay in hospitals have significant impacts on the patient's life. Making assumptions on what's best for the patient can bar effective communication and have negative impacts on care and disease outcomes. This was clearly brought out by respondent 18 who said:

"In fact, let me tell you, I asked the doctor, the first thing I asked him 'you are telling me to be admitted, for how long am I going to be admitted?', 'for months'. Then I said wow, if months, I can't make it let me just die' then I told him if it is for months, I won't make it, then he told me 'for a week?' then I said it's okay, that's when I went home"

Respondent 5 also reiterated the same sentiments noting that the nurses assumed that she was aware of everything concerning her treatment and thus did not bother to explain further;

"...the nurses assumed I am aware of it they just asked what I had come for and did not explain further"

4.6 Theme 3: Patients perceptions on respect for their values, preferences and expressed needs

Patients perceived that respect for their values, preferences and expressed needs involved health care workers being concerned about their well-being, being included in planning and decision making about their care, health providers communicating to them in a polite way as well as addressing their needs for physical comfort. There were four sub-themes identified namely: involvement of patients in care, addressing self-care needs, empathy and attitude of staff.

4.6.1 Sub-theme 1: Involvement of patients in care

By taking the time to explain to them the procedure/treatment that they were receiving, the respondents felt that the health providers respected their values and listened to their needs.

“They will always ask how I am feeling and they explain how my disease is because they have the gadgets. They have told me how brachytherapy kills the cancer cells to clear the tumour. In the ward, if I have questions, they will answer but those in the brachytherapy explain better”. [Respondent 4]

4.6.2 Sub-theme 2: Addressing self-care needs

Respect for values, preferences and needs was also perceived by the patients as having their self-care needs addressed by the healthcare providers.

“... respect is there, they have not done anything bad to me. They have not been rude to me. I have been given warm water for bathing and good clothes to wear.”
[Respondent 11]

“when I was bleeding, they always provided me with sanitary towels without delay. Sometimes they even gave me extra pads and diapers so I could keep for later use. They would not hesitate to provide” [Respondent 4]

4.6.3 Sub-theme 3: Empathy

When health care providers took the time to find out how their patients are faring, the patients feel valued by the healthcare providers. A 34-year-old lady receiving treatment for cervical cancer reported:

“There was a day I was not feeling well and I remained in bed which was unlike me. the nurses were concerned and came to find out what was wrong. This makes me feel appreciated and respected” [Respondent 5]

4.6.4 Sub-theme 4: Attitude of staff

A number of interviewees expressed their displeasure at the lack of respect coupled with a negative attitude that some healthcare providers portrayed.

“There are some nurses, like for me bleeding just start, so one day I bled a lot and since I cannot leave the bed, I put the soiled pads in a disposable bag so that it is discarded the following morning. One nurse came and really insulted me, until I asked myself.... Gaaki (Surely) do you know the suffering I have under gone. I cried and later stopped. I am not able to do much. I position my swollen leg to try and change the soiled diapers which they provide. This is something I have never had to do in my life. If she finds a dirty diaper, she really makes a lot of noise and insults me. in fact, nurses, they are very bad in this ward...my legs are so swollen, I cannot leave the bed and yet you are telling me to go and throw my dirty diaper in the bin? There is no hospitality, some of them, not all...” [Respondent 15]

4.7 Theme 4: Patient’s Perceptions on Family Involvement Family Involvement in Care

Under this theme, two sub-themes were identified; family support and absence of family involvement in the patient’s care.

4.7.1 Sub-theme 1: Family support

Almost all the interviewees reported that in one way or another, their family members and significant others offered support, whether emotional or financial.

“They are all supporting me...they are all supporting me, because now, even those medicine, my grandmother...she is the one who bought me drugs...” [Respondent 3]

Another interviewee reiterated,

“They are all supporting me...they are all supporting me, because now, even those medicine, my grandmother... she is the one who bought me drugs” [Respondent 19]

4.7.2 Sub-theme 2: Absence of family involvement in the patient’s care

When it came to healthcare workers involving family members and significant others in the patient’s care, all the interviewees said that they are the ones that directly contacted their relatives and significant others, no healthcare provider directly contacted their family members or significant others concerning their care.

“Whenever they say I need blood I usually call my relatives to come and donate. No one calls them directly. When a drug is missing, they give me a prescription. I then call my relatives to come and pick it then go and buy the drugs. I have not heard anyone being called to be told what I need or how I am faring on” [Respondent 6]

“The healthcare workers do not communicate directly with my relatives. I am the one who tells them how I am doing. If anything is needed, I call my relatives to come”
[Respondent 4]

“On discharge I am given all the information concerning my follow-up. My relative are not involved in any way. I am the one to share any information” [Respondent 14]

CHAPTER FIVE: DISCUSSION, CONCLUSION AND RECOMMENDATIONS

5.1 Introduction

This chapter discusses the findings of the study against what was revealed in the literature and as per the study objectives. The chapter also highlights conclusions drawn from the findings and the recommendations of the study. Awareness of the PCCC aspects and preconceived ideas concerning expected care from a patient with a gynaecological cancer allows the health care provider to provide improved assessment, anticipatory guidance, and share appropriate information while at the same time ensuring that the care is respectful of and responsive to individual patient preferences, needs and values.

5.2 Demographic data

The social economic characteristics of respondents can greatly affect uptake and accessibility of health care services. This study revealed that majority of the respondents were aged between 31 and 40. This is within the reproductive age, hence, women with gynaecological cancers are most likely to fall under this age group.

Most of the respondents had primary and secondary education as their highest level and majority (63%) were unemployed and married (68%). Studies have shown that the incidence of cancer is twice as great among women with low or no education as compared to those with higher education. One such study showed that women with the highest level of education were more likely to go for screening (Damiani et al., 2015). Women with low education levels usually have low income if any and many depend on their spouses for finances when they need to seek health services. Therefore, they may experience delay in seeking health services especially if their spouse also has low income sources. Low socio-economic status may also cause the women to seek alternative sources of therapy first instead of the conventional methods because they are cheaper and more patient friendly.

This study also established that most of the respondents (47%, n=9) had cervical cancer, diagnosed less than 6 months earlier (n=8, 58%) and 48%, (n=8) were on chemotherapy. Cervical cancer is preventable and can be cured if diagnosed early. The low socio-economic status of the respondents may have led to delay in seeking health care services before the pre-cancerous lesions became invasive cancer, needing chemotherapy or radiotherapy.

5.3 Patients' experiences with holistic cancer care

5.3.1 Overall perception of care

The individual patient and their families are considered independent and capable in their own ways of making informed decisions concerning their health (Fateel & O'Neill, 2015). PCCC includes informing, listening and involving patients in their care. Additionally, responding to the individual needs of patients in a holistic and patient-centered manner is extremely important in ensuring positive patient outcomes (Cadet, Davis, Elks, and Wilson, 2016). In this study, patients' positive experiences with holistic cancer care were closely coupled with improved general health and quality of life following care and treatment at the facility. This finding supports other findings centered around patients that saw approval and positive rating of care closely linked to the patients' outcome and general condition after treatment. Indeed, studies by Pitaloka (2006) and Wanga (2013) showed that overall, more than half of the patients were satisfied with the service that they had received. Holistic cancer care was further dissected into physical care (with five sub-themes), psychosocial care and spiritual care.

5.3.2 Physical care

In PCCC physical care ensures the patient's pain is controlled, they are assisted with bathing and toileting when they are unable to, the environment is kept clean, and they are provided with a well-balanced diet according to the individual needs.

Pain management is a critical component in physical care of cancer patients. The interviewees reported that their pain was adequately managed by the healthcare providers. The findings also

showed that patients were actively seeking out solutions to pain, if they had any. They would often reach out to healthcare providers to assist them with managing their pain and would often initiate the management in some cases. In patient-centered cancer care, patient involvement in pain management is critical in ensuring achievement of desired treatment outcomes. Our findings of improved pain management in cancer patients through patient involvement are similar to those by Carrie et al, (2009) that also showed that actively involving patients in pain management and encouraging them to be proactive in managing their pain, improved overall satisfaction with pain management. With good management of pain patients are able to go on with their normal routines such as bathing and toileting.

When patients are not able to bath and use the toilet independently, they require empathy when being assisted and need to be treated with dignity and integrity. Most of the respondents reported adequate support when they needed assistance with bathing and toileting. This is a role played by nurses and can be attributed to availability of all the necessary equipment and adequate staffing. However, some patients felt the services provided were not adequate, they felt more could have been done and some felt their privacy and dignity was not respected. Assistance with toileting is often a task that most nurses find distressing to do and is often accompanied by negative attitudes that may be projected towards the patient. These negative attitudes, evidenced by scolding, name calling or anger could be cumulative effects of unresolved issues such as lack of provision of required equipment, low nurse-to-patient ratios among others. When these attitudes are projected to the patient, they impact negatively and may cause unnecessary stress. When dignity is not ensured during care, patients feel devalued and disrespected. In this study, respect and dignity was found to be closely tied to honouring the patient's bodily concerns, offering assistance when needed and being sensitive to the patient's needs. These findings resonated with findings by Geller et al, (2015) that indicated that respectful behaviours when providing care to patients involved making an effort to honour

the patient's bodily concerns, being sensitive to the patient's needs and preferences as well as listening to the patient. Additionally, Johnson et al, (2015) emphasized that treatment with respect and dignity is fundamental to provision of high-quality patient-centered care. Treating one with dignity also means the environment with which they are in should be comfortable. The environment also plays a major role in the perception of the quality of care offered and influences the experience of patients while seeking care for their illness. In this study, most of the respondents stated that the environment was clean with fresh air and lots of space. This can be due to the large rooms which are well ventilated and also the fact that in the wards regular cleaning was done and patients did not have to share beds. Several studies have shown positive correlation of the work environment and the quality of care. A study by Kutney-Lee et al, (2009) indicated that the quality of the work environment had an influence on patient experiences of the quality of care received. Similarly, McHugh et al, (2011) concluded that nurses in a poor working environment negatively impacted patients' experiences with care. When individuals are pain free, comfortable and in a clean environment then psychologically they will be settled.

5.3.3 Psychosocial care

Addressing emotional, cognitive, social and functional problems often through psychological counselling and other social collaborations is a fundamental aspect in offering holistic care. In this study, psychological distress majorly related to separation from family, disease outcome and cost of care with a few being concerned with job security due to prolonged hospitalization. Cancer is a global condition people from all walks of life. However, third world countries are most affected because the majority of the people live below the minimum wage. They have to struggle to make ends meet and so health is not a priority. Hence, the respondent's major concerns were related to the change in lifestyle which has affected their already strained source of livelihood. These findings correspond with those from a study conducted by Barre et al,

(2018) that examined the stress and quality of life in cancer patients. They found that the major sources of stress for cancer patients were uncertainty, disease severity, physical difficulties and family issues among others. These can further compound to psychiatric conditions co-occurring alongside cancer that can further negatively impact the quality of life (Nikbakhash et al., 2014).

In dealing with these psychosocial issues, and given the lack of any social support system or counselling and other psychotherapeutic interventions within the facility, patients often resorted to sharing and discussing concerns with one another. Others preferred to simply keep to themselves and suffer in silence. None of the interviewees indicated that they had been offered any psycho-oncological intervention or referred for one. This may be as a result of lack of adequate, trained clinical psycho-oncologists and counsellors. Inadequate communication by the health care providers may also be viewed as lack of psychosocial support. In their study, Guo et al., (2013) found that out of a 41% of patients who needed psycho-oncological support, only 10% were referred yet these interventions are not only cost-effective but can also greatly improve patients' outcomes. Another cost-effective intervention in PCCC is spiritual care.

5.3.4 Spiritual care

Spiritual care involves acknowledging and respecting an individual's religion, culture and tradition as much as possible. In this study, some respondents felt health care providers were not sensitive to their spirituality. This was echoed in the study by Best, Butow & Olver, (2014) spirituality is universal and patients preferred care givers who were sensitive to their spiritual needs. This may be due to the fact that different religions behave differently and health care workers need to identify and acknowledge an individual's beliefs and values and respect them, so long as they are not interfering with others.

However, spirituality was considered to be integral by most of the respondents. When asked about their spirituality the respondents' replies indicated that spirituality was more internal that

external. They would pray individually, talk to their God privately and listen to gospel music to feed their inborn need for spirituality. On the other hand, spirituality was demonstrated externally through congregating together, having pastoral visits and having group fellowships. For those admitted to the hospital, external spiritual needs were met through phone conversations with fellow congregants or sometimes with their pastor. Minimal spiritual care was provided by the institution. This is similar to a study where a large number of patients with cancer did not receive the spiritual care they wanted while in hospital (Pearce et al., 2011). In this case it may have been as a result of the COVID-19 measures imposed by the hospital management to curb the spread of Sars CoV2.

5.4 Patient's perception on facilitators and barriers to healthcare provider-patient communication

Patients with cancer often need to be informed on their clinical status, prognosis of their disease as well as any foreseen changes in treatment regimens. In order to improve on quality of care it is important for healthcare providers to develop positive relationships with their clients by practicing good communication skills.

5.4.1 Facilitators to health care provider-patient communication

Good communication starts by being a good listener. In this study, the main facilitator to patient-provider communication was the patients' concerns and general questions regarding their condition being adequately addressed by the health care providers. Patients also consistently reported significantly higher satisfaction with communication from nurses and care givers. Being able to explain the treatment in details and in a way the patient can understand are positive ways of communicating and this enhances patient's compliance with treatment.

5.4.2 Barriers to health care provider-patient communication

Unfortunately, as stated by Street et al., (2016), the goals of patient-centered cancer care are not always realized due to poor communication between clinicians, patients and their families, leading to dissatisfaction with care. In this study, one of the perceived barriers was busy schedules of health care providers. This may be attributed to the poor nurse-patient ratio where one nurse has to take care of several patients at a time and hence may not have time to sit and properly communicate with one patient. This is similar to findings by Anoosheh et al., 2009 which showed heavy nurse workload was one of the main communication barriers. How health care providers perceive patients also matters.

Preconceived notions about patient's understanding on care and assumptions made by health care providers were also barriers identified. This may be attributed to language barrier and cultural differences between the health care providers and patients. These findings are similar to those of a study by Hasnain et al., (2011) where patients reported cultural and language barriers as barriers to therapeutic communication.

In this study other barriers established included information hoarding by HCWs and provision of incomplete information concerning care. This could have been attributed to the poor professional attitudes of the healthcare workers. Similarly, Moore et al., (2016) stated, some of the barriers of PCC were traditional practices and structures, professional attitudes and time constraints. Regardless of the situation, it is important that communication between the healthcare providers and patients includes involving patients in their care.

The findings also showed that patients yearned to be included in decision making about their care and be informed and kept up to date concerning the progress and prognosis of their condition. This could have been attributed to lack of knowledge by the HCWs on patient-centered care, which involves informing and engaging the patient in their care and allowing

them to make informed decisions on care. In his study, Mwanga (2013) found that communication helped reduce patients and family anxiety, promoted better care at home after discharge, and in other ways improved outcomes. He further noted that good communication is often the major factor affecting patients' perception on quality. Therefore, good communication enhances quality of care provided and in turn improves patient outcomes.

5.5 Respect for patients' values, preferences and expressed needs

Everyone is unique with unique values, preferences and needs and all should be treated as individuals. Patients value healthcare providers who treat them with dignity while catering to their needs while at the same time being respectful and mindful of their preferences (Lorenz & Chilingirian, 2010). Patient-clinician co-operation, has been shown to have not only positive patient outcomes but also lower the cost of care. In this study, those interviewed felt being left out in planning and decision making about their care and often being ambushed by decisions and changes as disrespectful. Not being informed on key issues can cause patients to feel unimportant and yet they are the ones to receive the care. Carrie et al., (2009), in their study on older people's experiences of patient-centered treatment for chronic pain, found that patient involvement in pain management is key in ensuring desired treatment outcomes further noting that healthcare providers should ensure patients are included in decision making about their care as this also ensures compliance with the treatment regimen.

Addressing self-care needs, such as assistance with bathing and toileting, controlling bleeding and showing empathy made them feel respected. This may be because these are what they perceived as immediate or priority needs at that time and how they were addressed mattered to them. Monsivais, & Engebretson, (2011) stipulated that patients often have preconceived notions about how they will be cared for when entering the healthcare system. When these assumptions are not met, and no communication is provided, patients often feel their values, needs and preferences have not been considered

However, poor attitude of clinicians with staff not considering the respondent's condition nor enquiring from them if they have a problem was portrayed as being disrespectful. During such instances where the patients felt that their values, needs and preferences were not addressed, they often referred to those experiences in the context of the quality of care provided. The poor attitude may be attributed to cultural differences, language barrier or overworked staff who project their frustrations to the patients.

5.6 Involvement of family and significant others in care

Family involvement can play a major role in providing psychological and emotional support to patients undergoing treatment in the hospital (Bellou & Georgia, 2014). This study established that the family of the respondent supported them whether financially or emotionally while they were hospitalised. This may be credited to the mobile phones which have made communication very easy.

On the contrary, in this study none of the interviewees reported direct involvement of their family members by the healthcare providers. The patient was left with the responsibility of contacting their family when needed, and therefore quality of care after discharge or follow-up was not guaranteed. Information about the patient's well-being was only shared with the relatives or significant others upon asking. This may be because they assume the patient is conscious enough to make their own decisions and will only require to contact relatives when the patient's condition deteriorates. This is in contrary to a study by Rustad (2017) who found that the next of kin was an important source of crucial information about the patient's health. To be able to achieve the best outcomes, Maltoni et al., (2016) pointed out that involving family members at proper times, often earlier on, was helpful to ensure they adapted to patients' illness, as this was also beneficial to them psychologically. Medical and nursing staff need to maintain continuous contact with parents and the significant other of patients, and provide them

with the appropriate information concerning the condition of their patient and the progress of the therapeutic program (Lippert et al., 2017).

5.7 Conclusion

The main aim of quality cancer care is to ensure improved quality of life despite the extent of the disease or the age of the patient. From the findings in this study, however, it can be concluded that the quality of PCCC provided in the gynaecological wards at KNH, as per the perceptions of the patient is below average. The psychosocial and spiritual care was not provided. Communication was affected by several factors culminating in ineffective communication on the patient's care. Patient's values and preferences were neither assessed nor were their expressed needs respected. The patients' families were also not involved in the patient's care and therefore, as per PCCC expectations, the patient's needs were not fully met.

5.8 Recommendations

Based on the study findings the following recommendations were made:

- Psychosocial and spiritual care requires improvement, communication needs to be enhanced, patient's values, preferences and expressed needs ought to be given more attention and the family or significant others should be incorporated in patient care.
- PCCC should touch on all aspects of a patient's life and should involve all cadres of providers within the care provision domain.
- In order to ensure quality patient-centered cancer care, all healthcare stakeholders from the primary care providers to the policy makers at the national level should be involved.
- One way of ensuring quality cancer care is by valuing the patient's perceptions on quality of care.
- PCCC is a health approach that should be adapted in all cancer treatment centres to ensure improved quality of cancer care.

- A tool to assess the quality of PCCC needs to be developed and adapted by both County and National Governments, in order to monitor and evaluate the quality of cancer care provided.

5.9 Further Research

Further research needs be conducted on the role of family or significant others in PCCC, perspectives of health leadership on PCCC in both national and county facilities. There is also need to carry out a study on the views of health care providers on PCCC, opinions of patients in private and faith-based organisations on PCCC and PCCC in out-patient clinics.

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APPENDICES

Appendix 1: ETHICAL APPROVAL LETTER



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

Ref: KNH-ERC/A/239

Julie Muthoni Matiba
Reg. No.H56/12162/2018
School of Nursing Sciences
College of Health Sciences
University of Nairobi

Dear Julie

RESEARCH PROPOSAL – QUALITY OF PATIENT—CENTERED CANCER CARE IN THE GYNAECOLOGICAL WARDS AT KENYATTA NATIONAL HOSPITAL (P82/02/2020)

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 23rd July 2020 – 22nd July 2021.

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.



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




KENYATTA NATIONAL HOSPITAL
P O BOX 20723 Code 00202
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Telegrams: MEDSUP, Nairobi

23rd July 2020

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

Yours sincerely,



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

- c.c. The Principal, College of Health Sciences, UoN
 The Director, CS, KNH
 The Chairperson, KNH- UoN ERC
 The Assistant Director, Health Information, KNH
 The Director, School of Nursing Sciences, UoN
Supervisors: Dr. Blasio O. Omuga, School of Nursing Sciences, UoN
 Dr. Joyce Jebet Cheptum, School of Nursing Sciences, UoN

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Appendix 2: KNH APPROVAL LETTER



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

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

Study Registration Certificate

1. Name of the Principal Investigator/Researcher
JULIE C. MUTHONI MATIBA
2. Email address: juliemuthoni70@gmail.com Tel No. 0723809979
3. Contact person (if different from PI)..... N/A
4. Email address: N/A Tel No. N/A
5. Study Title
QUALITY OF PATIENT-CENTERED CANCER CARE IN THE GYNAECOLOGICAL WARDS AT KENYATTA NATIONAL HOSPITAL
6. Department where the study will be conducted OBSTETRICS & GYNAECOLOGY
(Please attach copy of Abstract)
7. Endorsed by Research Coordinator of the KNH Department where the study will be conducted.
Name: DR. IKOL ADUNSO Signature [Signature] Date 29/07/2020
8. Endorsed by KNH Head of Department where study will be conducted:
Name: X. M. M. DUTTA Signature [Signature] Date 29/07/2020
9. KNH UoN Ethics Research Committee approved study number _____
(Please attach copy of ERC approval)
10. I JULIE C. MUTHONI MATIBA commit to submit a report of my study findings to the Department where the study will be conducted and to the Department of Research and Programs.
Signature [Signature] Date 29/07/2020
11. Study Registration number (Dept/Number/Year) Reproductive Health/390/2020
(To be completed by Research and Programs Department)
12. Research and Program Stamp _____

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

Appendix 3A: INFORMED CONSENT (English Version)

QUALITY OF PATIENT-CENTERED CANCER CARE IN THE GYNAECOLOGICAL WARDS AT KENYATTA NATIONAL HOSPITAL.

Introduction

My name is JULIE MUTHONI MATIBA, I am a postgraduate student at the University of Nairobi. I am inviting you to take part in a study that I'm conducting in this ward.

Before you decide to participate in this study, it is important that you understand why the research is being done and what it will involve. Please read the following information carefully. Please ask the researcher if there is anything that is not clear or if you need more information.

Purpose of Study

The purpose of this study is to establish patient's perceptions on the quality of patient-centered cancer care in the gynaecological wards at KNH.

Study Procedures

This study requires that you read and understand the information sheet provided before you sign the consent.

The study requires that you respond to questions in the discussion to the best of your knowledge and with all honesty. These discussions will take appropriately 30-45mins of your time and the researcher will guide the session. All discussions will be recorded for purposes of reviewing the talks at a later date and for the researcher to transcribe, interpret and write a study report. You may decline to answer any or all questions and you are allowed to leave at any time you choose.

Risks

There are no direct foreseen risks as there's no physical harm that will be inflicted on you.

Benefits

There will be no direct benefit to you for your participation in this study. However, we hope that the information obtained from this study will provide information that will help to improve health care services, health outcomes and reduce costs for both the individual patient and the community as a whole.

Confidentiality

Your responses to this study will be anonymous. The information provided during the discussions will be held in confidence and your identity will not be disclosed to any other person except those involved in the study.

Contact Information

If you have questions or concerns at any time about this study, or you experience adverse effects as the result of participating in this study, you may contact the following persons:

The Principal Investigator

Julie Muthoni Matiba,

Mobile number 0723802979

Email: juliemuthoni72@gmail.com.

Physical Address: School of Nursing Sciences

University of Nairobi, College of Health Sciences

Kenyatta National Hospital Campus

The Supervisors

Dr Blasio Osuga Omuga,

Mobile number 0722256080,

Email: osogo@uonbi.ac.ke

Physical Address: School of Nursing Sciences

University of Nairobi, College of Health Sciences

Kenyatta National Hospital Campus

Dr. Joyce Jebet Cheptum

Mobile number: 0721475165

Email: jjcheptum@gmail.com

Physical Address: School of Nursing Sciences

University of Nairobi, College of Health Sciences

Kenyatta National Hospital Campus

Ethics Review Committee, KNH/UON,

Prof. M.L. Chindia,

Secretary, KNH-UON Ethics Review Committee

Tel No. +254 2726300-9

Email: uonknh_erc@uonbi.ac.ke

Physical Address: School of Pharmacy Grounds

University of Nairobi, College of Health Sciences

Kenyatta National Hospital Campus

Voluntary Participation

Your participation in this study is voluntary. It is up to you to decide whether or not to take part in this study. If you decide to take part in this study, you will be asked to sign a consent form. After you sign the consent form, you are still free to withdraw at any time and without giving a reason. Withdrawing from this study will not affect the relationship you have, if any, with the researcher. If you withdraw from the study before data collection is completed, your data will be returned to you or destroyed.

CONSENT

I have read and I understand the provided information and have had the opportunity to ask questions. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason and without cost. I understand that I will be given a copy of this consent form. I voluntarily agree to take part in this study.

Participant's name _____

Signature _____ Date _____

Investigator's signature _____

Date _____

Appendix 3B: INFORMED CONSENT (Swahili Version)

JINSI WAGONJA WA SARATANI WANAVYO TUNZWA KATIKA WADI ZA WAMAMA ZILIZO HOSPITALI KUU YA KENYATTA.

Utangulizi

Jina langu ni Julie M. Matiba, mimi ni mwanafunzi katika juo kikuu cha Nairobi. Nakualika kushiriki katika utafiti ninaoufanya ukiwa mmoja wa wangonjwa wanaohudumiwa katika wodi hii Kabla ya kuamua kushiriki katika utafiti huu, ni muhimu kuelewa ni kwa nini utafiti unafanywa na nini kitahusisha. Tafadhali soma habari ifuatayo kwa uangalifu. Tafadhali muulize mtafiti ikiwa kuna chochote kisicho wazi au ikiwa unahitaji habari zaidi.

Lengo

Madhumuni ya utafiti huu ni kutathmini maoni yako juu ya ubora wa utunzaji wa wangonjwa wa saratani unaozingatiwa katika wodi za wanaougua ugonjwa wa njia ya uzazi.

Mikakati Itakayofuatwa

Utafiti huu unahitaji kusoma na kuelewa ukurasa wa habari uliopewa kabla ya kutia saini ya idhini .

Utafiti unahitaji kwamba ujibu maswali kwenye mjadala kwa maarifa yako bora na kwa uaminifu wote. Mazungumzo haya yatachukua ipasavyo dakika 30-45 ya muda wako na mtafiti ataongoza kikao. Mazungumzo yote yatarekodiwa kwa madhumuni ya kukagua mazungumzo katika siku za baadaye na kumwezesha mtafiti kuandika, kutafsiri na kuandika ripoti ya utafiti. Unaweza kukataa kujibu maswali yoyote na unaruhusiwa kuacha kikundi wakati wowote utakaochagua.

Athari

Hakuna hatari za moja kwa moja za kutabiri kwani hakuna madhara ya mwili ambayo yatasambazwa kwako.

Faida Ya Utafiti

Utafiti huu huenda usikufaidi kibinafsi lakini kushiriki kwako huenda kukaibua matokeo yatakayosaidia kuimarisha huduma za afya, kupunguza garama kwa mgonjwa na jamii kwa jumla.

Usiri Wa Mahojiano

Majibu yako juu ya utafiti huu hayatatambulika na habari itakayotolewa wakati wa majadiliano itafanyika kwa ujasiri na jina lako halitafichuliwa kwa mtu mwingine yeyote isipokuwa wale waliohusika kwenye utafiti.

Mawasiliano Na Wahusika

Ikiwa una maswali au wasiwasi wakati wowote juu ya utafiti huu, au unapata athari mbaya kama matokeo ya kushiriki katika utafiti huu, unaweza kuwasiliana na watu wafuatao:

Mtafiti Julie Muthoni Matiba, nambari ya simu 0723802979, barua pepe: juliemuthoni72@gmail.com. Ama mhadhiri msimamizi, Dr Blasio Osuga Omuga, nambari ya simu 0722256080, barua pepe: osogo@uonbi.ac.ke

Waweza pia kuwasiliana na kamati inayochanganuza maswala ya utafiti ya hospitali ya Kenyatta ikiungana na chuo kikuu cha Nairobi kupitia sanduku la posta 19676-00202, Nairobi ama nambari ya simu 2726300-9.

Kushiriki kwa Hiari na Kujiondoa kwa Maholiano

Ushiriki wako katika utafiti huu ni wa hiari yako. Uko huru kukataa kushiriki ama kujiondoa katika mahojiano wakati wowote na bila kutoa sababu. Kujitenga na utafiti huu haitaathiri uhusiano uliyonayo na mtafiti.

Ikiwa utaamua kushiriki katika utafiti huu, utaombewa kutia saini fomu ya idhini. Baada ya kusaini fomu ya idhini, bado uko huru kujiondoa.

DHIBITISHO LA IDHINI

Nimesoma na ninaelewa habari iliyotolewa na nimepata nafasi ya kuuliza maswali. Ninaelewa kuwa ushiriki wangu ni wa hiari na kwamba niko huru kujiondoa wakati wowote, bila kutoa sababu na bila gharama. Ninaelewa kuwa nitapewa nakala ya fomu hii ya idhini. Ninakubali kushiriki kwa hiari katika utafiti huu.

Jina la Mshiriki _____ Saini _____ Tarehe _____

Saini ya Mpelelezi _____ Tarehe _____

Appendix 4: INTERVIEW GUIDE

1. Introduction:

Introduce yourself and review the following:

- Who I am and what I'm trying to do? (*Mimi ni nani na ninataka kufanya nini?*)
- What will be done with this information? (*Ni nini kitafanyika na habari hii?*)
- Why I asked you to participate? (*Kwanini nilikuuliza ushiriki?*)

Thank you for consenting for participation. Before I start to record, I will ask some general questions about you.

Demographics

1. Age (*Umri wako*) (years/miaka)
2. DOA (*siku ya kulazwa*).....
3. What is your marital status? (*Hali yako ya ndoa?*)
4. Residence (*Makaazi yako*)
5. Level of education? (*kiwango cha elimu?*)
6. What is your occupation? (*Unafanya kazi gani?*)
7. Monthly income? (*Mapato ya kila mwezi?*)
8. Type of house? (*Aina ya nyumba?*)
9. Do you have children? (*Je, una watoto?*)
10. Time since diagnosis? (*wakati tangu utambuzi wa saratani*)
11. Type of cancer (*Aina ya saratani?*)
12. Treatment received (*matibabu unayopokea?*)

Thank you for sharing your background with me. Now, do I have your permission to start the recording?

[If No, thank participant for time and end the session] [If yes, continue with the interview]

Now that the recording has started, please say "Yes" to confirm that you approve of me recording the interview.

PROBE AND FOLLOW UP QUESTIONS

HOLISTIC CARE

Physical Care.

1. How do you feel about the care you are receiving since you were admitted? *Je! Unajisikiaje kuhusu utunzaji unaopokea tangu ulipolazwa?*
 - What are some of the things that are not so good about you stay in the hospital? *Je! Ni mambo gani ambayo sio mazuri sana wakati umekuwa hospitalini?*
 - What are some of the things that are good about you stay in the hospital? *Je! Ni mambo gani ambayo ni mazuri wakati umekuwa hospitalini?*
2. What was your experience when you were in pain? *Je! Ulihivipi wakati ulikuwa na uchungu?*

- What did the hospital staff do to control your pain? *Wafanyikazi wa hospitali walifanya nini kupunguza maumivu yako?*
 - What do you think the hospital staff should do to help control your pain? *Je! Unafikiria wafanyikazi wa hospitali wanapaswa kufanya nini kukusaidia wakati unamaumivu?*
 - What do you think the hospital staff did not do to help control your pain? *Je! Unafikiria ni nini wafanyikazi wa hospitali hawakufanya kusaidia kudhibiti maumivu yako?*
 - Do you think they did everything they could to help control your pain? *Je! Unafikiri walifanya kila wawezalo kusaidia kudhibiti maumivu yako?*
3. What was your experience when you needed assistance with toileting or bathing? *Ulikuwa unahisi nini wakati unahitaji msaada wa kutumia vyoo/kwenda haja au kuoga?*
- What was good about the assistance they gave with the bathing or toileting? *Ni nini kilikuwa kizuri juu ya usaidizi waliopeana wa kuoga au kutumia choo/kwenda haja?*
 - What was not good about the assistance they gave with the bathing and toileting? *Ni nini ambacho hakikuwa kizuri juu ya usaidizi waliopeana wa kuoga na kutumia choo/kwenda haja?*
4. How do you feel about the medication you are receiving? *Je! Unahisije kuhusu dawa unayopokea?*
- What are some of the things you do not like about the medication you are getting? *Je! Ni vitu gani ambavyo hupendi kuhusu dawa unayopata? Kwanini?*
 - What are some of the things you like about the medication you are getting? *Je! Ni vitu gani unapenda kuhusu dawa unayopata? Kwanini?*
5. How do you feel about the ward and hospital environment? *Je! Unahisije juu ya mazingira ya hospitali?*
- What are some of the things you like about the ward/hospital environment? *Je! Ni vitu gani unapenda kuhusu mazingira ya wadi / hospitali?*
 - What are some of the things you do not like about the ward/hospital environment? *Je! Ni mambo gani ambavyo hupendi kuhusu mazingira ya wadi / hospitali?*
 - What did you do when you needed to move around the hospital? *Je! Ulifanya nini wakati unahitaji kuzunguka hospitali? Ulipotea?*

Psychosocial Care

1. What are some of the things that make you afraid, anxious or worried while you are in hospital? *Je! Ni vitu gani ambavyo vinakufanya uogope, au uwe na wasiwasi wakati upo hospitalini?*
- How do you deal with these things as an individual? *Je! Unashughulikiaje mambo haya kama mtu binafsi?*

- What do you feel the hospital staff can do to help you deal with these concerns? *Je! Unahisi wafanyikazi wa hospitali wanaweza kufanya nini kukusaidia kukabiliana na haya mahafa?*
 - How does your family, friends, community or church support you during your stay in the hospital? *Je! Familia yako, marafiki, jamii au kanisa linakusaidia wakati wa kukaa hospitalini?* What is good about the support you get from family, friends, community or church? • *Ni nini nzuri juu ya usaidizi unaopata kutoka kwa familia, marafiki, jamii au kanisa?*
 - What is not good about the support you get? • *Ni nini sio nzuri juu ya msaada unaopata?*
2. How do you feel the hospital staff can help your family, friends, community members or church to support you? *Je! Unahisije wafanyakazi wa hospitali wanaweza kusaidia familia yako, marafiki, washiriki wa jamii au kanisa kukusaidia?*

Spiritual Care

1. How do you feel about your values and beliefs (spirituality) while in the hospital? *Je! Unahisije kuhusu maadili na imani yako (hali ya kiroho) wakati uko hospitalini?*
- What is good about the spiritual care you receive while you are in the hospital? *Ni nini nzuri juu ya utunzaji wa kiroho unaopokea ukiwa hospitalini?*
 - What is not good about the spiritual care you receive while you are in the hospital? *Ni nini sio nzuri juu ya huduma ya kiroho unayopokea ukiwa hospitalini?*
 - What do you feel the hospital team can do to help with your values and beliefs (spirituality) while you are in the hospital? *Je! Unahisi timu ya hospitali inaweza kufanya nini kusaidia na maadili yako na imani (kiroho) unapokuwa hospitalini?*

COMMUNICATION

1. What was your experience when communicating with the health care providers? *Je! Ulikuwa na uzoefu gani wakati wa kuzungumza na watoa huduma ya afya?*
- What was good during your communication with the health care workers? *Ni nini kilikuwa kizuri wakati wa mawasiliano yako na wafanyikazi wa huduma ya afya?*
 - What was not good during your communication? *Je! Nini haikuwa nzuri wakati wa mawasiliano yako?*
 - What do you think are some of the barriers to effective communication? *Je! Unadhani ni vipi baadhi ya vizuizi vya mawasiliano madhubuti?*
 - What do you feel should be done to improve communication between patients and the health care providers? *Je! Unahisi ni nini kinaweza kufanywa ili kuboresha mawasiliano kati ya wagonjwa na watoa huduma ya afya?*

RESPECT FOR PATIENT'S VALUES, PREFERENCES ND EXPRESSED NEEDS

1. What do you think respectful behaviour is? *Unadhani tabia ya heshima ni gani?*
2. What do you think is respectful during your stay in hospital for treatment? *Unadhani unapewa heshima gani wakati wa kukaa hospitalini kwa matibabu?*
 - What do you think was disrespectful during your stay in hospital? *Je! Unadhani ni nini kilikuwa na dharau wakati wa kukaa hospitalini?*
 - Describe examples of ways in which you have been treated with respect. • *Fafanua mifano ya njia ambazo umetendewa kwa heshima.*
 - Describe examples of ways in which you have been treated disrespectfully. *Fafanua mifano ya njia ambazo umetendewa bila heshima.*

INVOLVEMENT OF FAMILY

1. What do you feel about involvement of your family members (or significant other) in decisions about your care? *Je! Unasikia nini kuhusu kuhusika kwa wanafamilia wako (au marafiki) katika maamuzi juu ya utunzaji wako?*
2. How is your family being involved in your care while you were hospitalised? *Je! Familia yako inahusikaje katika utunzaji wako wakati uko hospitalini?*
 - What was positive about the involvement of your family? *Ni nini kizuri juu ya kuhusika kwa familia yako?*
 - What was negative about their involvement? *Je! Nini kibaya juu ya kuhusika kwao?*

That concludes our focus group. Thank you so much for coming and sharing your thoughts and opinions with us. *Hapa ndipo tutamalizia mawasiliano yetu. Asante sana kwa kuja na kushiriki maoni yako nasi.*

Materials and supplies for the interview

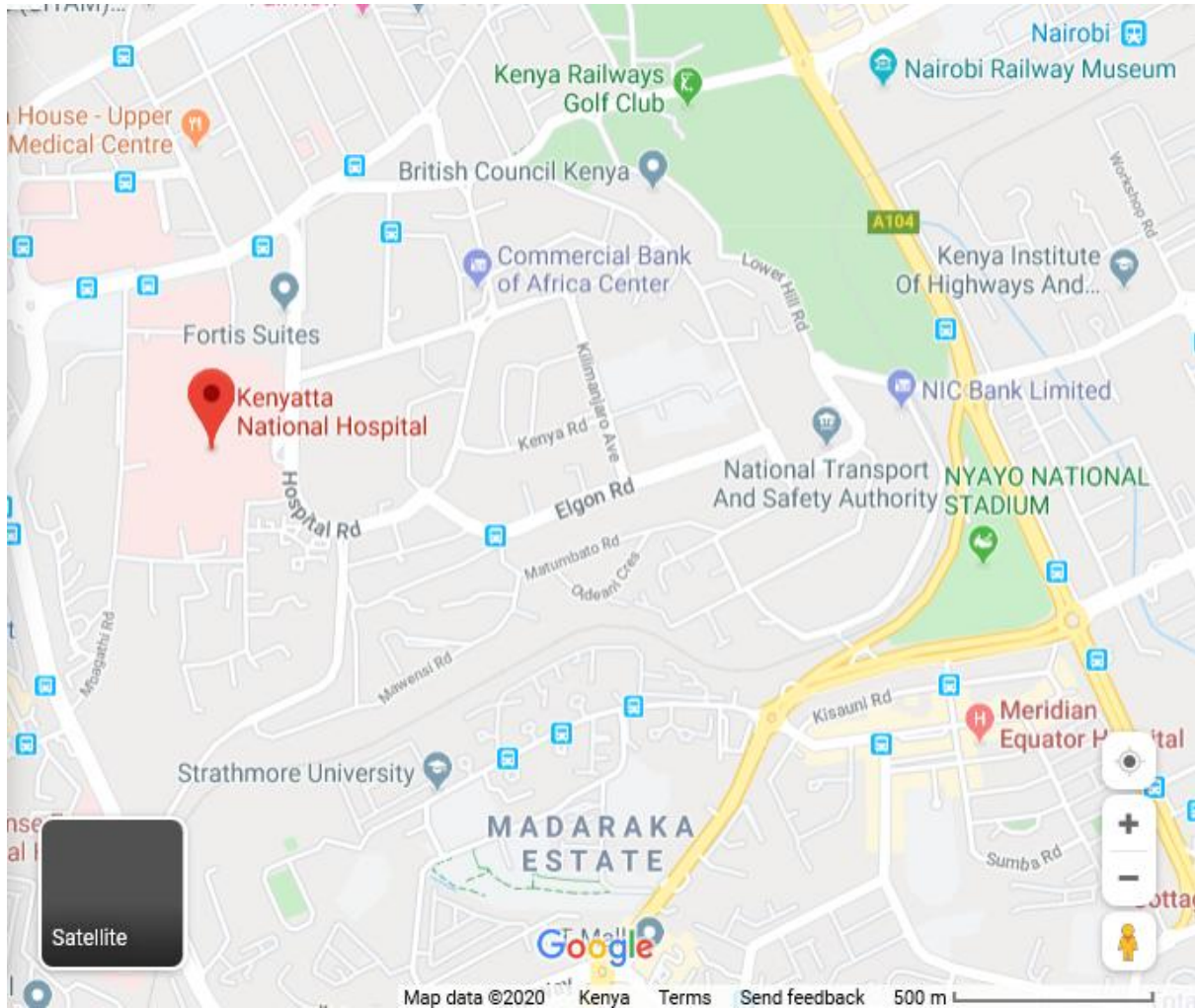
- Consent forms (one copy for participants, one copy for the team)
- Interview Guide for Facilitator
- Recording device
- Charger for recording device
- Notebook for note-taking

Appendix 5: CODE BOOK

CATEGORY (Theme)	SUBCATEGORY (Sub-theme)	DESCRIPTION
<p>1) Holistic care</p>	<p>Overall perception of care.</p> <ul style="list-style-type: none"> • Improved general health <p>Physical comfort</p> <ol style="list-style-type: none"> 1. Pain management <ul style="list-style-type: none"> • Pain well managed 2. Assistance with bathing and toileting <ul style="list-style-type: none"> • Assistance offered • No assistance offered • No privacy 3. Environment <ul style="list-style-type: none"> • Clean environment <p>Psychosocial care</p> <ol style="list-style-type: none"> 1. Sources of psychosocial distress. <ul style="list-style-type: none"> • Family • Job security • Financial cost of care • Inability to care for self 2. Dealing with psychosocial issues. <ul style="list-style-type: none"> • No psychotherapeutic interventions • Sharing with others • Keeping to self <p>Spiritual care</p> <ul style="list-style-type: none"> • Insensitivity to spiritual needs • Lack of in-hospital spiritual care • Effects of Covid 19 	<p>Participants give an overview of their perception with holistic care</p> <p>Participants describe how the nurses cater to their pain management needs</p> <p>Participants describe experiences with receiving assistance with toileting and bathing</p> <p>Participants describe the ward environment within which they are receiving care</p> <p>Participants describe sources of stress while receiving care</p> <p>Participants describe how they deal with psychosocial issues</p> <p>Participants describe lack of counsellors to provide psychosocial care</p> <p>Participants describe spiritual care received or otherwise while in the hospital</p> <p>Participants describe how the source for spiritual care outside of the hospital environment</p>

<p>2) Communication</p>	<p>Facilitators to health care provider-patient communication</p> <ul style="list-style-type: none"> • Response to inquiries from patients <p>Barriers to health care provider-patient communication</p> <ul style="list-style-type: none"> • Busy schedules of the HCWs • Preconceived notions about patient's understanding • Assumptions made by HCWs • Provision of incomplete information concerning care. • Lack of involvement in care planning and shared decision making 	<p>Participants describe communication in general terms</p> <p>Participants describe communication in relation to their care</p> <p>Respondents describe lack of involvement in planning their care and decisions concerning their care</p> <p>Respondents describe information shared or not shared on concerning side effects of their treatment</p>
<p>3) Respect for patient's values, preferences and expressed needs.</p>	<ul style="list-style-type: none"> • Involvement of care • Addressing self-care needs • Empathy • Attitude of staff 	<p>Participants describe instances where respect for their values was shown</p> <p>Participants describe their experiences of disrespect while receiving care</p>
<p>4) Involvement of family.</p>	<ul style="list-style-type: none"> • Family support • Absence of family involvement 	<p>Participants describe support from family members and relatives</p> <p>Participants describe whether or not healthcare providers involve family members in their care</p>

Appendix 5: MAP OF STUDY AREA.



(Source: Google Maps)

Appendix 6: PHOTO OF KENYATTA NATIONAL HOSPITAL



(Source: Google Maps)

QUALITY OF PATIENT-CENTERED CANCER CARE IN THE GYNAECOLOGICAL WARDS AT KENYATTA NATIONAL HOSPITAL

ORIGINALITY REPORT

14%

SIMILARITY INDEX

11%

INTERNET SOURCES

5%

PUBLICATIONS

8%

STUDENT PAPERS

PRIMARY SOURCES

1	erepository.uonbi.ac.ke Internet Source	1%
2	www.scribd.com Internet Source	1%
3	Submitted to Kenyatta University Student Paper	<1%
4	Submitted to Mount Kenya University Student Paper	<1%
5	Eleonora P. M. M. Uphoff. "Development of Generic Quality Indicators for Patient-Centered Cancer Care by Using a RAND Modified Delphi Method :", Cancer Nursing, 05/2011 Publication	<1%
6	www.npaf.org Internet Source	<1%
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