

**ASSESSING QUALITY OF LIFE AMONG GYNAECOLOGICAL  
CANCER PATIENTS RECEIVING CARE IN THE PALLIATIVE CARE  
UNIT AT KENYATTA NATIONAL HOSPITAL**

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## **DECLARATION**

I certify that this research dissertation is my original work and it does not incorporate without acknowledgment 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

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## **DEDICATION**

I dedicate this work to my dear wife Maureen and two sons Joel and Joshua for their understanding, love and support. I also dedicate the work to my parents for inspiring me in life.

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## **LIST OF ABBREVIATIONS AND ACRONYMS**

ANOVA – Analysis of Variance

CCRT – Concurrent Chemotherapy and Radiotherapy

CSCT – Concurrent Surgery and Chemotherapy

CT – Chemotherapy

ERC – Ethics and Research Committee

HIV – Human Immunodeficiency Virus

HRQOL – Health related Quality of Life

KNH – Kenyatta National Hospital

MVQOLI – Missoula Vitas Quality of Life Index

QOL – Quality of Life

RT – Radiotherapy

SPSS – Statistical Package for the Social Sciences

SSA – Sub Saharan Africa

UON – University of Nairobi

USA – United States of America

WHA – World Health Assembly

WHO – World Health Organization

## **OPERATIONAL DEFINITIONS**

**Age:** the measure of time of the existence of the person.

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

**Chemotherapy:** the specific treatment of a disease by administering chemical agents.

**Clinical:** refers to the practical observations and treatment of a disease.

**Gender:** the biological difference between men and women.

**Gynaecological cancers:** refers to cancers that affect a woman's reproductive system e.g. cervical, ovarian, endometrial, vulva and vaginal cancers

**Occupation:** the nature of work the individual is engaged in to earn a living.

**Pain:** a feeling of distress or suffering caused by stimulation of specialized nerve endings.

**Palliative:** a treatment that relieves discomfort but does not cure a disease.

**Physical:** all that relates to the body.

**Psychological:** all that relates to the mental processes.

**Quality of life:** An individual's sense of well being and ability to carry out various activities such as being able to work, enjoy life, sleep well, involvement with others e.t.c.

**Radiotherapy:** the treatment of proliferative diseases by X-rays and other forms of radiation.

**Social:** relates to ability to participate in various activities and involvement with others.

**Spiritual:** is a belief system ascribed by a particular religion to find meaning in life.

**Staging:** a process of measuring how advanced a tumour is and to which sites it has spread.

**Surgery:** Treatment of a disease by manual or operative measures.

**Time of diagnosis:** the measure of time when the decision about the disease was made

## ABSTRACT

Quality of life (QOL) assessment among cancer patients is considered to be an important aspect in palliative care. QOL assessment helps in the identification of the physical, psychological, social and spiritual needs of the patient. Gynaecological cancers are among the most common types of cancers afflicting women. Although patient assessment and palliative care among cancer patients is undertaken at the palliative care unit of Kenyatta National Hospital (KNH), how the disease and its treatment affect the QOL of these patients is unknown. This study sought to determine the QOL and its associated factors among Kenyan women with gynaecological cancers receiving palliative care. Predictors of QOL were also evaluated. A cross sectional descriptive study was conducted that included 108 respondents diagnosed with endometrial, ovarian, cervical or vulva cancers being followed up and treated in the palliative care unit at Kenyatta National Hospital. The data was collected between the months of April and June 2014. QOL was measured using the Missoula Vitas QOL Index. The association between socio-demographic and clinical factors with QOL was analyzed using one way ANOVA and linear regression analysis to identify the predictors of QOL. The mean total QOL score was reported to be 17.2 (expected range 0-30); mean global QOL score of 3.5 (range 0-5). The symptom subscale had the highest score (mean 8.2); followed by transcendent subscale (mean 6.2); then function subscale (mean 5.6); then interpersonal subscale (mean 5.3) and wellbeing subscale had the least score (mean -2.9). Women aged 65 years and above, with secondary or tertiary levels of education had high mean total QOL scores. Patients who were formally employed and earned more than 10,000 Kenyan shillings were reported to have high mean total QOL scores. Patients with ovarian and endometrial cancers were reported to have higher mean total QOL scores than those with cervical and vulva cancers. Age, level of education, occupation, average monthly income, type of cancer treatment, duration of illness and type of cancer were reported to be the independent predictors of QOL. The quality of life among gynaecological cancer patients receiving palliative care at KNH was moderate but tended towards high QOL. The psychological and social needs of these patients are not adequately identified and addressed. Age, education, occupation, income, type of cancer, type of cancer treatment and duration of illness were the factors influencing QOL. There is need to adopt a QOL assessment instrument in the palliative care unit to assist the palliative care team members in identifying and addressing specific needs that affect the QOL of patients with advanced cancer.

# CHAPTER ONE

## 1.0 INTRODUCTION

### 1.1 Background Information

Quality of life (QOL) is an important outcome measure when caring for cancer patients. QOL assessment among cancer patients has become necessary as a result of long term survival of the patients due to the modern methods of cancer screening and treatment. QOL has been defined as the subjective evaluation of life as a whole or the patients' appraisal and satisfaction with their current level of functioning compared with what they perceive to be possible or ideal (Safaei et al., 2008). QOL is multidimensional focussing on the physical, psychosocial and spiritual wellbeing of the patient. Cancer is a big burden in Sub Saharan Africa (SSA) with estimates that it accounts for one in every five deaths in the region (Parkin et al., 2008). Gynaecological cancers are among the most common types of cancers afflicting women. Premenopausal women predominantly suffer from cervical cancer while perimenopausal women exhibit high incidences of endometrial and ovarian cancers (Goncalves, 2010). Gynaecological cancers can impact on many aspects of a patient's life. A major concern has been on their effect on the physical, psychological, spiritual and social well being of the patient. The different treatment modalities in cancer care like chemotherapy, surgery and radiotherapy equally affect the QOL of these patients (Klee et al., 2000)

Few studies have been conducted to assess QOL of cancer patients in developing countries, Kenya included. Kenya is a country in the East African region with an approximate population of 40 million people. According to statistics from the country's Ministry of Health, cancer is the third leading cause of death after infectious diseases and cardiovascular diseases accounting for 7% of the total national mortality every year. It is estimated that the annual incidence of cancer is about 28,000 cases and the annual mortality to be over 22,000 (Cancer incident report, 2006). Over 60% of those affected by cancer are below the age of 70 years. The leading cancers in women are breast, oesophagus and cervical cancers while in men, oesophagus and prostate are the most common (Cancer incident report, 2006).

The increasing burden of cancer in Kenya makes palliative care an essential service in the health care system. The Ministry of Health has unveiled a national cancer control strategy with one of the key strategies outlined in the blue print being enhancing palliative care

services as part of the comprehensive cancer care. This is in line with the World Health Assembly report of 2005 that resolved, "Palliative care is an urgent humanitarian responsibility"(WHA, 2005). Palliative care services have currently been integrated into the national health services in Kenya. Assessing the QOL of gynaecological cancer patients receiving palliative care will not only inform the planning of care but also serve as an outcome measure of the palliative care services.

QOL assessment can accurately be done through getting the patients' experience with cancer and its management. Few studies if any, have examined QOL and patient experience on non physical aspects of cancer on the Kenyan population. There is paucity of information on the levels of QOL among gynaecological cancer patients on palliative care in the country. Given the high prevalence of gynaecological cancers seen in the palliative care unit, this study aims to assess the level of QOL and its associated factors among gynaecological cancer patients receiving palliative care at Kenyatta National Hospital. The study will also determine the predictors of QOL among these patients.

## **1.2 Statement of Problem**

Although patient assessment and palliative care is undertaken at the palliative care unit of Kenyatta National Hospital (KNH) for those suffering from advanced cancer, how the cancer and its treatment affect the QOL of these patients is unknown. The level of QOL among gynaecological cancer patients that represents the range of socio-demographic and clinical characteristics of patients undergoing palliative care in this setting is not known in Kenya. Since QOL focuses on the four dimensions of physical, social, psychological and spiritual well being, an assessment of QOL will give a holistic outcome of the patient's well being in the four dimensions from their own perspective. It will also indicate the extent to which patient needs in the four dimensions are met. There is evidence from a study conducted in Uganda and South Africa among cancer patients undergoing palliative care reporting poor QOL scores (Selman et al., 2011).

Modern cancer treatment methods are known to increase the survival rates of cancer patients but despite this, they are also associated with adverse effects on the patients (Klee et al., 2000). These adverse effects of cancer treatment could be affecting the gynaecological cancer patients being followed up in the palliative care unit at Kenyatta National Hospital. Therefore measurement of health related quality of life (HRQOL) establishes the psychosocial and physical effects of the treatments on the cancer patients.

Palliative care services in developing countries especially in Africa have focussed much on the physical aspects of care with less regard to holistic outcomes such as QOL. In a study conducted by Selman et al. (2011), it was reported that patients had better QOL scores in the symptom subscale that corresponds to physical well being and poor scores in the other domains which supported this view.

There is paucity of information on QOL among cancer patients undergoing palliative care in literature as little research has been conducted on this area in Africa. Given that social environment can change the perception about QOL, patient experiences on cancer and their perception on QOL in this setting has not been examined. Equally, no specific studies have evaluated the effect of socio-demographic and clinical factors on QOL among cancer patients in the Kenyan context. This indicates a lack of robust and persuasive evidence that can influence a change in clinical practice and indicate the benefits of palliative care among patients with advanced cancer in Kenya.

### **1.3 Justification of the Study**

Palliative care is an essential service that improves the quality of life of cancer patients. Palliative care services focus on the physical, psychological, social and spiritual well being of patients. Therefore an assessment of quality of life of gynaecological cancer patients will not only provide an outcome measure of the palliative care services but also give a holistic understanding of the physical, psychosocial and spiritual needs of these patients that will inform planning and delivery of an effective and appropriate care.

### **1.4 Research Question**

What is the quality of life of gynaecological cancer patients receiving palliative care at Kenyatta National Hospital?

### **1.5 Broad Objective**

To assess the quality of life of gynaecological cancer patients receiving palliative care at Kenyatta National Hospital

### **1.6 Specific Objectives**

1. Determine the level of quality of life among gynaecological cancer patients receiving palliative care at Kenyatta National Hospital.
2. Establish the association between socio-demographic factors and quality of life among the gynaecological cancer patients receiving palliative care at Kenyatta National Hospital.



3. Establish the association between clinical characteristics and quality of life among the gynaecological cancer patients receiving palliative care at Kenyatta National Hospital.
4. Determine the predictors of quality of life among the gynaecological cancer patients receiving palliative care at Kenyatta National Hospital.

### **1.7 Purpose of the Study**

This study will fill the knowledge gap that exists regarding the quality of life among gynaecological cancer patients in the country. The findings will enhance palliative care service provision through appropriate identification and address of patient needs. It will also inform health policy makers on the need to expand palliative care services within the health care system and build capacity among the practicing health care providers.

### **1.8 Study Benefits**

The hallmark of palliative care is to improve the quality of life for patients suffering from distressing illnesses like cancer. Therefore the findings of this study will help the health care providers in identifying the specific needs of gynaecological cancer patients and by addressing them, it will improve their quality of life.

## **CHAPTER TWO**

### **2.0 LITERATURE REVIEW**

#### **2.1 Introduction to Literature Review**

The current literature acknowledges the importance of QOL as an outcome of palliative care. This review highlights the concept of QOL in the context of this study. In research QOL assumes two dimensions, the health related QOL (HRQOL) and the non health related QOL. HRQOL is concerned with the domains of life that are directly affected by changes in health. Therefore measuring HRQOL is a standardized way of describing the physical, psychological and social effects of the disease, in this case cancer and its treatment (Klee et al., 2000). QOL assessment is based on the patient's own rating of simple questions and this can give a picture of how and to what extent a disease and its treatment affect the lives of the patient (Klee et al., 2000). This literature review also discusses the effects of socio-demographic profiles among gynaecological cancer patients on their quality of life. In addition, the clinical characteristics of the patients that include the duration of illness, the stage of the disease and the types of treatment used to manage the cancer are discussed in relation to their effects on the QOL of the patient.

#### **2.2 Quality of Life**

Quality of life as a multidimensional concept has both been subjective and varied in nature. QOL assessment has been conceptualized into both subjective and multidimensional perspectives. Subjectivity relates to the understanding of QOL from the patient's perspective while multi-dimensionality relates to assessing the different dimensions of the patient's life like physical, emotional, functional and social well being (Cella, 1992). This study focuses on both the overall and dimensional QOL scores. QOL has been defined as the subjective evaluation of life as a whole or the patients' appraisal and satisfaction with their current level of functioning compared with what they perceive to be possible or ideal (Safaei et al., 2008). In this study, the fifth item of each Missoula Vitas Quality of Life Index (MVQOLI) subscale assesses the subjective importance of that domain to the patient.

According to Alexander et al. (2003), QOL is the individual's sense of well being and ability to perform daily tasks, potentially affected by an illness and its treatment. The MVQOLI used in this study assesses the ability to perform daily tasks in the function subscale. According to the World Health Organization, QOL is 'an individual's perception of their position in life, in the context of the culture and value systems in which they live in relation to their goals, expectations, standards and concerns.' The concept of QOL especially in relation to its

dimensions namely physical, psychosocial and spiritual is important in palliative care. Palliative care has become essential in cancer care with its goal being to help the patient achieve the highest QOL (WHO, 2009). In most African countries, majority of cancer patients present to health facilities at advanced stages of the disease when cure is not possible which makes palliative care an important part of cancer management (Lingwood et al., 2008). A study conducted in Uganda and South Africa among cancer patients on follow up in palliative care clinics indicated relatively poor QOL scores (Selman et al., 2011). However, QOL for cancer patients can be enhanced with provision of quality health care services.

### **2.3 Physical Well Being**

The physical well being refers to the extent to which cancer and its treatment affect physical changes and cause disturbances in the performance of daily activities. It has been indicated that the physical functioning of a cancer patient was affected by the physical problems including exhaustion that occur following cancer treatment (Reis et al., 2010). However, this assertion excludes the wide range of sequel like pain and fatigue that result from the disease itself which also impairs physical functioning. Fatigue has been identified as the most significant factor affecting daily activities among cancer patients (Hoskins et al., 1997). For those patients who undergo surgery, the post operative period is associated with physical discomfort and pain which is reflected in functional deficits like inability to work. Cancer related pain is associated with reduced performance status and poor QOL (Delaney et al., 2008). A Study conducted among long term cervical cancer survivors reported a high prevalence of chronic pain in the lower back and hips following radiotherapy which affected their physical functioning (Vistad et al., 2011). This therefore necessitates provision of information to the patients and management of chronic pain syndromes by health care providers after radiotherapy. Relatively poor QOL scores on the symptom and function subscales using the MVQOLI that corresponds to physical well being have been reported among cancer patients in studies conducted in Uganda and South Africa (Selman et al., 2011) and also in the USA (Byock and Merriman, 1998; Steele et al., 2005).

### **2.4 Psychosocial Well Being**

The mental health status and social interactions can also be disrupted by cancer and its treatment. Cancer induced bone pain has been associated with anxiety and depression that affect the psychological well being of the patient (Delaney et al., 2008). Cancer patients undergoing chemotherapy and radiotherapy experience some psychological effects in their lives which cannot be overlooked like anxiety, stress and depression as reported in a long

term follow-up study of patients with advanced cervical cancer (Berclaz et al., 2002). Being a terminal disease, patients are inclined to remain worried about their future life and the prognosis of the disease. The fear about recurrence of the disease is a worrying feature among cancer patients even after undergoing radiotherapy (Klee et al., 2000). This state of anxiety can be allayed by health workers through a well scheduled follow up programme where adequate and appropriate information is shared with the patient concerning their illness. Anxiety about sexual performance following radiotherapy is also a major worry among cervical cancer patients (Park et al., 2007). Sexual relations become difficult or uncomfortable following cancer diagnosis and treatment. Impaired sexual functioning is a sensitive concern where partner involvement is important for mutual understanding to prevail especially during counselling sessions. However, a contrasting finding was made in a different study that showed no association between QOL and radiotherapy treatment (Cui et al., 2004). Long term cervical cancer survivors have been reported to have clinically significant worse body image and social functioning following cancer treatment (Park et al., 2007). This demands adequate social support from the family and involvement of the patient in social activities.

Generally depression and anxiety have been shown to increase in the life of a cancer patient mostly associated with the fear of recurrence or spreading of the disease which negatively affects the QOL of the patient (Reis et al., 2010). The interpersonal and wellbeing subscales in the MVQOLI corresponding to social and psychological well being exhibited poor QOL scores among cancer patients receiving palliative care in a study conducted in Uganda and South Africa (Selman et al., 2011) though the scores were higher for the interpersonal subscale in the studies conducted in USA (Byock and Merriman, 1998; Steele et al., 2005). This could be a function of differences in the perception of these dimensions between the Americans and Africans and/or the treatment and support administered in these two settings to meet the patient needs.

## **2.5 Spiritual Well Being**

Spiritual care among cancer patients accounts for a variance in their QOL. Patients with advanced cancer take spirituality seriously in their lives and many seek help for their spiritual needs (Peteet & Balboni, 2013). With cancer diagnosis, some patients lose meaning in life and depend on their spirituality for their continued existence in this world. Most patients with advanced cancer experience one or more spiritual concerns. Therefore understanding the spiritual themes including beliefs, community, coping, transformation and practices that are

active in their cancer experience is important (Alcorn et al., 2010). Although the palliative care specialists are trained on spiritual care, this is one point where a specialist in spiritual matters taking into consideration the patients' religion becomes important. It has been reported that patients with advanced cancer do have spiritual experiences that reduce their levels of anxiety and pain, alter their attitudes towards their illness, life, death and God resulting in higher QOL scores (Renz et al., 2013). This evidence concurs with yet another study (Balboni et al., 2010) that reported the impact of spiritual support to patients with advanced cancer by the medical team. In that study, patients who received spiritual support from the medical team had higher scores on QOL when they neared death.

The transcendent subscale in the MVQOLI corresponding to spiritual well being showed poor QOL scores among cancer patients receiving palliative care in a study conducted in Uganda and South Africa (Selman et al., 2011) though the scores were higher in similar studies conducted in USA (Byock and Merriman, 1998; Steele et al., 2005). This observed difference could be attributed to the differences in the perception of spirituality between the Americans and Africans and/or the spiritual treatment given in these two settings to meet the patient needs.

Cancer patients take spirituality to be an important aspect in their cancer experience and as such, health care providers must strive to meet the spiritual needs and desires of their patients.

## **2.6 Effects of Socio-Demographic Factors on Quality of Life**

Quality of life among cancer patients can be influenced by socio-demographic factors. A study conducted in Sudan established that being married, attaining at least a high school education and being employed were associated with higher QOL scores among breast and gynaecological cancer patients (Awadalla et al., 2007). This is supported by findings in yet another study carried out in Iran among breast cancer patients that also identified better QOL among employed women (Safaei et al., 2008). These studies assert that formal employment and being married yield higher QOL scores mainly due to the adequate social support associated with the two factors. Similarly tertiary level of education and a higher family monthly income resulted in higher QOL scores among Yemeni cancer patients (Redhwan et al., 2011). This depicts the influence of family income on the QOL of cancer patients.

The influence of age and level of education on QOL is exhibited in a study conducted among gynaecological cancer patients which showed that patients with less than high school education and were less than 50 years in age had lower overall QOL scores (Miller et al.,

2002; Chan et al., 2012). This contrasts findings from a study among Turkish gynaecological cancer patients that reported higher overall QOL scores among women less than 60 years (Goker et al., 2011). Again the age of cancer patients has been known to vary their perception of body image and physical attractiveness hence their QOL.

The impact of spiritual support to patients with advanced cancer by the medical team was reflected by higher scores on QOL when the patients neared death (Balboni et al., 2010). Patients who lacked spiritual support and therefore experienced low spiritual well being exhibited poor QOL scores. Ultimately this reflects the influence that religion or spirituality of a patient has on their QOL.

## **2.7 Effects of Clinical Characteristics on Quality of Life**

The type of cancer, duration of illness and the treatment cancer patients undergo usually affect their physical and psychosocial well being. The influence of the type of cancer on the QOL of a patient was reported in a study conducted in Turkey among gynaecological cancer patients. The study concluded that patients with ovarian and endometrial cancer had better health status, role function and social well being than patients with vulva and cervical cancers (Goker et al., 2011). Ovarian and endometrial cancers are usually common during the perimenopausal years (Goncalves, 2010) when most women are much older and the children they have are grownups who are able to provide them with the much needed social support. However, these findings are in contrast to those of Miller et al. (2002) who reported lower total QOL scores among patients with ovarian cancer.

It has been reported that cervical cancer survivors have a high prevalence of chronic pain in the lower back and hips attributed to late effects of radiotherapy that impairs their physical functioning (Vistad et al., 2011). Radiotherapy and multi-modal therapy has also been associated with lower total QOL scores among gynaecological cancer patients (Miller et al., 2002). Vaginal stenosis and fibrosis has been associated with chemo-radiotherapy treatment for patients with cervical cancer leading to a reduced sexual desire and sexual performance (Berclaz et al., 2002). According to Abayomi et al. (2005), 80% of all patients treated for pelvic cancers such as cervical, prostate, endometrial and bladder will experience a permanent change in bowel habit after radiotherapy. These effects of radiotherapy impair the QOL of the cancer patients. The effects of radiotherapy to patients highlights the dilemma health care providers find themselves in before initiating the treatment. Whereas on one end the treatment is meant to improve the QOL of the patient, the effects on the other hand lower

the QOL of the patient. However, it is important to appreciate that some of the effects are self and time limiting, hence the need to continue with the treatment.

Depending on the clinical situation and other prevailing circumstances, the choice of treatment modality has a bearing on the QOL of the patient. Findings from a study conducted in China among gynaecological cancer patients reported that patients treated with chemotherapy had lower QOL than those treated with surgery (Chan et al., 2001). Similarly patients treated with surgery or chemotherapy alone returned to relatively normal functioning as opposed to those treated with radiotherapy that were more likely to complain about urinary, sexual and gynaecological symptoms (Greimel et al., 2009).

The emotional well being of breast cancer patients are associated with the type of surgery they were to undergo (Redhwan et al., 2011). This suggests different perceptions about body image depending on whether the patient underwent lumpectomy or mastectomy. This finding is in contrast with another study reporting no significant association between type of surgery and QOL (Lu et al., 2007).

A study conducted among breast cancer patients who had been diagnosed for the disease in less than four months reported a lower QOL score (Safaei et al., 2008). During the initial phases following a diagnosis of cancer, the patients' reaction to the news of the diagnosis, his/her interpretation of the disease and the reaction of friends and relatives may negatively affect their QOL. Therefore the duration of illness can influence the QOL of cancer patients. Despite these findings, a general observation has been made that gynaecological cancer patients tend to have an improved overall QOL following completion of cancer treatment (Chan et al., 2001).

## **2.8 Gaps in Literature Review**

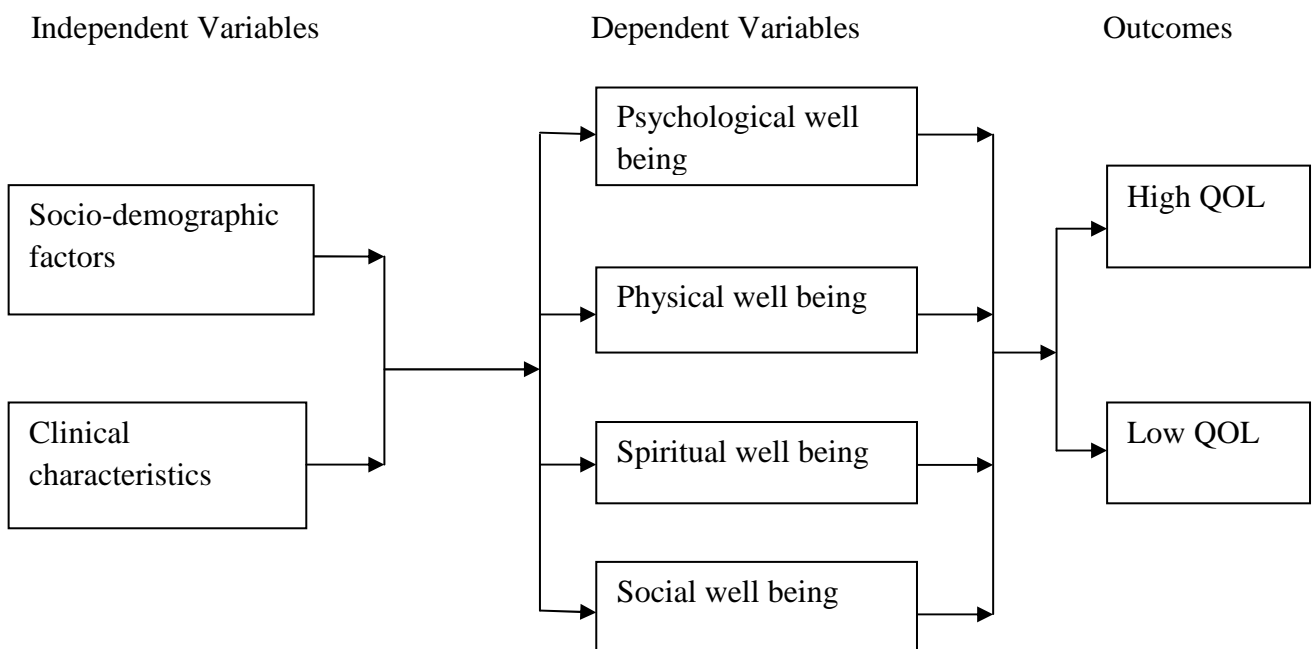
The literature review revealed a contrasting evidence regarding the association between age, levels of education and QOL scores as highlighted in these studies (Miller et al., 2002; Awadalla et al., 2007; Goker et al., 2011; Chan et al., 2012). This necessitates conducting further research in this area. QOL issues among cancer patients are considered important and have led to an emerging research body. Few studies have documented QOL among cancer patients in Africa. Given that social environment can change the perception about quality of life, a research gap exists on the QOL among cancer patients in the Kenyan population. Equally, no specific studies have shown the effect of socio-demographic and clinical factors on QOL of cancer patients in the Kenyan context. Hence the need to conduct research in this area to fill the knowledge gap.

## 2.9 Theoretical Framework

The City of Hope Model has been used in assessing the QOL for cancer patients (Ferrel, Grant, Padilla, Vemuri & Rhiner, 1991). This model views QOL from a subjective and multidimensional perspective. The individual is viewed as complex being, QOL as dependent on the unique perspective of the individual and health as a multidimensional construct. This model identifies the four dimensions of QOL as physical well being and symptoms, psychological, social and spiritual well being.

This study has adopted the City of Hope Model in assessing the QOL among the gynaecological cancer patients. In the context of this study, the four dimensions of QOL were utilized as dependent variables namely physical, psychological, social and spiritual well being. The study also employed the Missoula Vitas QOL Index as the assessment instrument to obtain patient perceptions on their QOL.

## 2.10 Conceptual Framework

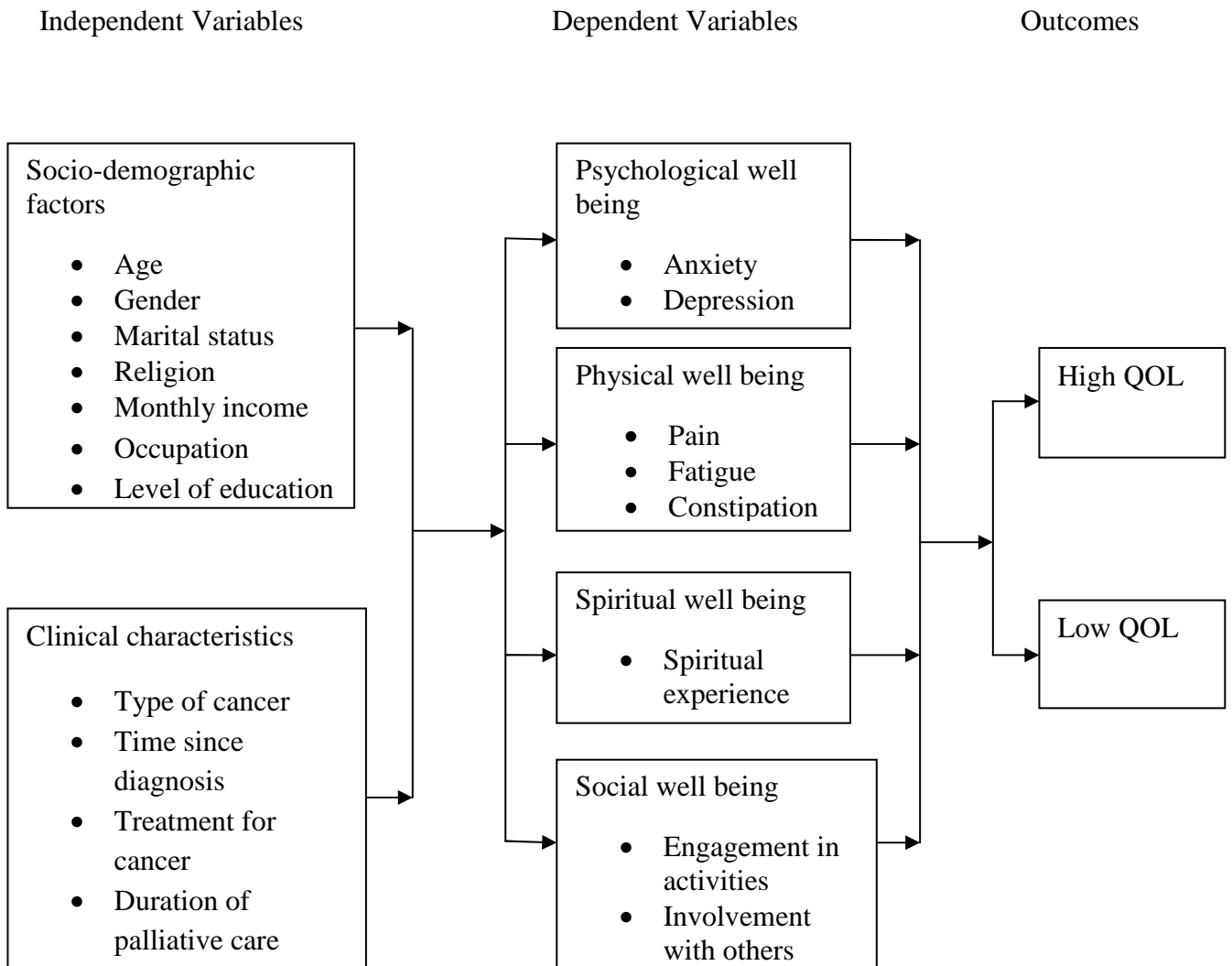


(Source: Ogoncho 2014)

**Figure 1: Conceptual Framework**



## 2.11 Operational Framework



(Source: Ogoncho 2014)

Figure 2: Operational Framework

## **2.12 Definition of Key Variables**

Quality of life: An individual's sense of well being and ability to perform daily tasks or contentment with everyday life; the degree of enjoyment and satisfaction experienced in everyday life as opposed to financial or material well being.

Physical well being: refers to the extent to which cancer and its treatment affect physical changes and cause disturbances in the performance of daily activities.

Psychological well being: refers to the extent to which cancer and its treatment cause symptoms like depression, loss of fertility and anxiety in the patient.

Social well being: refers to the extent to which cancer and its treatment affect the engagement in activities and involvement with others in the society.

Spiritual well being: refers to the extent to which cancer and its treatment affect the spiritual experience of the patient.

Clinical characteristics: refers to the clinical aspects of cancer that the patient is suffering from which affect quality of life e.g. the type of cancer, time of diagnosis, the stage of the cancer and the types of treatment used to manage the cancer.

Socio-demographic factors: refers to the inherent personal characteristics that influence the health of the patient e.g. age, gender, level of education, marital status, occupation, religion and income.

## **CHAPTER THREE**

### **3.0 MATERIALS AND METHODS**

#### **3.1 Study Area Description**

This study was conducted at Kenyatta National Hospital in the palliative care unit, Nairobi, Kenya. This is a 2000 bed capacity hospital that serves as a referral health facility for East and Central Africa. It also serves as a teaching hospital for several institutions notably the University of Nairobi, Kenya Medical Training College and others. The palliative care unit was established in 2007 and is currently run by six palliative care nurses and one specialist doctor. It offers out-patient palliative care services but also receives referrals from the wards and the cancer treatment centre. The referrals from the wards are followed up in their respective admission wards by specialist palliative care nurses/doctor from the palliative care unit as assigned.

#### **3.2 Study Design**

A cross sectional descriptive design was employed in the study. The study was undertaken in a period of six weeks.

#### **3.3 Study Population**

The study population comprised of gynaecological cancer patients receiving care in the palliative care unit at Kenyatta National Hospital. It involved female patients suffering from cervical, endometrial/uterine, ovarian, vulva and vaginal cancers who were above 18 years of age. These were out-patients on follow up at the palliative care unit or admitted patients who were being followed up in their respective wards by specialist palliative care nurses/doctor from the palliative care unit.

#### **3.4 Study Variables**

##### **3.4.1 Dependent variables**

1. Quality of life
2. Physical well being
3. Psychological well being
4. Social well being
5. Spiritual well being

##### **3.4.2 Intervening variable**

Concurrent chronic illness

### **3.4.3 Independent variables**

1. Socio-demographic characteristics: age, gender, level of education, religion, marital status, average monthly income and occupation.
2. Clinical characteristics: duration of illness, palliative care services received, duration of palliative care, type of cancer diagnosis, type of cancer treatment and duration of cancer treatment.

## **3.5 Recruitment Procedure**

### **3.5.1 Inclusion criteria**

Gynaecological cancer patients receiving care at the palliative care unit, Kenyatta National Hospital. Eligible respondents were those patients who were 18 years and above in age, had no known psychiatric or cognitive disorders, attended the unit as a routine follow up or were being followed up by specialist palliative care nurses/doctor in the wards and consented to participate in the study.

### **3.5.2 Exclusion criteria**

The determination of those who did not participate in the study included: Patients with non-gynaecological cancers; gynaecological cancer patients receiving care at the palliative care unit, Kenyatta National Hospital who were under 18 years of age, patients who had dementia and cognitive impairments and eligible respondents who did not consent to participate in the study.

## **3.6 Consenting Procedure**

The information sheet containing study information and the consent form were translated into Kiswahili (see Appendix II & III). The eligible participants were taken through the contents in the information sheet that included purpose and procedures to be used, voluntary participation in the study, potential risks and benefits of the study, the participants' choice to withdraw from the study at any time without any negative repercussions.

The eligible participants were allowed to ask questions and clarifications were made on whatever aspects about the study that had been unclear to the participants. A witnessed signature or thumbprint was obtained from the eligible participants before interviews began.

### 3.7 Sample Size Determination

Sample size was determined using the standard formula for a known population size for a cross sectional study. The Yamane formula according to Yamane Tore, 1967 is shown below

$$n = \frac{N}{[(1 + N(e)^2)]}$$

Where: n=sample size of adjusted population  
N=population size  
e=accepted level of error taking alpha as 0.05.

The estimated number of gynaecological cancer patients seen at the palliative care unit based on the hospital records was approximately 150 monthly. Substituting this figure into the formula above, a sample size of 109 was obtained as shown.

Calculation of sample size:  $n = 150/1+150(0.05)^2$

$$n = 150/1+150(0.0025)$$
$$n = 150/1+0.375$$
$$n = 150/1.375$$
$$n = 109$$

### 3.8 Sampling Procedure

Consecutive sampling was used to select participants for the study. Every eligible gynaecological cancer patient receiving care at the palliative care unit, Kenyatta National Hospital and consented to participate in the study was interviewed. This process was repeated until the required sample size was obtained.

### 3.9 Data Collection Procedure

Data was collected using a structured questionnaire (see Appendix I) that adopted the Missoula Vitas Quality of Life Index (MVQOLI). The MVQOLI is a 26 item quality of life questionnaire with one global QOL item and five subscales. The subscales include symptoms, function, interpersonal, well being and transcendent which covers the physical, social, psychological and spiritual domains respectively. Weighted subscale scores range from -30 to 30 while the total QOL score is calculated from the weighted subscale scores ranging from 0 to 30. The global QOL score is the patients' rating of their overall QOL ranging from 1 to 5. The tool was designed to assess the patients' personal experience in each of those domains.

MVQOLI was validated in the USA where it had an adequate internal consistency ( $\alpha = 0.77$ ) and broad construct validity ( $r = 0.43$ ) with the total scores (Byock & Merriman, 1998). The tool has been tested in a similar population of cancer patients in Uganda and South Africa (Selman et al., 2011). Eligible participants were ascribed to a quiet and confided area within the facility from where the questionnaire was then administered.

After the interviews, all the questionnaires were reviewed daily for completeness and accuracy.

### **3.10 Data Management**

The collected data was uploaded into a computerized database using Microsoft Office Excel 2007 and then exported to Stata version 11 for analysis. Descriptive statistics was used to analyze the socio-demographic, clinical characteristics and the MVQOLI scores. Bivariate analyses were conducted between independent variables using cross tabulations of counts and percentages; and chi-square tests. The association between socio-demographic and clinical characteristics with QOL scores was analyzed using one-way ANOVA. Predictors of the patients' QOL was identified using a multivariate linear regression modelling to adjust for the effect modifying variables identified in bivariate analysis.

The data was presented in the form of bar graphs, pie charts and frequency tables.

### **3.11 Ethical Considerations**

Ethical clearance to conduct the study was obtained from the University of Nairobi and Kenyatta National Hospital, Ethics and Research Committee. Permission to conduct the study was obtained from the management of Kenyatta National Hospital.

The purpose, risks and benefits of the study was explained to the participants by the researcher before obtaining a written consent from them. Participation in the study was voluntary and participants were informed that they could withdraw from the study at any stage of the interview if they so desired without any penalty.

Confidentiality was assured by maintaining the anonymity of the participants and storing the data in password protected files.

### **3.12 Study Limitations**

The cross sectional design used in the study did not allow for measuring the true impact of palliative care services at different points in time. The study also mixed patients at different stages of their cancers and on different types of cancer treatment.

A longitudinal study design and an improvement on the homogeneity of study participants can help overcome these limitations. Despite this, the study findings still highlighted the level of QOL among gynaecological cancer patients in Kenya.

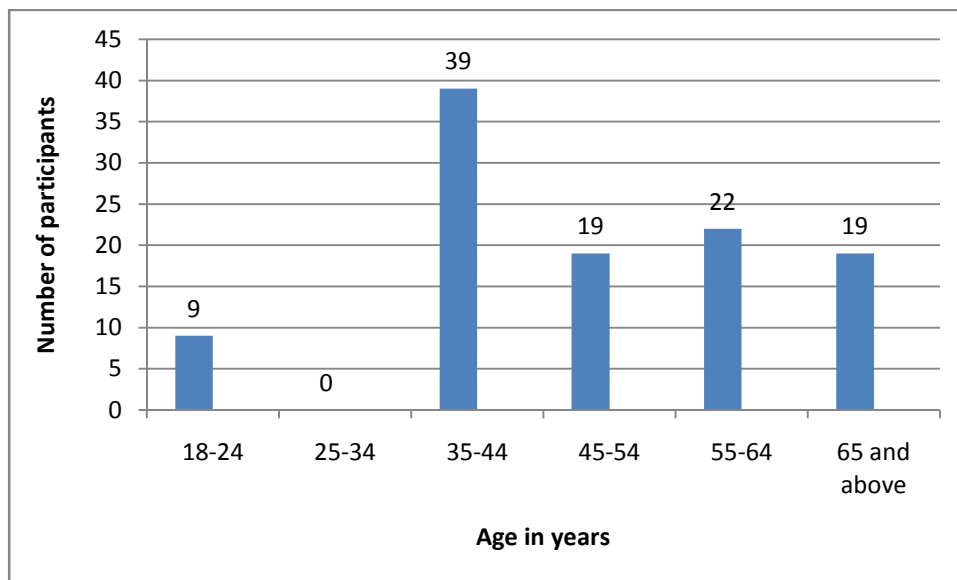
## CHAPTER FOUR

### 4.0 RESULTS

During the study period a total of 108 female gynaecological cancer patients receiving palliative care were interviewed. The proportion of outpatients included in the study was 20% (n=22). Findings of the analysis of participants' characteristics and cancer related effects on quality of life are presented in this chapter.

#### 4.1 Socio-demographic characteristics of the participants

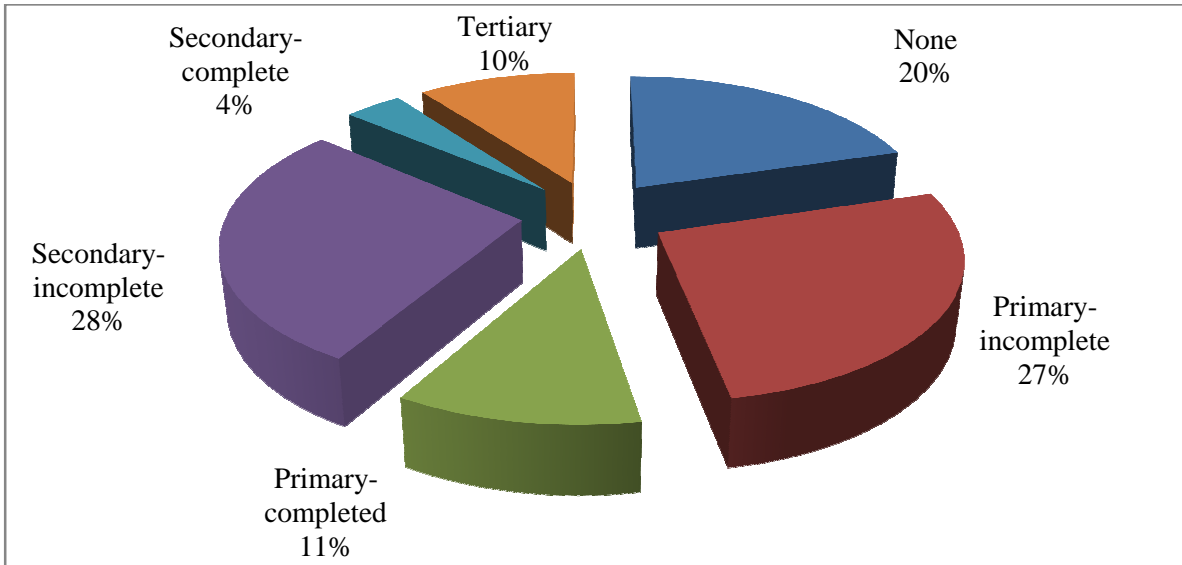
The average age of the participants was 48 years, range 18 to 72 years. Majority of them, 82% (n=89) were aged 64 years and below. Only 18% (n=19) were aged above 65 years. Most participants 36% (n=39) were aged between 35-44 years, Figure 3.



**Figure 3: Age of Participants**

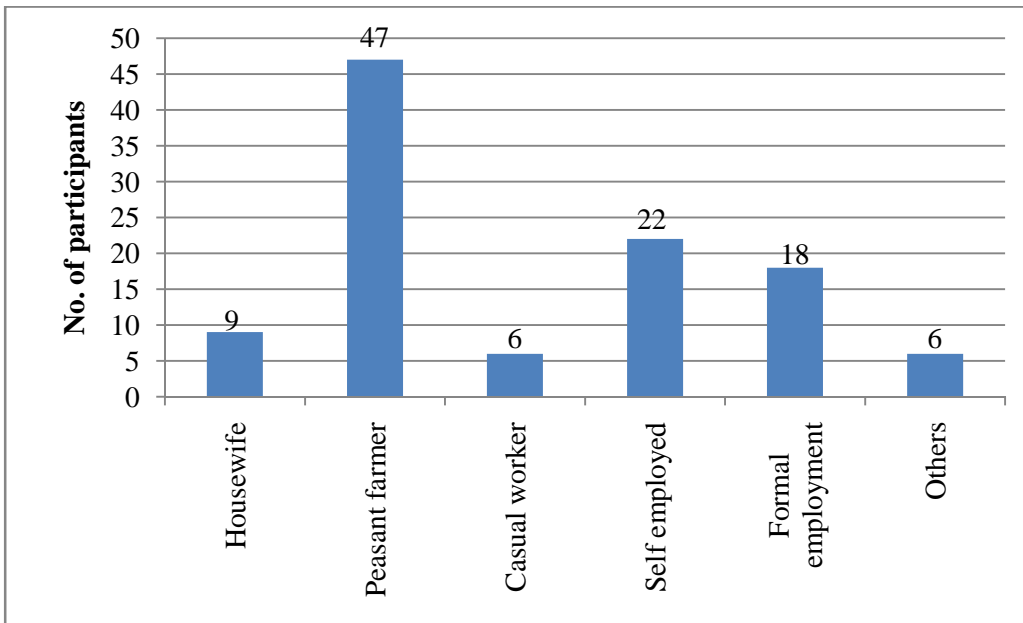
Majority of the participants 80% (n=86) had attained some level of formal education. Incomplete primary 27% (n=29) and secondary 28% (n=30) levels of education were predominant, Figure 4.





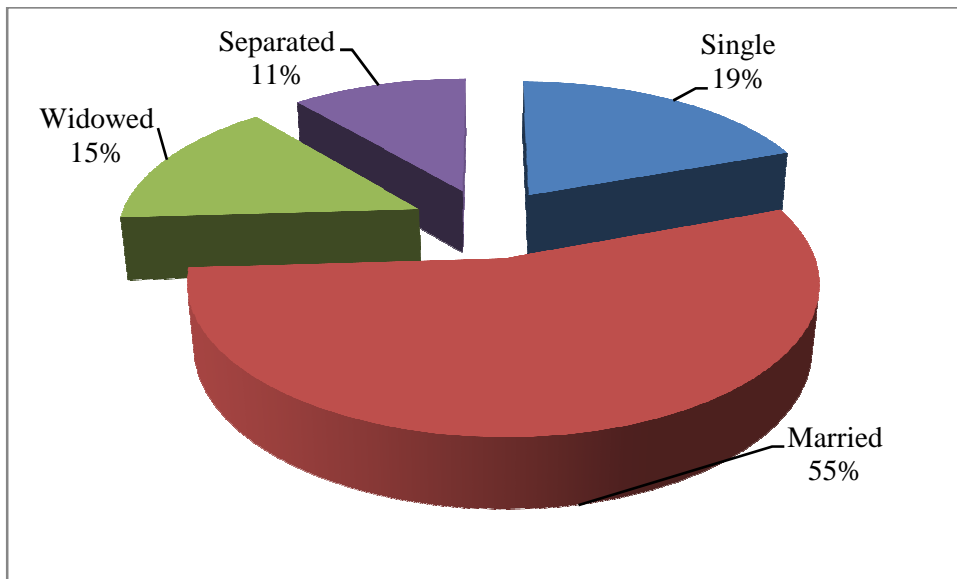
**Figure 4: Participants' Level of Education**

Most participants, 44% (n=47) were peasant farmers. Only 17% (n=18) of them were formally employed, Figure 5.



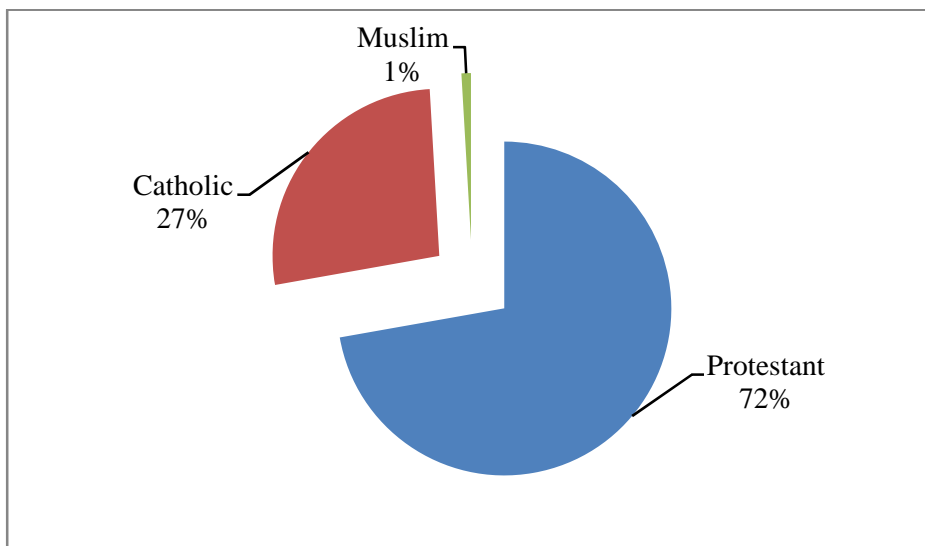
**Figure 5: Participants' Occupation**

Majority of the participants 55% (n=59) were married with 19% (n=21) being single. The widowed accounted for 15% (n=16) of the participants, Figure 6.



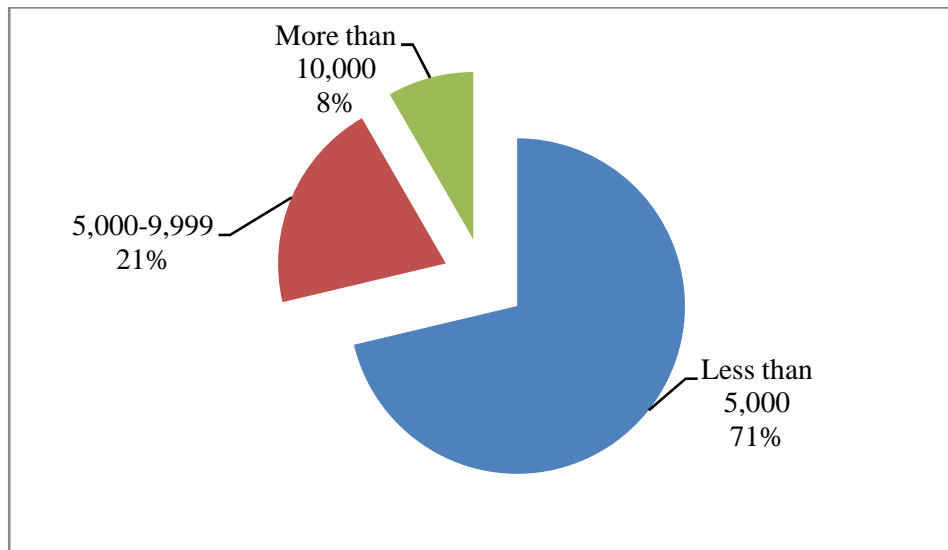
**Figure 6: Participants' Marital Status**

The religious affiliation of the study participants had most of them being protestants 72% (n=78) with 27% (n=29) being Catholics, Figure 7.



**Figure 7: Participants' Religion**

Most participants in the study 71% (n=77) had an income of less than Kshs. 5000 per month. Only 8% (n=9) earned more than Kshs. 10000 per month, Figure 8.



**Figure 8: Participants' Average Monthly Income**

#### **4.2 Clinical Characteristics**

The study sought to investigate the clinical characteristics that participants with gynaecological cancers had. The distribution of the cancers among the participants was as follows: ovarian (24%), cervical (56%), endometrial (19%) and vulva cancer (1%).

Out of the 108 participants in the study, 20% (n=22) had other chronic illnesses notably hypertension, HIV and chronic kidney disease apart from the cancer they were suffering from. The results below highlight the other clinical findings.

There was a significant association ( $p < 0.05$ ) between age, level of education, occupation and marital status with the type of cancer suffered by the women, Table 1.

Ovarian cancer was more common 54% (n=14) among women above 55 years of age while cervical and endometrial cancers 42% (n=25) and 50% (n=11) respectively were predominant among women aged between 34-44 years.

Cervical and endometrial cancers were predominant among those women having primary level of education with 38% (n=23) and 50% (n=11) respectively. The three cancers were more common among the married women with 39% (n=10) ovarian, 57% (n=34) cervical and 68% (n=15) endometrial cancers.

Women suffering from the three cancers were predominantly peasant farmers with 50% (n=13) ovarian, 45% (n=27) cervical and 68% (n=15) endometrial cancers. Similarly majority of them were protestants with 85% (n=22) ovarian, 65% (n=39) cervical and 77% (n=17) endometrial cancers.

**Table 1: Relationship between Participant Characteristics and Type of Cancer**

Variables		Ovarian	Cervical	Endometrial	Chi square	P value
Age	18-24 years	6(23.1)	3(5.0)	0(0.0)	38.2	<b>&lt;0.001</b>
	35-44 years	3(11.5)	25(41.7)	11(50.0)		
	45-54 years	3(11.5)	16(26.7)	0(0.0)		
	55-64 years	7(26.9)	13(21.7)	2(9.1)		
	>65years	7(26.9)	3(5.0)	9(40.9)		
Level of Education	None	1(3.8)	18(30.0)	3(13.6)	50.7	<b>&lt;0.001</b>
	Primary-incomplete	7(26.9)	11(18.3)	11(50.0)		
	Primary- complete	0(0.0)	12(20.0)	0(0.0)		
	Secondary-incomplete	9(34.6)	16(26.7)	5(22.7)		
	Secondary-complete	0(0.0)	1(1.7)	3(13.6)		
	Tertiary	9(34.6)	2(3.3)	0(0.0)		
Occupation	Housewife	1(3.8)	3(5.0)	5(22.7)	30.4	<b>0.001</b>
	Peasant farmer	13(50.0)	27(45.0)	7(31.8)		
	Casual worker	0(0.0)	3(5.0)	3(13.6)		
	Self employed	0(0.0)	18(30.0)	4(18.2)		
	Formal employment	8(30.8)	7(11.7)	3(13.6)		
	Others	4(15.4)	2(3.3)	0(0.0)		
Marital Status	Single	9(34.6)	6(10.0)	6(27.3)	13.9	<b>0.031</b>
	Married	10(38.5)	34(56.7)	15(68.2)		
	Widowed	4(15.4)	11(18.3)	1(4.5)		
	Separated	3(11.5)	9(15.0)	0(0.0)		
Religion	Protestant	22(84.6)	39(65.0)	17(77.3)	4.2	0.38
	Catholic	4(15.4)	20(33.3)	5(22.7)		
	Muslim	0(0.0)	1(1.7)	0(0.0)		
Monthly Income	Less than 5,000	20(76.9)	39(65.0)	18(81.8)	13.7	0.09
	5,000-9,999	3(11.5)	18(30.0)	1(4.5)		
	10,000 and above	3(11.5)	1(1.7)	3(13.6)		

(Figures in parentheses are percentages)

Type of cancer was significantly associated to both duration of illness (p=0.001) and cancer treatment (p=0.006), Table 2.

Ovarian and endometrial cancers were newly diagnosed with 50% (n=13) and 55% (n=12) respectively of the patients being diagnosed within six months.

Cervical cancer was predominantly treated with chemotherapy 28% (n=17), surgery 37% (n=22) or radiotherapy 28% (n=17); ovarian cancer was mainly treated by chemotherapy 35% (n=9) and combined therapy 39% (n=10). Endometrial cancer was predominantly treated by surgery 32% (n=7) and combined therapy 32% (n=7).

**Table 2: Relationship between Types of Cancer, Duration of Illness and Type of Cancer Treatment**

Variables		Ovarian	Cervical	Endometrial	Chi square	P value
Duration of Illness	One to three months	7(26.9)	4(6.7)	9(40.9)	25.8	<b>0.001</b>
	Four to six months	6(23.1)	18(30.0)	3(13.6)		
	Seven to nine months	10(38.5)	21(35.0)	1(4.5)		
	One year	0(0.0)	9(15.0)	6(27.3)		
	More than a year	3(11.5)	8(13.3)	3(13.6)		
Type of Cancer Treatment	Chemotherapy	9(34.6)	17(28.3)	5(22.7)	18.1	<b>0.006</b>
	Surgery	4(15.4)	22(36.7)	7(31.8)		
	Radiotherapy	3(11.5)	17(28.3)	3(13.6)		
	Combined therapy	10(38.5)	4(6.7)	7(31.8)		

(Figures in parentheses are percentages)

Chemotherapy and surgery were the predominant treatment methods at 71% (n=22) and 49% (n=16) respectively for those diagnosed with cancer within six months. Radiotherapy and combined therapy at 74% (n=17) and 86% (n=18) respectively were mainly applied for those patients who had been ill for more than six months.

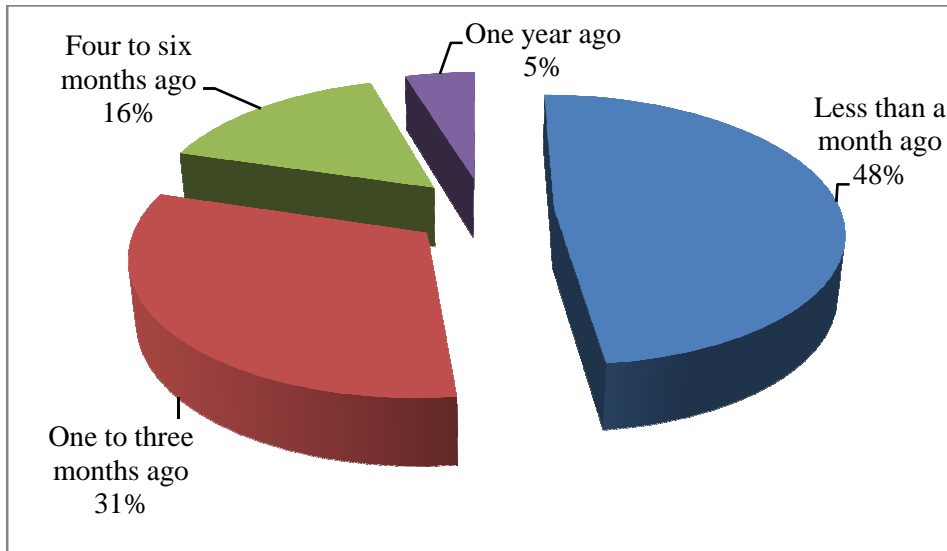
There was a significant association ( $p < 0.05$ ) between the type of cancer treatment and duration of illness, Table 3.

**Table 3: Relationship between Types of Cancer Treatment and Duration of Illness**

Variables		Chemotherapy	Surgery	Radiotherapy	Combined therapy	Chi square	P value
Duration of Illness	One to three months	10(32.3)	10(30.3)	0(0.0)	0(0.0)	33.1	<b>0.001</b>
	Four to six months	12(38.7)	6(18.2)	6(26.1)	3(14.3)		
	Seven to nine months	5(16.1)	9(27.3)	10(43.5)	8(38.1)		
	One year	3(9.7)	6(18.2)	3(13.0)	3(14.3)		
	More than a year	1(3.2)	2(6.1)	4(17.4)	7(33.3)		

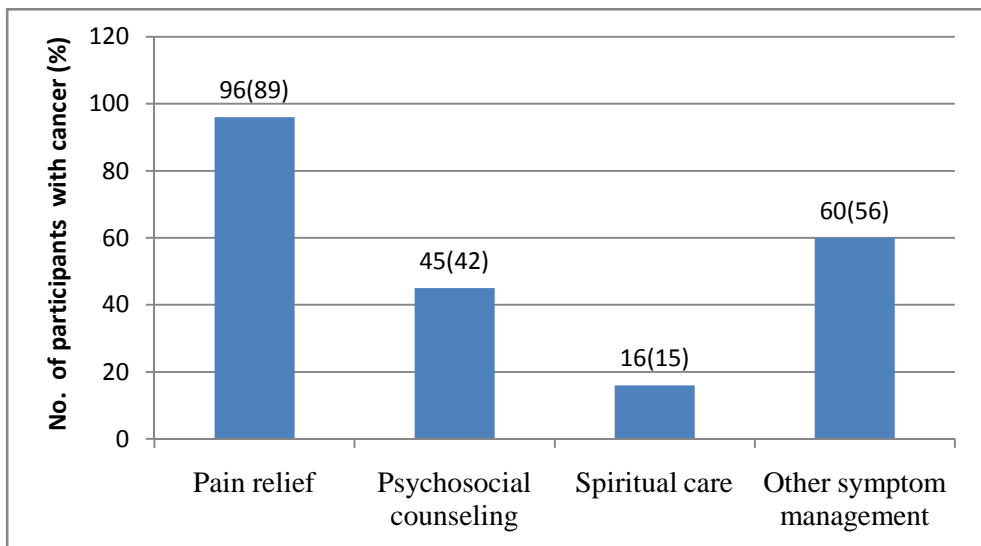
(Figures in parentheses are percentages)

The duration of time from the last cancer treatment received by the patient showed that most participants 48% (n=52) had received their cancer treatment in a time less than a month, Figure 9.



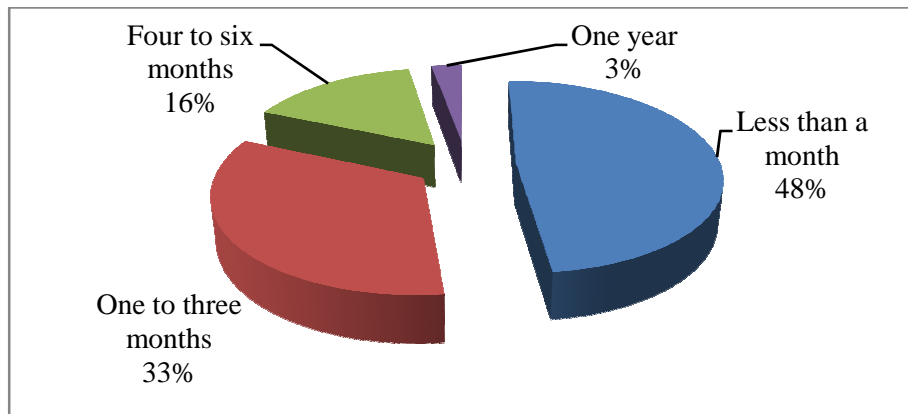
**Figure 9: Duration of Time from the Last Cancer Treatment**

All the 108 participants received palliative care services but with variations. Pain relief and other symptom management at 89% (n=96) and 56% (n=60) respectively were the predominant palliative care services offered to the participants, Figure 10.



**Figure 10: Type of Palliative Care Services received by the Participants**

Most participants, 48% had received palliative care services in less than a month. Those participants who had received palliative care services in a time between one and three months were 33%, Figure 11.



**Figure 11: Duration of Palliative Care**

#### 4.3 Quality of Life Scores

The mean scores on the MVQOLI shown in table 4 indicated that the patients scored poorly on the wellbeing subscale (mean -2.9), followed by interpersonal (mean 5.3), function (mean 5.6), transcendent (mean 6.2), and symptom subscales (mean 8.2) respectively. The subscale scores are expected to range from -30 to 30. The mean global QOL score was 3.5 (range 0-5) while the mean total QOL score was 17.2 (range 0-30).

The poor score on the wellbeing subscale indicated that the subscale had a negative contribution to QOL while the symptom subscale had the highest positive contribution to QOL of the participants.

**Table 4: MVQOLI Scores**

MVQOLI scores	Subjects	Mean	Standard Deviation	Minimum	Maximum
Symptom subscale	108	8.2	11.6	-20	27.5
Function subscale	108	5.6	10.5	-20	20
Interpersonal subscale	108	5.3	11.9	-15	27.5
Wellbeing subscale	108	-2.9	14.1	-20	25
Transcendent subscale	108	6.2	11.9	-24	27.5
Global QOL score	108	3.5	0.9	2	5
Total QOL score	108	17.2	4.2	9	25.2

**Table 5: Association between Socio-Demographic Factors and QOL scores**

Variables	F Mean (SD)	IP Mean (SD)	Sx Mean (SD)	T Mean (SD)	WB Mean (SD)	Total QOL Mean (SD)
<b>Age</b>						
18-24 years	8.3(3)	5(.87)	13(13)	-2.5(7.8)	0.17(2)	17(1.2)
35-44 years	5.7(10)	-2.4(11)	6.3(14)	3.9(9)	-6.4(8.7)	16(3.3)
45-54 years	2.7(12)	9.4(8.5)	6.5(11)	0.74(14)	-11(11)	16(4.1)
55-64 years	5.7(12)	5.5(11)	7.3(10)	8.8(12)	-2.9(17)	17(4.7)
>65years	6.8(10)	17(9.7)	13(4.1)	17(7.9)	11(17)	21(3.4)
<b>P value</b>	0.2	0.679	<b>&lt;0.001</b>	<b>&lt;0.001</b>	<b>&lt;0.001</b>	<b>&lt;0.001</b>
<b>Level of Education</b>						
None	2.7(13)	4.7(9.8)	6.1(9.1)	3.3(7)	-13(9.8)	15(2.6)
Primary- incomplete	6.2(11)	10(13)	10(9.1)	9.1(16)	3(18)	19(5.3)
Primary- complete	7.9(3)	-1.5(11)	16(8.1)	2.3(2.4)	-3.9(3.1)	17(1.3)
Secondary- incomplete	4.5(11)	2.5(12)	2.5(14)	5.8(11)	-5.6(12)	16(4.2)
Secondary-complete	7.5(3)	-4.1(5.3)	18(3)	18(12)	5.3(7.5)	19(1.9)
Tertiary	9.7(3.5)	12(8.5)	12(11)	5(14)	6.8(7.3)	19(3.4)
<b>P value</b>	<b>0.002</b>	0.464	<b>0.003</b>	<b>&lt;0.001</b>	0.11	<b>0.004</b>
<b>Occupation</b>						
Housewife	11(5.3)	0.44(11)	-4.2(12)	6.1(14)	-6.1(10)	16(4.5)
Peasant farmer	2.8(12)	6.9(11)	3.1(11)	4.8(13)	-3.4(16)	16(4.7)
Casual worker	-3.8(15)	-3.5(9.3)	15(1.1)	2(2.2)	-8.8(9.6)	15(1.6)
Self employed	8.9(9.3)	1.8(14)	17(7.4)	6.9(8.7)	-6.5(12)	18(3.6)
Formal employment	8.6(3.7)	11(11)	13(8.5)	14(11)	5.2(14)	20(3.2)
Others	7.2(2.8)	5.2(.75)	17(10)	-4.6(8.9)	0.58(2.2)	18(1.1)
<b>P value</b>	<b>0.009</b>	<b>0.032</b>	<b>&lt;0.001</b>	<b>0.009</b>	0.079	<b>0.012</b>
<b>Marital Status</b>						
Single	7.6(7.1)	9(12)	14(10)	7.4(12)	4.4(10)	19(3.2)
Married	3.3(12)	5.3(11)	5.3(12)	5.8(13)	-5.7(15)	16(4.3)
Widowed	7.8(8.7)	8.7(9.7)	4.6(10)	7.3(12)	-0.13(16)	18(4.6)
Separated	10(4.2)	-5.3(14)	17(5.2)	4.3(6.9)	-5.4(10)	17(3.3)
<b>P value</b>	<b>&lt;0.001</b>	0.08	<b>0.003</b>	<b>0.025</b>	0.865	<b>0.046</b>
<b>Religion</b>						
Protestant	5.3(11)	4.9(12)	7.9(13)	6.3(11)	-1.3(14)	17(4.2)
Catholic	6.4(9.3)	6.3(11)	8.7(8.9)	6(14)	-6.4(15)	17(4.2)
Muslim	2.5(0)	10(0)	16(0)	2(0)	-20(0)	16(0)
<b>P value</b>	0.755	0.864	0.808	0.111	0.933	0.931
<b>Monthly income</b>						
Less than 5,000	5.9(9.3)	3.9(12)	7(13)	5(12)	-2.5(13)	17(4.2)
5,000-9,999	2.9(15)	8(11)	11(8.7)	3.9(7.8)	-11(12)	16(3.5)
10,000 and above	8.6(2.5)	7.3(15)	12(7.3)	21(9.3)	13(11)	21(2.5)
<b>P value</b>	0.221	0.237	0.114	<b>&lt;0.001</b>	<b>&lt;0.001</b>	<b>0.002</b>

F, function; Sx, symptom; T, Transcendent; IP, Interpersonal; WB, Wellbeing subscales; SD, Standard Deviation.



A statistically significant association ( $p < 0.05$ ) was identified between age, level of education, marital status, occupation, average monthly income and the mean total QOL scores, Table 5. There was no significant association ( $p > 0.05$ ) identified between religion and mean total QOL scores.

There was a significant association ( $p < 0.05$ ) between age and symptom, transcendent and wellbeing subscale scores. There was also a significant association ( $p < 0.05$ ) between level of education and marital status with symptom, function and transcendent subscale scores. Occupation had a significant association ( $p < 0.05$ ) with the symptom, function, interpersonal and transcendent subscale scores. The association between income and transcendent, wellbeing subscale scores was also significant ( $p < 0.05$ ).

**Table 6: Association between Clinical Characteristics and QOL scores**

Variables	F Mean (SD)	IP Mean (SD)	Sx Mean (SD)	T Mean (SD)	WB Mean (SD)	Total QOL Mean (SD)
<b>Type of Cancer</b>						
Ovarian	8.7(6.4)	11(11)	7.8(9.1)	11(11)	10(11)	20(3.3)
Cervical	3.2(12)	2.7(11)	8.2(13)	0.99(8.6)	-11(8.7)	15(3.2)
Endometrial	9(9.7)	6(15)	9.6(12)	17(10)	5.6(12)	20(4.5)
Vulva	-2.5(0)	-2(0)	-10(0)	-24(0)	-20(0)	9.1(0)
<b>P value</b>	0.964	<b>0.029</b>	<b>0.009</b>	<b>&lt;0.001</b>	<b>&lt;0.001</b>	<b>&lt;0.001</b>
<b>Duration of Illness</b>						
One to three months	5.1(12)	8.5(12)	13(8.2)	8.8(14)	3.8(14)	19(4.7)
Four to six months	3.9(10)	0.89(9.4)	8.1(14)	5.9(10)	-4.3(12)	16(3.6)
Seven to nine months	11(7.7)	8(11)	7.3(9.9)	8.3(9.9)	-3(16)	18(3.9)
One year	-0.8(13)	0.8(16)	6(14)	3(6.7)	-9.4(5.4)	15(2.3)
More than a year	5.1(6.6)	8.1(11)	5.9(13)	1.4(18)	-2.6(18)	17(5.5)
<b>P value</b>	0.266	<b>0.007</b>	<b>0.037</b>	0.079	0.233	<b>0.027</b>
<b>Type of Cancer Treatment</b>						
Chemotherapy	-0.26(13)	6.1(11)	5.8(13)	5.3(9.7)	-4.1(12)	16(4.1)
Surgery	7.2(8.2)	4.8(13)	13(11)	3.8(12)	-4.1(14)	17(4.3)
Radiotherapy	10(7.8)	-0.83(8.4)	3.5(11)	1.5(12)	-10(14)	15(4)
Combined therapy	6.8(9.3)	12(13)	10(7.4)	16(7.3)	9(12)	20(2.3)
<b>P value</b>	<b>0.011</b>	<b>0.001</b>	<b>0.004</b>	<b>&lt;0.001</b>	<b>&lt;0.001</b>	<b>&lt;0.001</b>
<b>Duration of Time from the Last Treatment</b>						
Less than a month	5.3(11)	5.3(11)	11(8.4)	6.9(12)	-0.7(14)	18(3.7)
One to three months	5.2(11)	4.7(13)	5(14)	3.7(13)	-5.3(14)	16(5)
Four to six months	9.2(6.7)	4.1(12)	6.9(14)	7(11)	-4.2(15)	17(4.3)
One year	-0.4(16)	14(7.7)	4.8(4.4)	13(5)	-4.3(5.5)	18(7.2)
<b>P value</b>	0.085	0.283	0.357	0.468	0.317	0.453
<b>Duration of Palliative Care</b>						
Less than a month	7.6(11)	2.5(12)	5.5(12)	4.8(13)	-3.5(15)	17(4.9)
One to three months	2.7(9.7)	8(12)	11(11)	5(9)	-3.8(13)	17(3.3)
Four to six months	8.8(6.4)	5.7(9.8)	11(9.5)	11(13)	1(15)	19(3.5)
One year	-12(0)	20(0)	8(0)	15(0)	-2.5(0)	18(0)
<b>P value</b>	0.104	<b>0.001</b>	<b>0.021</b>	0.656	0.105	0.317

F, function; Sx, symptom; T, Transcendent; IP, Interpersonal; WB, Wellbeing subscales; SD, Standard Deviation.

A statistically significant association ( $p < 0.05$ ) was identified between type of gynaecological cancer, the duration of illness, the type of cancer treatment the patient was undergoing and mean total QOL scores, Table 6. The duration of time from the last cancer treatment did not significantly ( $p > 0.05$ ) affect the mean total QOL scores.

There was a significant association ( $p<0.05$ ) between the type of cancer and symptom, transcendent, interpersonal and wellbeing subscale scores. The duration of illness and duration of palliative care had significant association ( $p<0.05$ ) with symptom and interpersonal subscale scores. The type of cancer treatment had significant association ( $p<0.05$ ) with all the five dimension scores.

**Table 7: Association between Palliative Care Services and Mean Total QOL scores**

Variables		<b>F</b> Mean (SD)	<b>IP</b> Mean (SD)	<b>Sx</b> Mean (SD)	<b>T</b> Mean (SD)	<b>WB</b> Mean (SD)	<b>Total QOL</b> Mean (SD)
Pain relief	Yes	5.4(11)	4.3(12)	7.4(12)	6(12)	-3.7(14)	17(4.2)
	No	6.9(3.4)	14(7.1)	15(6.6)	7.4(15)	3.8(16)	20(3.4)
	<b>P value</b>	0.66	<b>0.008</b>	<b>0.03</b>	0.71	0.08	<b>0.03</b>
Psychosocial counselling	Yes	7.1(11)	4.4(11)	7.1(14)	4.1(14)	-2.3(14)	17(5)
	No	4.5(11)	6(13)	9(9.6)	7.7(10)	-3.3(14)	17(3.5)
	<b>P value</b>	0.21	0.51	0.40	0.12	0.74	0.66
Spiritual care	Yes	8.6(7.5)	0.69(9.9)	4.4(9.9)	3.8(19)	-7.3(15)	16(5.1)
	No	5.1(11)	6.1(12)	8.9(12)	6.6(10)	-2.1(14)	17(4)
	<b>P value</b>	0.21	0.09	0.16	0.39	0.18	0.21
Other symptom management	Yes	4.5(12)	10(12)	9.2(9.7)	8.5(11)	-2.1(15)	18(4.1)
	No	7(9)	-0.53(9.1)	7(14)	3.2(12)	-3.9(12)	16(4)
	<b>P value</b>	0.23	<b>&lt;0.001</b>	0.33	<b>0.02</b>	0.52	<b>0.03</b>

**F**, function; **Sx**, symptom; **T**, Transcendent; **IP**, Interpersonal; **WB**, Wellbeing subscales; SD, Standard Deviation.

There was a statistically significant association ( $p<0.05$ ) between pain relief and interpersonal, symptom subscales and mean total QOL scores. The association between other symptom management and interpersonal, transcendent subscales and mean total QOL scores was also significant ( $p<0.05$ ), Table 7. However, those who received pain relief services had lower mean scores than those who didn't which could be due to the severity of the pain they were experiencing. Psychosocial counselling and spiritual care did not significantly affect ( $p>0.05$ ) the subscale and mean total QOL scores in this study.

#### 4.4 Predictors of Quality of Life

**Table 8: Linear Regression Analysis**

Variables		Coefficient	Standard Error	t	P value	95% confidence interval	
						Lower	Higher
Age	35-44 years	1.90	2.76	0.69	0.494	-3.60	7.39
	45-54 years	3.06	2.62	1.17	0.247	-2.16	8.28
	55-64 years	3.57	2.85	1.25	0.214	-2.11	9.25
	>65years	5.38	2.74	1.96	<b>0.053</b>	-0.08	10.83
Level of education	Primary- incomplete	2.97	0.97	3.07	<b>0.003</b>	1.04	4.90
	Primary- complete	7.83	1.22	6.4	<b>&lt;0.001</b>	5.40	10.27
	Secondary- incomplete	-1.88	1.11	-1.69	0.095	-4.10	0.34
	Secondary-complete	-5.87	2.98	-1.97	<b>0.052</b>	-11.81	0.06
	Tertiary	6.19	2.70	2.3	<b>0.024</b>	0.82	11.57
Occupation	Peasant farmer	-4.30	1.02	-4.22	<b>&lt;0.001</b>	-6.33	-2.27
	Casual worker	-9.55	1.84	-5.18	<b>&lt;0.001</b>	-13.21	-5.88
	Self employed	-0.57	0.99	-0.58	0.566	-2.53	1.40
	Formal employment	-7.42	2.56	-2.9	<b>0.005</b>	-12.53	-2.32
	Others	-6.72	3.38	-1.99	<b>0.05</b>	-13.46	0.01
Monthly income	5,000-9,999	2.26	0.71	3.2	<b>0.002</b>	0.85	3.66
	10,000 and above	5.85	1.95	3	<b>0.004</b>	1.96	9.74
Type of treatment	Surgery	-2.33	0.89	-2.62	<b>0.011</b>	-4.09	-0.56
	Radiotherapy	-1.04	0.86	-1.22	0.228	-2.75	0.66
	Combined therapy	6.06	1.42	4.25	<b>&lt;0.001</b>	3.22	8.89
Duration of illness	Four to six months	-0.90	0.98	-0.92	0.36	-2.85	1.05
	Seven to nine months	-2.28	1.08	-2.11	<b>0.038</b>	-4.44	-0.12
	One year	-8.81	1.13	-7.78	<b>&lt;0.001</b>	-11.06	-6.56
	More than a year	-6.85	1.33	-5.17	<b>&lt;0.001</b>	-9.49	-4.22
Type of cancer	Cervical	-1.15	1.27	-0.9	0.37	-3.67	1.38
	Endometrial	1.98	0.83	2.39	<b>0.019</b>	0.33	3.62
Palliative care service	Pain relief	-0.82	2.08	-0.4	0.693	-4.97	3.32
	Other symptom management	-0.30	0.70	-0.43	0.67	-1.68	1.09
<b>Intercept</b>		19.86	4.74	4.19	<b>&lt;0.001</b>	10.41	29.30

The multivariate linear regression analysis is shown in table 9. The model predicting quality of life scores and adjusting for the effect of patient age, education, occupation, income, cancer treatment, duration of illness, cancer type and palliative care services had an adjusted R-squared of 0.81 indicating that these factors explained 81% of the variance in quality of life scores among cancer patients in the study. In the adjusted analysis, palliative care service was not found to be significantly associated with patient QOL scores ( $p > 0.05$ ).

The average quality of life score for a patient with the minimum value for all the variables in the model (intercept) was estimated to be 19.86. The effects of the significant variables on the QOL score is calculated by adding the coefficient of that variable to the intercept. The QOL of patients with endometrial cancer was on average 1.98 points higher than that of patients

with cancer of the ovary ( $p=0.019$ ) while there were no significant differences in QOL scores for patients with cancer of the cervix compared to cancer of the ovary ( $p=0.37$ ).

Longer durations of illness impacted negatively on quality of life resulting in significantly lower QOL scores at 7-9 months (coefficient = -2.28), 1 year (coefficient = -8.81) and more than 1 year (coefficient = -6.85). Peasants (coefficient = -4.30), casual workers (coefficient = -9.55), and patients in formal employment (coefficient = -7.42) had significantly lower QOL scores compared to housewives.

Based on the results of the regression, it can therefore be concluded that age, level of education, occupation, average monthly income, type of cancer treatment, duration of illness and type of cancer are independent predictors of QOL.

## CHAPTER FIVE

### 5.0 DISCUSSION

This study evaluated the QOL among gynaecological cancer patients receiving palliative care and its relationship to socio-demographic and clinical variables. Findings from the study established that age, level of education, occupation and monthly income influenced the QOL of gynaecological cancer patients in this setting. The study also established a significant association between the types of gynaecological cancer, the duration of illness and the type of cancer treatment the patient was undergoing with QOL scores.

The mean total QOL score in the study was 17.2 out of the expected range of between 0 and 30 according to the MVQOLI scoring system. Though the MVQOLI does not provide for absolute QOL, from the expected score range, it can be inferred that the QOL of the gynaecological cancer patients receiving palliative care at KNH was moderate with a tendency towards high QOL. Among similar studies utilizing MVQOLI, (Selman et al., 2011) reported a mean total QOL score of 18.4 in Uganda and South Africa while a mean total QOL score of 19.9 was reported in the USA (Byock and Merriman, 1998). These findings indicated that the mean total QOL scores among cancer patients in this study were relatively lower than similar studies.

The symptom subscale had the highest mean score of 8.2 hence had the highest positive contribution towards the patients' QOL. This essentially meant that cancer patients in this setting were satisfied with the management of their pain and other symptoms with similar findings having been reported by Selman et al (2011). The interpersonal subscale with a mean score of 5.3 had the least positive contribution towards the patients' QOL. This indicated a lack of close relationships between the cancer patients with their relatives and friends. However, this could be attributed to the large proportion (80%) of the study patients who were inpatients and therefore spent less time with their relatives and friends. The wellbeing subscale means score of -2.9 had a negative contribution towards the patients' QOL. This indicated a lack of psychological preparedness on the part of the study patients to leave this life and that their daily life affairs had not been fully put in order.

This study reported lower scores in the interpersonal, well being and transcendent subscales but higher scores in the symptom subscale compared to two other studies in USA that utilized MVQOLI (Byock and Merriman, 1998; Steele et al., 2005). The well being subscale had the

poorest QOL scores followed by the interpersonal subscale and then function subscale. The well being subscale also scored the worst QOL in the study by Byock and Merriman (1998).

Although higher scores were reported in the symptom and function subscales in this study, lower scores were reported in the well being, interpersonal and transcendent subscales especially when compared to similar studies conducted in Uganda and South Africa. The observed difference could be attributed to the primary place of palliative care during the study period. Majority (80%) of the patients in this study were inpatients compared to most respondents cared for as outpatients, at home or in the community in similar studies. The home or community environments provided good psychosocial and spiritual support to patients by their relatives, friends and church members.

From regression analysis having endometrial cancer, being on combined therapy, a monthly income of 5000 shillings and above, being 65years or older and having primary or tertiary levels of education positively influenced QOL of gynaecological cancer patients in this study. However, having surgical treatment, a long duration of illness, being a peasant farmer or casual worker and having completed secondary education negatively influenced QOL in these patients. Therefore patients who were peasants or casual workers, underwent surgical treatment and had a long duration of illness were the more vulnerable group who required special attention and focus from the care givers.

Patients aged 65 years and above had higher physical, spiritual, psychological and total QOL scores compared to other age groups. This was consistent with findings of Chan et al. (2012) but contrasted findings from a study by Goker et al. (2011) who reported higher physical and overall QOL scores among younger Turkish gynaecological cancer patients. This difference could be due to the positive coping methods and social support older women in the African setting obtain from family and friends.

The patients' occupation was significantly associated with QOL. The formally employed had higher social, psychological, spiritual and total QOL scores compared to peasant farmers and casual workers. Formal employment is associated with adequate social support based on the high income earnings. This finding was consistent with that of Awadalla et al. (2007) among breast and gynaecological cancer patients where those with higher levels of employment had higher QOL.

The patients who earned more than 10,000 Kenyan shillings had higher psychological and total QOL scores compared to those who earned less. This finding was consistent with other studies that have reported a significant association between monthly income and overall QOL (Conde et al., 2005; Awadalla et al., 2007; Redhwan et al., 2011). High income earnings are associated with adequate social support while low income earnings are associated with poverty and low socioeconomic status in the society which are a risk to cancer development (Kagawa-Singer, 1995). Cancer patients with lower socioeconomic status have a more limited access to health care and receive less aggressive treatment for their cancers leading to poor QOL (Bindmann et al., 1995; VanEenwyk et al., 2002).

Gynaecological cancer patients who had completed secondary and tertiary levels of education had higher total QOL scores compared to those with lower levels of education. Low levels of education have been associated with decreased awareness of the disease. This often contributes to a large number of the women being less likely to be screened early for their cancers which makes them increasingly present to health facilities in the late stages of their cancers leading to poor prognosis hence low QOL scores. These findings are consistent with those by Awadalla et al. (2007) in Sudan reporting higher QOL scores with higher levels of education while lower levels of education were associated with lower QOL scores in two other studies (Miller et al., 2002; Peuckmann et al., 2007).

The married women had the lowest psychological and total QOL scores in the study. This was in contrast to other studies (Awadalla et al., 2007; Reis et al., 2010; Goker et al., 2011) that found married women having higher overall QOL and role function scores. The low psychological domain scores could be attributed to disease changes that made sexual relations among these patients and their partners difficult or uncomfortable as a result of the cancer and its treatment effects.

Patients who suffered from ovarian and endometrial cancers had higher physical, social, psychological and total QOL scores than those with cervical and vulva cancers. This finding was consistent with that of another study (Goker et al., 2011), where ovarian and endometrial cancer patients had better health status, role function and social well being than those with vulva and cervical cancers. The observed difference could be attributed to good prognosis following early diagnosis and the pathogenesis of ovarian and endometrial cancers. Normally, women with early stage ovarian cancer tended to have good prognosis following surgical treatment (Arriba et al., 2010). Endometrial cancer also has the best prognosis when



diagnosed early and has a slow growth process and late metastasis (Goker et al., 2011). Ovarian and endometrial cancers are also known to affect older women who tended to have good social support systems. However, the same findings were in contrast to those of Miller et al. (2002) who reported lower total QOL scores among patients with ovarian cancer.

Although the design of the questionnaire was not structured to capture the side effects and adverse effects of cancer treatment, this study reported a significant association between the type of cancer treatment and QOL scores which was consistent with literature. Patients on surgical treatment had higher total QOL scores, followed by chemotherapy with the least scores being observed under radiotherapy. Goker et al. (2011) found that patients who underwent surgery had higher physical, social and role function scores. Similar findings were reported in a study conducted in China which showed that patients treated with chemotherapy had lower QOL than those treated with surgery (Chan et al., 2001). Accordingly, patients treated with surgery or chemotherapy alone returned to relatively normal functioning as opposed to those treated with radiotherapy that were more likely to complain about urinary, sexual and gynaecological symptoms (Greimel et al., 2009).

Despite there having been no significant association between the duration of time since the last cancer treatment and QOL scores, literature documents otherwise. According to findings in a study conducted by Klee et al. (2000), patients treated with chemotherapy had decreased QOL up to six months after treatment but tended to return to normal levels at twelve months. Radiotherapy was associated with a chronic and negative impact on QOL (Abayomi et al., 2005).

Despite all the patients having received palliative care for some time, most of them (48%) had received palliative care in a period less than one month yet more than 50% of the patients had been diagnosed of the disease for more than six months. This reflected the nature of late referrals made by clinicians and other health care providers for palliative care services when active cancer management and pain control had become ineffective. However, the study findings showed that despite lower mean subscale and total QOL scores, there was a significant effect between pain relief and QOL scores. This observation could be attributed to increased patient satisfaction in the control of their pain by the palliative care team. Pain is one of the most physically distressing symptoms among cancer patients and similar findings have been reported by Selman et al. (2011).

From the regression analysis, age, level of education, occupation, average monthly income, type of cancer treatment, duration of illness and type of cancer were found to be independent predictors of QOL among gynaecological cancer patients in this study. This finding was consistent with those of other studies (Miller et al., 2002; Chan et al., 2012) which identified age, type of cancer, type of cancer treatment and level of education as predictors of QOL among gynaecological cancer patients.

## **5.1 CONCLUSION**

The quality of life among gynaecological cancer patients receiving palliative care at KNH was moderate but tended towards high QOL. The psychological and social needs of the patients were not adequately identified and addressed. Some of the factors that enhanced the QOL among patients in this study included high income earning, advanced age and higher levels of education.

Based on the findings of the study, age, level of education, marital status, occupation and monthly income were identified as the socio demographic factors affecting QOL among gynaecological cancer patients.

The patients' type of cancer, type of cancer treatment, duration of illness and palliative care services were the clinical characteristics identified in the study that affected QOL among gynaecological cancer patients.

Age, education, occupation, income, type of cancer, type of cancer treatment and duration of illness were the independent predictors of QOL reported in the study. The regression analysis identified the vulnerable groups among the gynaecological cancer patients that will guide the palliative care team in addressing their specific needs.

## **5.2 RECOMMENDATIONS**

Based on the conclusions, the following were recommended:

1. Adoption of a QOL assessment instrument in the palliative care unit to assist the palliative care team members in identifying and addressing specific needs that affect the QOL of patients with advanced cancer.
2. Health care providers should strive to provide relevant information to the patient and the family regarding cancer and its treatment effects.
3. Special focus and attention should be provided to the more vulnerable gynaecological cancer patients identified including the young, less educated and those with a longer duration of illness.
4. The health policy makers need to incorporate palliative care services at all levels of the health care system given the increasing incidence of cancer in the country.

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## TIME FRAME

Duration in Weeks / Activity	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18
Problem Identification																		
Proposal Writing																		
Seeking consent from Ethical committee																		
Recruitment and training of research assistants																		
Piloting of study tools																		
Administration of tools																		
Data cleaning and entry																		
Data analysis																		
Report writing and presentation																		
Compilation of final report and dissemination																		



## BUDGET

ITEM	UNIT COST	QUANTITY	COST	TOTAL COST
HUMAN RESOURCE				
(a) Training of research assistants				
Research assistants allowance(2)	500	2x2x500	2,000	
Principal researcher(1)	1,000	1x2x1,000	2,000	
(b) Pre-testing of questionnaire				
Research assistants(2)	500	2x2x500	2,000	
Principal researcher(1)	1,000	1x2x1,000	2,000	
(c) Data collection				
Research assistants(2)	500	2x5x6x500	30,000	
Principal researcher(1)	1,000	1x5x6x1,000	30,000	
<b>SUB-TOTAL</b>				<b>68,000</b>
MATERIALS AND SUPPLIES				
Biro pens(1 dozen)	220	220x1	220	
Pencils(1 dozen)	120	120x1	120	
Rubbers(3)	20	20x3	60	
Folders(3)	100	100x3	300	
Field books	90	90x3	270	
Stapler and staples	600	600	600	
<b>SUB-TOTAL</b>				<b>1,570</b>
PROPOSAL AND THESIS				
Proposal printing & photocopy (5 copies)	250	250x5	1250	
Printing & photocopying final report (6 copies)	450	450 x6	2700	
<b>SUB-TOTAL</b>				<b>3,950</b>
<b>TOTAL</b>				<b>73,520</b>

## APPENDICES

### APPENDIX I: QUESTIONNAIRE ASSESSING QUALITY OF LIFE AMONG GYNAECOLOGICAL CANCER PATIENTS RECEIVING CARE AT THE PALLIATIVE CARE UNIT IN KENYATTA NATIONAL HOSPITAL

Date: .....

Serial Number .....

#### Section 1.0 Socio- Demographic Data

Q 1.1 How old are you?

1. 18-24 years [ ]    2. 25-34 years [ ]    3. 35-44 years [ ]  
4. 45-54 years [ ]    5. 55-64 years [ ]    6. 65 years and above [ ]

Q 1.2 What is your gender?

1. Male [ ]    2. Female [ ]

Q 1.3 What is your level of education?

1. None [ ]    2. Primary-incomplete [ ]  
3. Primary-complete [ ]    4. Secondary-incomplete [ ]  
5. Secondary-complete [ ]    6. Tertiary [ ]  
7. Other [ ] (Specify).....

Q 1.4 What is your occupation?

1. Housewife [ ]    2. Peasant farmer [ ]    3. Casual worker [ ]  
4. Self employed [ ]    5. Formal employment [ ]  
6. Other [ ] (Specify).....

Q 1.5 What is your marital status?

1. Single [ ]    2. Married [ ]    3. Widowed [ ]    4. Separated [ ]  
5. Divorced [ ]    6. Other [ ] (Specify).....

Q 1.6 What is your religion?

- 1. None [ ]    2. Protestant [ ]    3. Catholic [ ]
- 4. Muslim [ ]    5. Other [ ] (Specify).....

Q 1.7 What is your average monthly income (In Kshs)?

- 1. Less than 5,000 [ ]    2. 5,000-9,999 [ ]    3. More than 10,000 [ ]

**Section 2.0 Clinical Characteristics**

Q 2.1 What disease are you suffering from?

.....

Q 2.2 Which type of cancer do you have?

- 1. Ovarian [ ]    2. Cervical [ ]    3. Endometrial/uterine [ ]
- 4. Vulva [ ]    5. Vaginal [ ]

Q 2.3 When were you diagnosed with the cancer?

- 1. One to three months ago [ ]    2. Four to six months ago [ ]
- 3. Seven to nine months ago [ ]    4. One year ago [ ]
- 5. More than one year ago [ ]

Q 2.4 Have you received any treatment for the cancer?

- 1. Yes [ ]    2. No [ ]

Q 2.5 If yes, what type of treatment did you receive?

- 1. Chemotherapy [ ]    2. Surgery [ ]    3. Radiotherapy [ ]
- 4. Surgery and Chemotherapy [ ]    5. Chemotherapy and Radiotherapy [ ]
- 6. Surgery, radiotherapy and Chemotherapy [ ]

Q 2.6 When did you last receive this treatment?

- 1. Less than a month ago [ ]
- 2. One to three months ago [ ]
- 3. Four to six months ago [ ]
- 4. Seven to nine months ago [ ]
- 5. One year ago [ ]

Q 2.7 What services have you received as part of your care?

- 1. Pain relief [ ]
- 2. Psychosocial counselling [ ]
- 3. Spiritual care [ ]
- 4. Other symptom management [ ]
- 5. Other [ ] (Specify).....

Q 2.8 When did you start receiving these services?

- 1. Less than a month ago [ ]
- 2. One to three months ago [ ]
- 3. Four to six months ago [ ]
- 4. Seven to nine months ago [ ]
- 5. One year ago [ ]
- 6. Other [ ] (Specify).....

Q 2.9 Are you currently suffering from any other chronic illness?

- 1. Yes [ ]
- 2. No [ ]

Q 2.10 If yes, which illness?

.....

### **Section 3.0 The Missoula Vitas Quality of Life Index (MVQOLI).**

#### **SYMPTOM**

Q 3.1 My symptoms are adequately controlled

- 1. Strongly agree [ ]
- 2. Agree [ ]
- 3. Neutral [ ]
- 4. Disagree [ ]
- 5. Strongly disagree [ ]

Q 3.2 I feel sick all the time

1. Strongly agree [ ] 2. Agree [ ] 3. Neutral [ ]  
4. Disagree [ ] 5. Strongly disagree [ ]

Q 3.3 I accept my symptoms as a fact of life

1. Strongly agree [ ] 2. Agree [ ] 3. Neutral [ ]  
4. Disagree [ ] 5. Strongly disagree [ ]

Q 3.4 I am satisfied with the current control of symptoms

1. Strongly agree [ ] 2. Agree [ ] 3. Neutral [ ]  
4. Disagree [ ] 5. Strongly disagree [ ]

Q 3.5 Physical discomfort overshadows any opportunity for enjoyment

1. Strongly agree [ ] 2. Agree [ ] 3. Neutral [ ]  
4. Disagree [ ] 5. Strongly disagree [ ]

**FUNCTION**

Q 3.6 I am dependent on others for personal care

1. Strongly agree [ ] 2. Agree [ ] 3. Neutral [ ]  
4. Disagree [ ] 5. Strongly disagree [ ]

Q 3.7 I am no longer able to do many of the things I like to do

1. Strongly agree [ ] 2. Agree [ ] 3. Neutral [ ]  
4. Disagree [ ] 5. Strongly disagree [ ]

Q 3.8 I am satisfied with my ability to take care of my basic needs

1. Strongly agree [ ] 2. Agree [ ] 3. Neutral [ ]

4. Disagree [ ] 5. Strongly disagree [ ]

Q 3.9 I accept the fact that I can not do many of the things that I used to do

1. Strongly agree [ ] 2. Agree [ ] 3. Neutral [ ]

4. Disagree [ ] 5. Strongly disagree [ ]

Q 3.10 My contentment with life depends upon being active and being independent in my personal care

1. Strongly agree [ ] 2. Agree [ ] 3. Neutral [ ]

4. Disagree [ ] 5. Strongly disagree [ ]

**INTERPERSONAL**

Q 3.11 I have recently been able to say important things to the people close to me

1. Strongly agree [ ] 2. Agree [ ] 3. Neutral [ ]

4. Disagree [ ] 5. Strongly disagree [ ]

Q 3.12 I feel closer to others in my life now than I did before my illness

1. Strongly agree [ ] 2. Agree [ ] 3. Neutral [ ]

4. Disagree [ ] 5. Strongly disagree [ ]

Q 3.13 In general, these days I am satisfied with relationships with family and friends

1. Strongly agree [ ] 2. Agree [ ] 3. Neutral [ ]

4. Disagree [ ] 5. Strongly disagree [ ]

Q 3.14 At present, I spend as much time as I want to with family and friends.

1. Strongly agree [ ] 2. Agree [ ] 3. Neutral [ ]

4. Disagree [ ] 5. Strongly disagree [ ]

Q 3.15 It is important to me to have close personal relationships.

1. Strongly agree [ ] 2. Agree [ ] 3. Neutral [ ]

4. Disagree [ ] 5. Strongly disagree [ ]

### **WELLBEING**

Q 3.16 My affairs are not in order, I am worried that many things are unresolved.

1. Strongly agree [ ] 2. Agree [ ] 3. Neutral [ ]

4. Disagree [ ] 5. Strongly disagree [ ]

Q 3.17 If I were to die suddenly today, I would feel prepared to leave this life.

1. Strongly agree [ ] 2. Agree [ ] 3. Neutral [ ]

4. Disagree [ ] 5. Strongly disagree [ ]

Q 3.18 I am more satisfied with myself as a person now than I was before my illness.

1. Strongly agree [ ] 2. Agree [ ] 3. Neutral [ ]

4. Disagree [ ] 5. Strongly disagree [ ]

Q 3.19 The longer I am ill, the more I worry about things getting out of control.

1. Strongly agree [ ] 2. Agree [ ] 3. Neutral [ ]

4. Disagree [ ] 5. Strongly disagree [ ]

Q 3.20 It is important to me to be at peace with myself.

1. Strongly agree [ ] 2. Agree [ ] 3. Neutral [ ]

4. Disagree [ ] 5. Strongly disagree [ ]

**TRANSCENDENT**

Q 3.21 I feel more disconnected from all things now than I did before my illness.

1. Strongly agree [ ] 2. Agree [ ] 3. Neutral [ ]

4. Disagree [ ] 5. Strongly disagree [ ]

Q 3.22 I have a better sense of meaning in my life now than I have had in the past.

1. Strongly agree [ ] 2. Agree [ ] 3. Neutral [ ]

4. Disagree [ ] 5. Strongly disagree [ ]

Q 3.23 I am comfortable with the thought of my own death.

1. Strongly agree [ ] 2. Agree [ ] 3. Neutral [ ]

4. Disagree [ ] 5. Strongly disagree [ ]

Q 3.24 Life has lost all value for me, every day is a burden.

1. Strongly agree [ ] 2. Agree [ ] 3. Neutral [ ]

4. Disagree [ ] 5. Strongly disagree [ ]

Q 3.25 It is important to me to feel that my life has meaning.

1. Strongly agree [ ] 2. Agree [ ] 3. Neutral [ ]

4. Disagree [ ] 5. Strongly disagree [ ]



**GLOBAL**

How would you rate your overall quality of life?

1. Worst possible [ ]    2. Poor [ ]    3. Fair [ ]

4. Good [ ]    5. Best possible [ ]

Thank you for your time and participation

## **APPENDIX IIA: CONSENT EXPLANATION (ENGLISH VERSION)**

### **I. Purpose**

My name is Isaac Machuki Ogoncho, a postgraduate student at the University of Nairobi. I am inviting you to participate in a study I am conducting in this unit. The purpose of this study is to obtain your experience as a cancer patient on the palliative care services in this hospital. This study is being conducted in this unit with permission from the management of the hospital. I am requesting you to participate in this study since you are one of the patients receiving palliative care in the unit.

### **II. Procedure**

If you agree to participate in the study, then you will be required to respond to questions in an interview which will take approximately 25 minutes.

### **III. Risks**

There is no physical harm that will be inflicted on you during this process as it doesn't involve an invasive procedure but there are minimal risks to you for participating in this study. There is a possibility that some of the questions you will be asked may make you uncomfortable. Should this happen feel free to inform the interviewer and the interview will be temporarily stopped. A counselling session will be held in such cases to support the patient as need be.

### **IV. Benefits**

This study may not benefit you directly but your participation and the findings from this study will provide important information that will be used to improve care for cancer patients.

### **V. Voluntary Participation and Withdrawal**

Your participation in the study is completely voluntary. You are free to decline participating in the study or withdrawing from the interviews at any point. Your decision will not lead to any form of victimization or bias in the subsequent medical care in this hospital.

## VI. Confidentiality

Some questions may involve providing personal information but the information provided will be kept confidential and anonymous. Your personal particulars will not be included in the questionnaire or any written reports from this study. Information collected will be saved on password protected files and computers.

## VII. Contact Persons

Should you have any questions or concerns about the content of this study or your rights as a participant in this study, feel free to contact the researcher, Isaac M. Ogoncho, School of Nursing Sciences, University of Nairobi, mobile 0721553403; email - isaacmachuki@yahoo.com. The lead supervisor Dr. Blasio Osogo Omuga, School of Nursing Sciences, University of Nairobi, mobile 0722256080; email – mitenga@yahoo.com. You may also contact the Chairperson of Ethics and Research Committee, KNH/UON through the following address: University of Nairobi, College of Health Sciences, P. O. Box 19676-00202 Nairobi or Tel no. +2542726300 Ext 44102.

**APPENDIX IIB: CONSENT FORM (ENGLISH VERSION)**

**I. Confirmation of consent**

I confirm that I have read the consent information and received an explanation on the purpose and benefits of the study. I have had a chance to ask all questions regarding the study. I hereby voluntarily agree to participate.

Name: .....

Sign: ..... Date: .....

Researcher .....

Sign: ..... Date: .....

**II. Contact Persons**

Should you still have any questions or concerns about the content of this study or your rights as a participant in this study, feel free to contact the researcher, Isaac M. Ogoncho, School of Nursing Sciences, University of Nairobi, mobile 0721553403; email - isaacmachuki@yahoo.com. The lead supervisor Dr. Blasio Osogo Omuga, School of Nursing Sciences, University of Nairobi, mobile 0722256080; email – mitenga@yahoo.com. You may also contact the Chairperson of Ethics and Research Committee, KNH/UON through the following address: University of Nairobi, College of Health Sciences, P. O. Box 19676-00202 Nairobi or Tel no. +2542726300 Ext 44102.

## **APPENDIX IIIA: CONSENT EXPLANATION (SWAHILI VERSION)**

### **I. Lengo**

Kwa majina naitwa Isaac Machuki Ogoncho, mwanafunzi katika chuo kikuu cha Nairobi. Nakualika kushiriki katika utafiti ninaoufanya katika kliniki hiki. Lengo kuu la kufanya utafiti huu ni kupata kufahamu munayoyapitia kama wagonjwa wanaougua Saratani wahudumiwapo katika kliniki hiki. Utafiti huu umeidhinishwa na wasimamizi wa hospitali hii. Ukiwa mmoja wa wagonjwa wanaohudumiwa katika kliniki hiki, nakuomba uweze kushiriki katika utafiti huu.

### **II. Mikakati itakayofuatwa**

Ukikubali kushiriki katika utafiti huu, utahitajika kujibu maswali utakayoulizwa katika mahojiano utakayokuwa nayo na mtafiti ambayo yatachukua muda wa dakika ishirini na tano.

### **III. Madhara yanayokusudiwa**

Hakuna madhara yoyote utakayoyapata katika zoezi hili lakini huenda baadhi ya maswali utakayoulizwa yakakukera kidogo. Hili likitendeka kuwa huru kumjulisha anayekuhoji ili asimamishe hayo mahojiano na aweze kulishughulikia jambo hilo

### **IV. Faida ya utafiti**

Utafiti huu huenda usikufaidi kibinafsi lakini kushiriki kwako huenda kukaibua matokeo yatakayosaidia kuimarisha huduma munayopata katika kliniki hiki.

### **V. Kushiriki kwa hiari na Kujiondoa katika mahojiano**

Kushiriki kwako katika utafiti huu ni kwa hiari yako. Uko huru kukataa kushiriki ama kujiondoa katika mahojiano utakayoshiriki na mtafiti wakati wowote. Uamuzi wako hautashawishi kwa vyovyote vile huduma utakayoendelea kupata katika hospitali hii.

### **VI. Usiri wa Mahojiano**

Baadhi ya maswali utakayoulizwa yatahusisha utoaji wa maelezo kuhusu nafsi yako lakini majibu yote utakayoyatoa yatabakia kuwa siri na jina lako halitafichuliwa. Maelezo kuhusu nafsi yako hayatajumuishwa katika ripoti itakayoandikwa kutokana na utafiti huu. Maelezo haya yatafichwa katika tarakilishi zilizobanwa ambapo hakuna yeyote anayeweza kuyafikia.

## VII. Mawasiliano na Wahusika

Ikiwa utakuwa na maswali ama jambo lolote ungependelea kujua kuhusiana na haki zako kama mshiriki katika utafiti huu, jisikie huru kuwasiliana na mtafiti, Isaac M. Ogoncho, Shule ya Uuguzi, Chuo Kikuu cha Nairobi, namba za rununu 0721553403; barua pepe - isaacmachuki@yahoo.com. Ama mhadhiri msimamizi wa mtafiti Dr. Blasio Osogo Omuga, Shule ya Uuguzi, Chuo Kikuu cha Nairobi, namba za rununu 0722256080; barua pepe – mitenga@yahoo.com. Waweza pia kuwasiliana na mwenyekiti wa kamati inayochanganuza maswala ya utafiti ya hospitali ya Kenyatta na Chuo Kikuu cha Nairobi kupitia sanduku la posta 19676-00202 Nairobi ama nambari ya simu 2726300

## APPENDIX IIIB: CONSENT FORM (SWAHILI VERSION)

### I. Dhibitisho la Idhini

Mimi nadhibitisha ya kwamba nimeyasoma maelezo yaliyopo kuhusu utafiti huu na nimefafanuliwa zaidi kuhusu lengo na umuhimu wa utafiti huu. Nimepewa fursa ya kuuliza maswali kuhusiana na utafiti huu na nimeridhishwa. Nimeamua kwa hiari yangu kuidhinisha kushiriki kwangu katika utafiti huu.

Jina: .....

Sahihi: ..... Tarehe: .....

Mtafiti .....

Sahihi: ..... Tarehe: .....

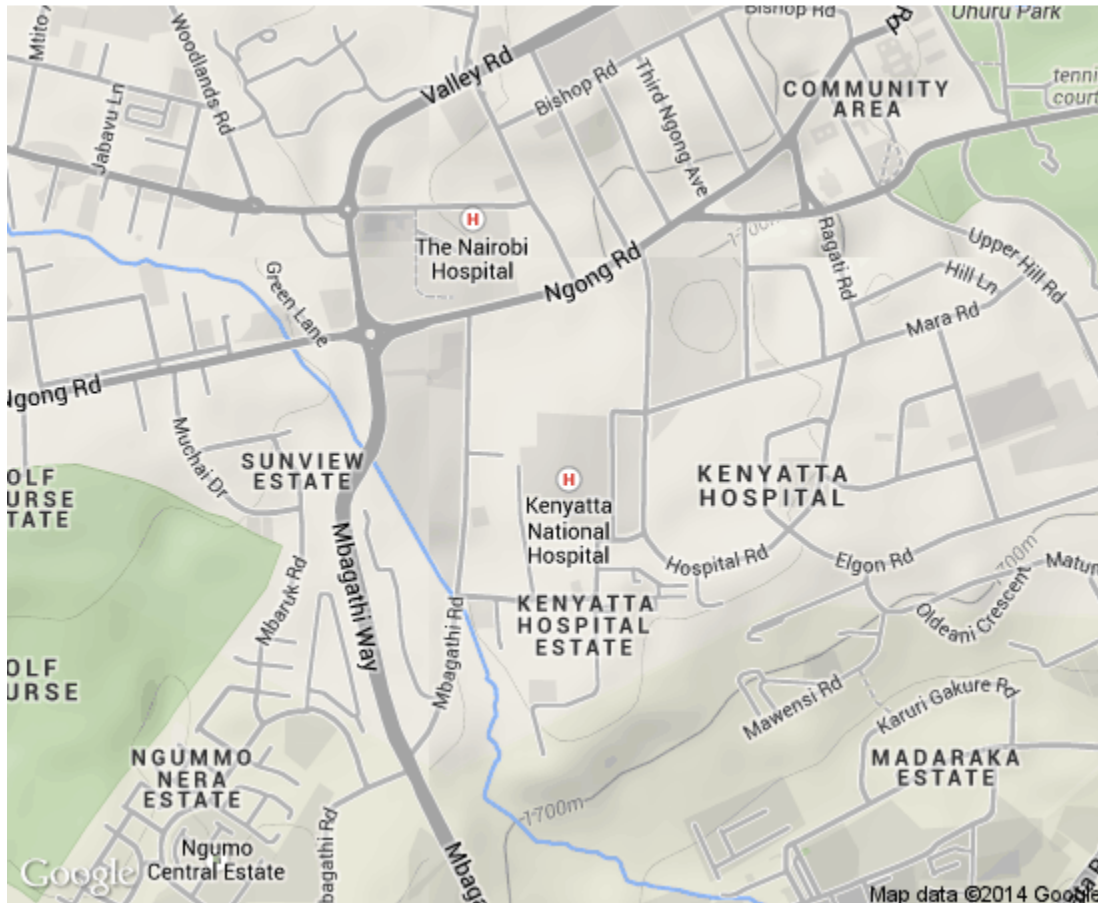
### II. Mawasiliano na Wahusika

Ikiwa bado utakuwa na maswali ama jambo lolote ungependelea kujua kuhusiana na haki zako kama mshiriki katika utafiti huu, jisikie huru kuwasiliana na mtafiti, Isaac M. Ogoncho, Shule ya Uuguzi, Chuo Kikuu cha Nairobi, namba za rununu 0721553403; barua pepe - isaacmachuki@yahoo.com. Ama mhadhiri msimamizi wa mtafiti Dr. Blasio Osogo Omuga, Shule ya Uuguzi, Chuo Kikuu cha Nairobi, namba za rununu 0722256080; email – mitenga@yahoo.com. Waweza pia kuwasiliana na mwenyekiti wa kamati inayochanganuza maswala ya utafiti ya hospitali ya Kenyatta na Chuo Kikuu cha Nairobi kupitia sanduku la posta 19676-00202 Nairobi ama nambari ya simu 2726300

## APPENDIX IV: PREVIEW OF STUDY AREA

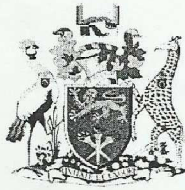
### KENYATTA NATIONAL HOSPITAL

Kenyatta National Hospital is the largest National and Referral Hospital in Kenya. It is the apex of the referral system in the health sector in Kenya. It is located in the upper hill area which is about 2.5 kilometres to the west of the Central Business District, in Nairobi City. The hospital covers an area of about 45 Hectares.





## APPENDIX V: ETHICAL APPROVAL



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

KNH/UON-ERC  
Email: uonknh\_erc@uonbi.ac.ke  
Website: www.uonbi.ac.ke



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

Ref: KNH-ERC/A/90

Link: [www.uonbi.ac.ke/activities/KNHUoN](http://www.uonbi.ac.ke/activities/KNHUoN)

8<sup>th</sup> April 2014

Isaac Machuki Ogoncho  
School of Nursing Sciences  
College of Health Sciences  
University of Nairobi

Dear Isaac

**RESEARCH PROPOSAL: ASSESSING QUALITY OF LIFE AMONG GYNAECOLOGICAL CANCER PATIENTS RECEIVING CARE IN THE PALLIATIVE CARE UNIT AT KENYATTA NATIONAL HOSPITAL (P63/02/2014)**

This is to inform you that the KNH/UoN-Ethics & Research Committee (KNH/UoN-ERC) has reviewed and **approved** your above proposal. The approval periods are 8<sup>th</sup> April 2014 to 7<sup>th</sup> April 2015.

This approval is subject to compliance with the following requirements:

- Only approved documents (informed consents, study instruments, advertising materials etc) will be used.
- All changes (amendments, deviations, violations etc) are submitted for review and approval by KNH/UoN ERC before implementation.
- Death and life threatening problems and severe 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.
- 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.
- 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)*.
- Clearance for export of biological specimens must be obtained from KNH/UoN-Ethics & Research Committee for each batch of shipment.
- 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.

Yours sincerely

PROF. M. L. CHINDIA  
SECRETARY, KNH/UON-ERC

- c.c. The Chairperson, KNH/UoN-ERC  
The Deputy Director CS, KNH  
The Principal, College of Health Sciences, UoN  
The Director, School of Nursing Sciences, UoN  
The Assistant Director, Health Information, KNH  
Supervisors: Dr. Blasio Osogo Omuga, Dr. Sabina Wakasiaka, Mrs. Margaret Muiva

**APPENDIX VI: PERMISSION TO CONDUCT RESEARCH AT KNH**

KNH/R&P/FORM/01



**KENYATTA NATIONAL HOSPITAL**

Hospital Rd. along, Ngong Rd.

P.O. Box 20723, Nairobi.

Tel: 2726300-9 Fax: 2725272

Research & Programs: Ext. 44705

Email: [k.research@knh.or.ke](mailto:k.research@knh.or.ke)

**Study Registration Certificate**

1. Name of the PI ISAAC MACHUKI OGONCHO
2. Email address: isaacmachuki@gmail.com Tel No. 0721553403
3. Contact person (if different from PI) DR. BLASIO OJOGA OJUGA
4. Email address: mitenga@yahoo.com Tel No. 0722256080
5. Study Title  
ASSESSING QUALITY OF LIFE AMONG GYNAECOLOGICAL  
CANCER PATIENTS RECEIVING CARE IN THE PALLIATIVE  
CARE UNIT AT KENYATTA NATIONAL HOSPITAL
6. Department where the study will be conducted PALLIATIVE CARES UNIT
7. Endorsed by Head of Department where study conducted  
Name: Dr. Esther Mwangi Signature: [Signature] Date: 14/4/2014
8. KNH UoN Ethics Research Committee approval number P63/02/2014  
(Please attach copy of ERC approval)
9. I ISAAC MACHUKI OGONCHO 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: 10/4/2014
- Endorsed by Chair Department (only for students) of X/A  
Signature: \_\_\_\_\_ Date: \_\_\_\_\_
10. Study Registration number (Dept/Number/Year) PALLIATIVE / 001 / 2014  
(To be completed by Research and Programs Department)
11. 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.

Version 1: Nov, 2013