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**ASSESSMENT OF THE QUALITY OF LIFE ISSUES OF WOMEN
WITH GYNAECOLOGICAL AND BREAST CANCERS IN KENYA**

MARGARET N. MUIVA (MSc. Nursing)

**A THESIS SUBMITTED IN FULFILMENT OF THE REQUIREMENTS FOR
THE DEGREE OF DOCTOR OF PHILOSOPHY IN NURSING OF THE
UNIVERSITY OF NAIROBI**

NOVEMBER 2014

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DECLARATION

I hereby declare that the thesis is my original work and has not been presented for award of a degree in any other university. All sources of information and ideas of others that I have used in this thesis have been duly cited.

Margaret N. Muiva

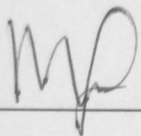
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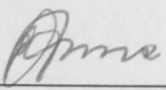
27/11/2014

APPROVAL

This thesis has been submitted for examination with our knowledge and approval as university supervisors.

Prof. W. O. Mwanda  (MB CHB, PMRCPPath, MD)

Date 27/11/2014

Dr. A. Obondo  (BA Hons, MSW, PDIP. in PSW, PhD)

Date 27/11/2014

DEDICATION

This work is dedicated to my family – my late husband Dr. P. M. Muiva who was very supportive throughout until he succumbed to cancer in March 2008; and my three children – Cecilia, Juliana and Janet for their continued support; and to all those women with the cancers for their endurance and their wish to live despite the fear of death.

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OPERATIONAL CONTEXTUAL DEFINITIONS

1. Quality Of Life (QOL)

The value a person places on "life" with regard to his/ her physical, mental, social and spiritual well-being and the ability to carry out tasks or roles pertaining to his/ her position in society.

2. Quality of life issues

These are the expressions of dis-ease/stress or evaluable outcomes or simply effects of the disease or its treatment, such as pain, nausea, vomiting, inabilities, disabilities, disfigurement, insomnia, debilitation, fatigability, diminished self-care and disruption of work and family roles. These issues commonly manifest emotionally as fears, anxiety/worries, depression and stigma related to uncertainty around the cancer experience i.e. social isolation associated with gynecological cancer due to, at times, the foul-smell lesions, and concerns with (femininity), fertility and sexuality.

3. Domains - compartments of the person

These are the global dimensions of well-being or otherwise with respect to physical, psychological, social and spiritual states.

i Physical domain

Is the structural composition of the body's physical and functional state. Changes in this domain can be caused by or influence treatment for example pain, fatigue, appetite and weight changes, sleep changes, changes in body features, appearances, menstrual changes and functional dysfunctions.

ii Emotional domain

This domain encompasses features related to the 'mind' that commonly find expression in symptoms of anxiety, mood changes, sadness, associated with the perceptions in the body image and feelings.

iii Social domain

This functioning of the social domain is captured through expressions in relationships with spouses, peers and in interactions with the environment and social support as well as the financial issues related to the disease and treatment process.

iv Functional domain

The ability to perform or carry out activities to the level of one's satisfaction.

STUDY VARIABLES

i) Independent variables

- Demographic characteristics: -
Age, education, marital status, income, ethnicity, religion
- Type of cancer
- Stage of disease
- Treatment modality: -
Surgery, chemotherapy, radiotherapy, combinations

ii) Dependent variables

- Quality of life outcome/ issues in terms of the domains: -
Physical, emotional, social and functional

ABBREVIATIONS

BMT	Bone Marrow Transplant
BSE	Breast Self Examination
CARES	Cancer Rehabilitation Evaluation System
ECOG	Eastern Cooperative Oncology Group
FAACT	Functional Assessment of Anorexia/Cachexia Treatment
FACIT	Functional Assessment of Chronic Illness Therapy
FACT	Functional Assessment of Cancer Therapy
FACT-G	Functional Assessment of Cancer Therapy - General
FIGO	International Federation of Gynaecology and Obstetrics.
FLIC	Functional Living Index Cancer
HrQOL	Health Related Quality of Life
KDHS	Kenya Demographic and Health Survey
KNH	Kenyatta National Hospital
LRT	Likelihood Ratio Test
MOH	Ministry of Health
MTRH	Moi Teaching and Referral Hospital
POMS	Profile of Mood States
QOL	Quality of Life; Health related Quality of Life.
WHOQOL	World Health Organisation Quality of Life

ABSTRACT

Background

Gynaecologic and breast malignancies are certainly the commonest forms of cancers in women in Kenya. For a long time the focus has been on clinical management of cancers but now Quality of Life (QOL) is emerging as an important health outcome which requires to be incorporated in the holistic management of patients. There are very few African studies that have investigated QOL issues.

Objectives

This study set out to determine the quality of life issues of women with gynaecological and breast cancer; and establish the roles of an oral interview and that of an established QOL instrument – Functional Assessment of Cancer Therapy (FACT), in assessing the QOL of the women in the Kenyan setting.

Study Area

The study was carried out at the two national teaching and referral hospitals in Kenya, Kenyatta National Hospital (KNH) and Moi Teaching and Referral Hospital (MTRH), three Provincial Hospitals and four Hospices during 2006-2008.

Study Design

This study was a cross-sectional survey conducted using a quantitative and qualitative design.

Materials and Methods

Two assessment tools were administered to participants aged 18 years and above, with a documented histological diagnosis of gynaecological or breast cancer. An interview was conducted with each patient prior to administration of the validated Functional Assessment of Cancer Therapy (FACT) questionnaire. In addition an interview guide was used to gather narrated information from patients' experiences. Data analysis was conducted using SPSS version 19. Associations

between patient characteristics and cancer diagnosis, and its staging were examined using cross tabulations. Multinomial regressions were used to identify significant association between patient characteristics and cancer diagnosis. The quality of life issues were identified by calculating the percentage of patients giving each of the five possible Likert scale ratings. A multivariable regression model was then run for each quality of life issue. Deductive analysis based on HRQoL domains was used to identify themes describing patient perception of QOL.

Results

Out of the 27 QOL issues in the FACT-G tool, 14 were important issues for Kenyan patients. The leading quality of life issues among the 394 patients with breast and gynaecologic cancers in Kenya are: worrying that condition will get worse (93.9%), lack of satisfaction with sexual life (84.1%), losing hope (83.7%), worry about dying (83.1%), lack of fulfilment in work (77.7%) and feeling nervous (77.4%). The issues in the emotional domain were most affected by cancer. Overall quality of life (FACT-G) was influenced by type of cancer and treatment modality ($p < 0.05$). In comparison to FACT-G, which reported that emotional wellbeing issues were the leading QOL issues, content analysis of patient narratives identified functional and physical issues including pain as important issues and deductive analysis showed that patients perceived the term quality of life as having three interrelated components: preserving pre-diagnosis capacities, a personal or individualised meaning, and effects of cancer. In addition, spirituality and positive living were identified as important factors in Kenyan patients' QOL.

Conclusions and Recommendations

The leading quality of life issues among Kenyan women are in the emotional domain and these can be remedied by nursing intervention including providing holistic patient care and emphasising the psycho-social support of patients through

counselling and patient education. The FACT-G tool captures general QOL issues but the qualitative analysis showed that future studies need to incorporate the positive living and spiritual issues which were important factors in Kenyan female cancer patients' narratives.

CHAPTER 1

1.1 INTRODUCTION

There is growing interest in quality of life (QOL) as an important component of nursing care and health care. During the last two decades there has been compelling need to complement the orthodox evaluation of cancer patients, in particular for treatment, with an assessment of patient reported quality of life (QOL) related to cancer diagnosis, disease progression and treatment.^{1, 2} Furthermore there is demand for quality of life (QOL) research in nursing, especially in relation to cancer patients.³ Of particular interest to nursing of cancer patients are the unresolved questions of what QOL entails, and how to measure QOL in relation to how cancer affects an individual's QOL.⁴ Since nurses are primarily concerned with ensuring patients are comfortable and enhancing patient wellbeing, another focus of interest is how nurses can restore or improve an individual's QOL. Indeed, the concept of QOL and its assessment has been widely and sometimes controversially discussed.^{5, 6} In developing countries the concept of QOL rarely receives any consideration outside the confines of teaching and conference venues. It is only in the last decade that papers have been published from Kenyan universities on the subject, an indication of concern deserving in depth action.⁷⁻⁹ In fact Andersen in 1993 published an article acknowledging a grave lack of research on quality of life and challenged institutions and study groups, to support QOL research for women with gynaecological cancers.¹⁰

Quality of life is defined as a subjective evaluation of the positiveness or negativeness of attributes that characterise ones' life making its assessment difficult.¹¹ Alternatively, QOL may be considered as the overall enjoyment of life

with regard to the individual's sense of well-being and ability to carry out various tasks. It is the extent to which an individual perceives herself as being able to function physically, psychologically and socially. Thus quality of life may be viewed as an individual's satisfaction or happiness with life in domains he or she considers important.¹² To allow objective assessment of QOL, all-encompassing definitions that allow individual components of quality of life to be delineated have been proposed.¹³ Health related quality of life (HRQoL) is a patient-reported outcome that is usually measured using carefully designed and validated instruments such as questionnaires and interview schedules and core components of the multidimensional HRQoL assessment include physical, functional, psychosocial or emotional and functional or occupational domain.^{14, 15} The HRQoL approach is used to study QOL issues in the current study.

In general, QOL issues can be grouped into domains and factors that affect the domains.¹⁴ These issues can in turn influence, determine and be used as perceptions and measurements of one's values of life. These are some of what sums up as its issues or events that when one pursues, can reflect and express as happiness or otherwise in one's life, or contribute to what makes life enjoyable or constitutes happiness. In other words, if the issues or activities involved in physical, spiritual, social, psychological aspect of one's life are altered in the negative or contrary direction, then the quality of life is altered. Certainly the level of possible changes is related to age, life experiences, disease treatment and other individual characteristics. Furthermore, it would be conceivable that the impact of QOL issues is influenced by geographical, cultural and ethnic impositions. In addition to the type of disease, culture, tradition and customs can influence every aspect of the experience of health and illness, as

perceptions of QOL are embedded in cultural beliefs about what constitutes normality and health.¹⁶

Data and information on the quality of life of cancer patients are necessary for purposes of identifying any areas requiring enhancement or improvement. There are very few studies on the holistic impact of cancer among Kenyan cancer patients, and association between demographic variables and QOL among cancer patients has rarely been assessed.^{8, 17} The reasons for this relative lack of literature may be poor survival outcomes with current treatments as many of these cancers are diagnosed at an advanced stage, or a focus on breast cancers as the most common cancer in women.¹⁸ However, women with gynaecological cancers survive longer with the new treatments and the advances in the field, and it is deemed necessary to evaluate the impact of the disease and its treatments on the lives of women with gynaecological and breast cancers. It may also help in defining standards for comprehensive quality management of gynaecological and breast cancer patients, in the local Kenyan environment. It is against this background of missing information that this study was conducted.

The investigator therefore, focussed on patients already diagnosed to have a gynaecological or breast cancer in order to assess their quality of life, by identifying issues that influence quality of life, and the areas in which these women need further support.

1.2 Quality of life (QOL)

No formal definition of QOL has been accepted as yet as many definitions of QOL have been advanced and healthcare providers in cancer care continue to address the QOL concerns of patients.¹⁹

The existing definitions of QOL can be categorized as related to normal life happiness/satisfaction, achievement of personal goals, social utility or natural capacity.²⁰ The category related to satisfaction/happiness seems best suited to serve as a focus in nursing.²¹ Despite the absence of a consensual definition of QOL, there is considerable agreement among QOL researchers today that QOL is subjective, includes both positive and negative facets of life and is multidimensional.²² Even if objective factors such as vomiting influence one's QOL, the perceived importance or in what way it impacts on QOL are individual.²⁰ To get the correct picture of an individual's QOL, the individual's perception about both positive and negative dimensions must be addressed.²²

After reviewing the literature on QOL Rustoen,²¹ chose to base the study on Ferrans'²⁰ definition of QOL: 'a person's sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her'. This definition emphasizes the subjective perspective and takes into account both satisfaction and dissatisfaction. This definition of QOL further comprises four underlying domains: a health/functioning domain, a socio-economic domain, a psychological/spiritual domain and a family domain.²⁰ Thus QOL is defined as a multidimensional construct covering all aspects of life. Cancer can affect all these domains, and in order to maintain or improve QOL the nurse must bear all four in mind when dealing with cancer patients.

Similar definitions of QOL have been applied in the field of oncology, where QOL has been defined as a personal sense of well-being encompassing a multidimensional perspective that includes physical, psychological, social and spiritual dimensions. Thus with regard to cancer, quality of life encompasses

even a broad spectrum of issues including aspects of physical, social, cognitive, spiritual, psychological, emotional, and role functioning. In addition there are other factors influencing these domains such as emotional distress. This has been noted to be very common in cancer patients, and includes problems such as anxiety, depression, fears and uncertainty around the cancer experience.²³ Changes in one domain can influence perceptions in other domains.

Generally, it is perceived that the diagnosis of cancer is stressful not only to the patient but also those especially close to the patient. Usually, it is not just having the cancer that triggers off reactions, including psychological, but the implied connotations that may be attached to the disease, such as pain, disfiguration, hospitalisation, loss of work ability, concerns of health, family, finance,¹⁷ and the fear of death.²⁴ Such factors have a negative effect on the person's self-esteem and can adversely affect the domains of the quality of life determinants.

Quality of life framework

Caplan²⁵ provided a framework for applying the quality of life concept within cancer psychosocial research, dividing the concepts of QOL into three major dimensions:

- a) Physical dimension (physical) symptoms; treatment toxicity; body image, and mobility;
- b) Psycho-social dimension (psychological symptoms); interpersonal relationships; happiness; spiritual and financial issues); and

- c) Wider dimensions (the individual's perception of QOL; cultural influences; political and philosophical dimensions and the time dimension).

Body image, although the result of treatment toxicity, physical symptoms and/or invasive medical procedures, should be, however, included in the psycho-social dimension, because of its effect on personality, behaviours and interpersonal relationships of the individual.

Caplan²⁶ also stated that QOL is an assessment of the potential for growth. It is concerned with the difference between perceived and actual goals. It is the difference, at a particular point in time, between hopes and expectations of the individual, and the individual's present experience. This means that QOL is viewed as a complex abstract term that depends on the individual's experiences and expectations from his life. Thus, even within the same individual, QOL can fluctuate over time, because of developmental factors. A good QOL is usually expressed in terms of satisfaction, contentment, happiness, fulfilment and the ability to cope.²⁶ As a result, QOL is the perception of the individual about his life, because satisfaction with life, fulfilment or happiness are relative terms, and what makes somebody happy, satisfied or fulfilled with something does not necessarily produce the same feelings to somebody else.

Description of the conceptual model

The perception of the stressor (stage I) is divided into two distinct sub stages, the primary and secondary appraisal.^{27, 28} The primary appraisal refers to the way an individual is interpreting the stressor or the meaning of the stressor. If the stressor is perceived as a threat, the individual comes eventually to deal with

it. This refers to the secondary appraisal.²⁷ In both stages social support is a highly influential factor, as it can provide the necessary resources for the person to enhance understanding of the stressor, acceptance and a more positive outlook.²⁹

During the process of cognitive assessment of the stressor, socio-demographic and developmental characteristics of the encounter, such as ego structure, personality, age, education and past experiences can play a catalytic role in determining the degree and/or quality of the reaction (stage II). Increased social support and certain socio-demographic/developmental characteristics (i.e. higher educational level or history of effective coping with past stressful events), provide the basis for a healthier reaction. The degree of reaction to the stressor (life-threatening disease), is also very much dependent on the disease itself (i.e. its physical characteristics), as well as philosophical dimensions, such as the meaning of the situation to the individual,³⁰ or the patient's views about death.

Prognosis of the disease might be the most important aspect of the ill-health situation, giving us insight about the level of adaptability of the encounter in the next two stages (stages III and IV). For example, no matter how much social support or education is received by the encounter, it is more likely that a diagnosis of severe aplastic anaemia or a metastatic cancer, with a life expectancy of a few months with conventional treatment, will lead to more severe psycho-social maladjustment syndromes than an early diagnosis of a curable gynaecological cancer.

Coping is however one factor, which influences all the domains. The coping stage is the consequence of the encounter's reaction to stressor(s). Coping is the initiation of ego-mechanisms in order to defend the stressor.³¹ Patients can use either effective or ineffective coping mechanisms in dealing with a stressor. Effective coping is defined as the use of an ego-mechanism leading to adaptiveness. Use of more coping strategies is usually associated with better psychological functioning.^{32, 33} Furthermore, stabilized illness or improvement of health is usually associated with use of positive ego-defence mechanisms, whereas deterioration of the health status is probably associated with a decline over time of the use of effective coping mechanisms.

Through coping, the process progresses eventually to the degree of adaptation (stage IV). In this stage, specific components of life are contributing to the perception of QOL and thus, these components are responsible for adaptation.³⁴³⁵ There are probably two groups of components influencing QOL: the primary components, including the physical, psychological and social dimensions of QOL, and the secondary components, including cultural, individual and spiritual dimensions. This division in primary and secondary QOL components was the result of patient's responses in recent studies: primary components refer to QOL domains which were mentioned by all or the majority of respondents in past studies, whereas secondary components refer to QOL domains which were mentioned less frequently by the respondents.³⁶⁻³⁸

The physical dimension refers to treatment outcomes and toxicities, degree of activity and presence of physical symptoms, as quantified in the study by Molassiotis et al.³⁸ The psychological dimension refers to presence of

psychological symptoms, anxiety, mood changes associated with change in the body image. In the latter study, a considerable number of BMT survivors as well as survivors with haematological malignancies treated with conventional chemotherapy, demonstrated clinical signs of anxiety, depression and body image changes. Finally, the social dimension refers to interpersonal relationships and social support, family relations and financial issues of the treatment process.²⁵ Social support and family relationships were also found to affect the perception of QOL in recent studies,^{29, 39} justifying the influence of the social dimension to QOL in the present framework.

After the dynamic and continuous exchange between disease-treatment and the psychosocial dimensions of QOL, there is the final stage of the process, the outcome. The outcome can be either adjustment or at least an acceptable level of QOL (defined in individual terms), or maladjustment. Outcomes are likely to be more favourable if prevention or interventions are applied at certain points of the process. Thus, it is suggested that prevention of negative occurrence can be achieved if applied between stages I and II, i.e. during the person's interpretation of the stressor and before any reactions. Assessment at this point can identify power-generating individual or environmental structures, which can be manipulated for the encounter's benefit. Education at this stage about what the individual patient can expect in the future regarding ill health may desensitise him/her and prevent or control future psycho-pathological manifestations. It is possible that early identification of dysfunctional psychosocial areas at this stage can facilitate better professional 'handling' of the situation.

Another common factor, which influences all the domains, is pain. Pain as a factor found commonly as a physical symptom affects the quality of life of women with advanced cancer.⁴⁰ Other factors included that are key in dependency include finances, sexuality, psychological health and spirituality of women with gynaecological cancer.⁴¹

However, there have been conflicting reports. Previous studies done on the quality of life of women diagnosed with gynaecological cancer did not reveal much on perception as a major issue on quality of life in gynaecological oncology. Nevertheless, a lot more work on quality of life of breast cancer patients have been done worldwide.

There have been documented aspects of these factors and domains locally. Although psychological aspects have been evaluated in studies in Kenya, the overall quality of life of women diagnosed to have gynaecological and breast cancer in Kenya have not been studied even though some of these diseases are a common cause of morbidity and mortality in women.^{17, 42}

Worldwide however, issues of quality of life such as patients' reactions to cancer may vary remarkably depending on various factors such as age, education, socio-economic and ethnic factors,^{16, 43} cultural and religious beliefs,⁴⁴ and practices. Culture and ethnicity influence health and illness, as it is the society that defines normality and health. These factors may have an impact on the patients' daily activities and therefore quality of life. In addition, various modalities of cancer management, including supportive care available, have direct impact on the physical, psychological and social domains of life and

therefore its quality.^{45, 46} It is documented that anxiety and depressive symptoms are the most common forms of emotional distress in cancer patients,⁴⁷ as patients experience fears, not only of the disease, but also its anticipated treatment and outcome.

Other factors such as, uncertainty about cancer and its management outcome, evoke several reactions. Uncertainty is described as the inability to determine the meaning of illness related events or to accurately predict an outcome and can be influenced by many illness specific and individual factors.^{48, 49} The consequences of uncertainty for ill adults include issues in psychological domain such as anxiety and depression, diminished self-care and disruption of family roles and relationships.⁵⁰⁻⁵⁸ These factors can be found in the domains of quality of life.

1.3 QOL issues

There are many issues related to QOL that involve and influence the major domains of individual wellbeing and other aspects of life.¹⁴ These issues are enhanced or perceived differently by persons with cancer.^{25, 26, 59} Cancer, regardless of the anatomic site involved, is a feared disease among most communities as it is usually associated with no cure and to many, implies imminent death. In particular, cancer of the breast and the cervix are the two most common and most dreaded cancers, as they are generally known to be 'killer diseases' for women.⁶⁰ For instance, one major negative effect of cancer is its influence on health that directly impacts on quality of life. The nature of cancer raises issues such as fears and worries to both the patient and her family. The fear of cancer leads to other issues such as pain, debilitation, and at times

foul-smelling lesions, while the nature of the disease requires long periods of hospitalisation.⁴⁷ Cancer management also involves therapy-induced discomforts, and has massive financial implications on households. Due to the stigma attached to cancer, the patient may experience feelings of guilt and sadness, a sense of failure and self accusation, which have a ripple effect on the psychological and social domains, leading to issues of withdrawal, insomnia and fatigability.⁶¹ Pain is probably the most talked about issue among patients with advanced cancer and hence, the most feared symptom as many patients experience changes in the physical, psychological, and social domains due to uncontrolled pain, where pain medication is either not easily available or affordable.⁶²

Issues of perception emanating from cancer, weigh heavily on the patient and the family. Furthermore most of these cancers usually occur at middle age when most children may be grown-ups,⁶⁰ have left home for various chores, or are married thus leaving the parents with "an empty-nest". This may lead to changes in one's life domains and additional concerns especially for women who are primary caregivers for family members whenever household members fall ill.⁷ The investigator was interested in finding out what issues influence physical, psychological/emotional and social dimensions that women with gynaecological and breast cancer could experience, once diagnosed with the cancer and have to live with it.

Also the degree to which adults with cancer can understand and make sense of their experiences, might determine how well they adjust to the physical and

emotional demands of cancer and its treatment. The question is, are there underpins for this theory in African/Kenyan cancer patients?

On the other hand, the perceived survival in gynaecological cancer patients is poor, and quality of life is considered to be an important outcome in those who develop the most common forms of cancer. Studies have shown that quality of life in cancer patients is a significant predictor of survival, and therefore it should be considered as a clinical status that has to be established by those involved in the management of the patient before treatment starts.⁶³ Furthermore little is known about quality of life issues and their relationship to patients' physical, socio-economic, psychological, spiritual status and individual characteristics in our setting. I am unaware of any studies that have addressed the quality of life issues in a purely African context and specifically within the Kenyan environment.

1.4 Gynaecological and breast cancers

Gynaecological cancers are associated with special QOL needs, although to date little attention has focussed on this area. This state of affairs is mainly explained by poor prognosis associated with some of the gynaecological cancers such as the ovarian cancer, and the focus on breast cancer as the most common female cancer. Advances in the treatment of gynaecological cancers are promising and survival rates are increasing. Auchincloss *et al* discussed how gynaecological cancers were associated with social stigma, probably related to its historically poor prognosis and its presence in female sexual response and reproductive organs, often leaving women with a sense of loneliness.⁶⁴ Concerns with

sexuality, fertility, and femininity may be higher in this patient group compared to other female cancers.

Among women, cancers of the breast and the cervix are significant and are the most prevalent cancers in women worldwide. In the less developed parts of the world, the most common cancers in women also follow the world pattern with breast cancer leading, followed by cervical cancer, cancer of the ovary and corpus uteri cancer.⁶⁰

In Kenya, much of the data on the incidence of cancer is mainly based on in-patient records. A report by the Ministry of Health for 1996 to 1999 shows that neoplasms accounted for 2% of all hospitalisations, while 72% of all neoplasms were malignant. The report shows that cancers of the uterus, the cervix and the breast are the leading cancers by anatomic site.⁶⁵

In most cases in Kenya, cancers are a major cause of death due to the late stages at which most diagnoses are made. While surgery, chemotherapy, radiotherapy, or a combination may be required as the means of treatment, some patients may only be able to benefit from palliative care. These modalities of treatment are however not widely available in the country. Kenyatta National Hospital in Nairobi is the only public institution providing Radiotherapy services. Consequently, delays may occur due to the high demand for the service, in addition to the cost for the service. Further delays could also be attributed to the social stigma attached to cancer, and the knowledge, beliefs and attitudes about cancer among individuals. Such delays would worsen the prognosis of the disease.

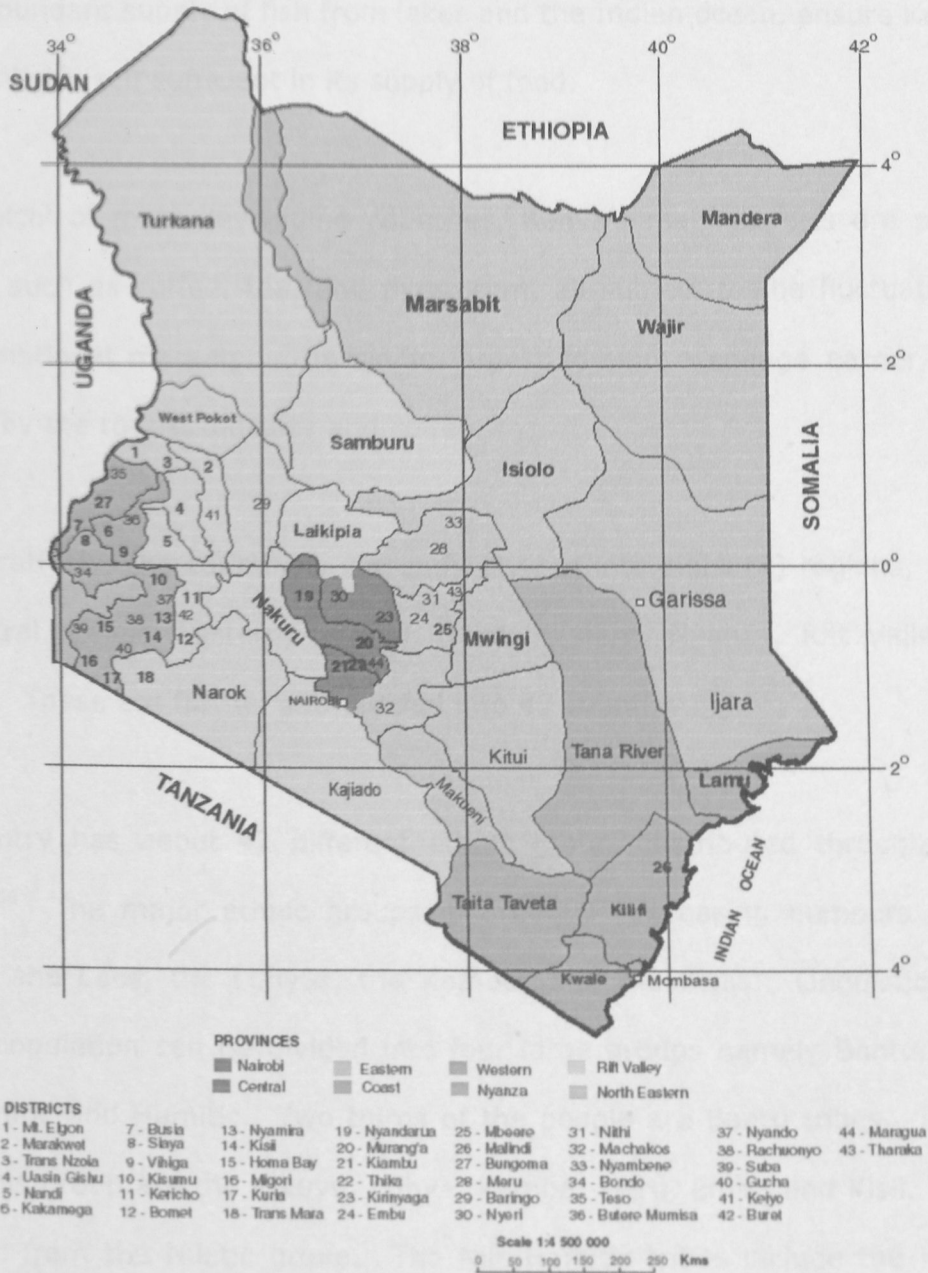
The other treatment modalities are however available at the National and Provincial hospitals of the public sector, and some private hospitals where medical specialists are available. It is appreciable to note that palliative care has also grown since 1990 with the establishment of Hospices now in Nairobi, Eldoret, Kisumu, Meru, Nyeri and Mombasa. These hospices help provide palliative care including pain relief, to the terminally ill cancer and AIDS patients.

1.5 BACKGROUND INFORMATION ON KENYA

1.5.1 Geography

Kenya is one of the three East African countries. It lies between latitudes 5 degrees north and south of the equator and between longitudes 34 and 42 degrees to the east as shown on the administrative map of the country as at the time of implementing this study.

MAP OF KENYA SHOWING PROVINCES AND DISTRICTS



The country covers a total area of 582,646 sq. km 80% of which is arid or semi-arid, with only 20% of the land being arable.⁶⁶

Kenya is essentially an agricultural country with a predominantly rural population. Important farming products include maize, wheat, barley, rice and a

variety of fruits and vegetables. These, with the dairy and ranching industries, and an abundant supply of fish from lakes and the Indian ocean, ensure Kenya is almost entirely self sufficient in its supply of food.

As is typical of most developing countries, Kenya's main exports are primary products such as coffee, tea, and pyrethrum, all subject to the fluctuations of the international markets. The single largest foreign exchange earner is tea, followed by the tourist industry and coffee.

Administratively, the country is currently divided into eight (8) regions, namely the Central, Coast, Eastern, Nairobi, North Eastern, Nyanza, Rift Valley, and Western. These are further sub-divided into 47 counties.

The country has about 42 different ethnic groups distributed throughout the country.⁶⁶ The major ethnic groups in order of decreasing numbers are the Kikuyus, the Luos, the Luhyas, the Kambas and the Kisiis. Linguistically the African population can be divided into four large groups namely Bantu, Nilotic, Nilo-Hamitic and Hamitic. Two thirds of the people are Bantu tribes. Included within this group are the Kikuyu, Luhya, Kamba, Meru, Embu and Kisii. The Luo tribe are from the Nilotic group. The Nilo-Hamitic tribes include the Kalenjin, Nandi, Masai, Turkana and Pokot tribes. These are largely semi-pastoral people although a few like the Nandi are also agriculturists. The Hamitic group forms only a small part of the population and these live mostly in the Northern and North Eastern parts of the country. English is the official language while Kiswahili is the national language. Christianity and Islam are the main religions in the country.

1.5.2 Demography

According to the 2009 population census, Kenya's population was 38.6 million, having tripled, from 10.9 million in 1969.⁶⁶ The country's population is characterized by a youthful population, with 43% of the population being younger than 15 years, which is typical of a population with a high fertility and a declining mortality.⁶⁷ Only 4% of the population is 65 years and above. Thus, the age sex structure of Kenya's population is wide based even though the percentage of the younger population (below 15 years) has been falling while the percentage of those aged 15-64 years has been increasing, and constitutes 52% of the population. About 32% of the population lives in urban areas while the rest are rural.⁶⁷ Urban centres in order of size and population density are Nairobi, Mombasa, Kisumu, Nakuru and Eldoret.

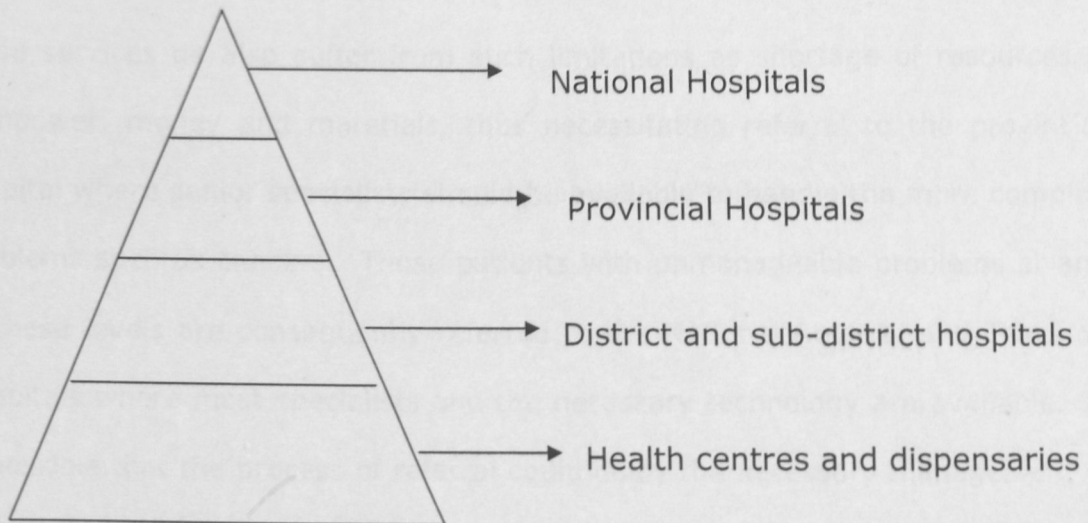
1.5.3 Education and marriage

Most Kenyan's have received some education, however, 13% women aged 15-49 years have had no education at all, while more of Kenyan men (40%) tend to complete higher levels of education compared to women (29%).⁶⁷

51% of women are married by their 20th birthday. Age at marriage greatly increases with education. The women who marry early often also give birth to more children than those who marry late. The median age at first sexual intercourse has risen from 17.8 years in 2003 to 18.2 years in 2008/9.⁶⁷

1.5.4 Health care system and facilities

Government health services in Kenya are pyramidal in structure as the dispensaries and health centres form a wide base at the bottom with the sub-district and district hospitals in the middle, while the 8 provincial hospitals fall just below the two National Referral and Teaching Hospitals – the Kenyatta National Hospital being the oldest, and Moi Hospital developed in the mid 1990s.



There are approximately 3,500 health care facilities in Kenya, operated by the government, non-governmental organizations and private providers. Of these services providers, the government is the largest health care provider managing the majority (56%) of hospitals, health centres and dispensaries.⁶⁸

This organization of health facilities facilitates the referral process depending on the manageability of the health problem, from the health centre level through to the National level. Common ailments are managed by the clinical officers who diagnoses and treats at the health centre level but refer more complex cases,

such as those with cardiac problems and other chronic diseases including suspected cancers, to the medical officer of health at the district level. At the district hospital, necessary service departments such as Operating Theatres, Radiology and laboratory services, as well as specialist doctors, such as obstetrician, paediatrician, physician and surgeon are available.

Curative, preventive and promotive health services are more widely provided by the team of doctors and nurses and other workers at the district level. However, these services do also suffer from such limitations as shortage of resources – manpower, money and materials, thus necessitating referral to the provincial hospital where senior specialists should be available to handle the more complex problems such as cancers. Those patients with unmanageable problems at any of these levels are consequently referred to the National Referral and Teaching Hospitals where most specialists and the necessary technology are available. It is possible that the process of referral could delay the necessary management of a health problem. In addition a lot of the resources could be availed at the higher levels of the health system structure at the expense of availing basic resources at the base for basic health services in the control of most common ailments.

1.6 Statement of the Problem

Gynaecologic and breast malignancies pose special risks for quality of life. This is so because of the femininity, cultural, social, and physical constraints borne by these organs of the body. Despite the fact that gynaecologic and breast malignancies are the commonest forms of cancers in women in Kenya, QOL has

not been researched in depth, with the bulk of research being devoted to curative interventions and prolongation of life. Reports in the literature have been conflicting, with some finding deterioration in QOL and some finding stability or improvement over time. Little has been documented about the impact of various treatments, diagnoses, stages of illness, and other risk factors on QOL in these patients. Given the challenges and changes that women must face after a diagnosis of breast and gynaecologic cancer, QOL issues are a particularly pertinent area on which to focus.

Before drawing any conclusions regarding QOL, however, several caveats are important to note. First, it is important to utilize a well validated instrument to measure QOL in order to compare QOL in patients with gynaecologic malignancies to any other group of patients. In general, most current studies tend to do so⁶⁹⁻⁷¹ applying various instruments none of which has been primarily developed and validated in African populations. Hence there is need to develop workable instruments or modes of assessing QOL in largely African settings.

Second, due to the relatively small number of gynaecologic cancer patients seen at any cancer centre, most of the research studies afore stated have grouped gynaecologic cancer patients into one group, as opposed to separating out by diagnosis making interpretation of the impact of diagnosis on QOL difficult. Related to this is the fact that the type of treatment may be reflective of stage of disease (i.e. patients with advanced disease will be more likely to have multi-modality treatment, while patients with early stage disease may have surgery alone). As such, any interpretations of the impact of treatment type on QOL

have to be done cautiously and in the context of the disease stage. These need to be also staged in terms of QOL issues.

Finally, recommendations are difficult to make based on research from other parts of the world. The author intended to investigate how relevant in this setting is the use of an interview schedule for an open interview as compared to the more widely used instruments like Functional Assessment of Cancer Therapy – General (FACT-G).

There is little doubt that the measurement of quality of life is an increasingly important issue particularly in regard to treatment of severe and chronic diseases.⁷² In Kenya, among the hospitalised patients, cancers of the breast, the cervix and the uterus, are among the leading cancers by site, in women.⁶⁵ Unpublished hospital based data and existing Kenyan cancer registries show that there is an increase in gynaecological and breast cancer morbidity and mortality.

Many studies outside Kenya and the developed world have looked at major domains of quality of life (QOL) in cancer patients. This is so because QOL encompasses a broad spectrum of issues in cancer including physical, social, cognitive, spiritual, emotional and role functioning as well as psychological symptomatology. Several studies have honed in on the effect of pain and other common physical symptoms on specific disease and patients characteristics.

The quality of life of women with gynaecological and breast cancer in Kenya is not established, yet these cancers are common malignancies in women particularly breast and cervical cancer. These diseases are associated with both

a high morbidity and mortality due to the late stage at which most women are diagnosed with the disease.⁷³

The dire need for emphasis on QOL in the Kenyan setting stems from the fact that lateness in diagnosis could be associated with a lack of awareness, cultural beliefs and attitudes, and traditional practices that may hinder health-seeking behaviours. It is reported in some communities in Kenya for instance, that it is taboo for one to discuss issues regarding sexual activities or sexual organs in a public place. In addition, the availability and cost of screening, for example, mammography, are also hindrances that contribute to diagnosis of advanced disease. At these late stages, some of the women tend to die following diagnosis and treatment. Consequently, some women have been known to advise others not to go for treatment especially for breast cancer. It is pertinent to establish the existence of cultural beliefs, attitudes, and practices in relation to the cancers.

Apart from breast and cervical cancers, other gynaecological cancers like ovarian cancer, endometrial cancer, carcinomas of the vulva and vagina, though not as common as the two major types of cancer, follow a similar pattern in diagnosis. With a late diagnosis, an effective curative treatment may be difficult to achieve; hence some patients may only require palliative management for alleviation of the symptoms including pain. With Hospice care services being in the nascent stage in Kenya, not many people are aware of such services or able to reach them. Presently only six (6) Hospice services exist in Nairobi, Nyeri, Eldoret, Kisumu, Meru and Mombasa. These centres should in fact intensify efforts on QOL, therefore would need appropriate data and information. This would

minimize the present situation of lack of knowledge of the cancers. Unavailability, inaccessibility, and unaffordability of the services may be some of the factors causing delays in obtaining health care. In addition, the beneficial as well as the side effects of the modalities of treatment, for those women diagnosed in time when they can still benefit from surgery, chemotherapy, radiotherapy or a combination, may not be well understood by many. Besides, radiotherapy services for the general public are only available at Kenyatta National Hospital for the total Kenyan population; hence the overall impact of this situation on QOL is not available.

Due to the lack of awareness of the diseases and their treatment modalities, women who may benefit from the services may therefore suffer a lot of psychological distress, in the form of fears and worries, emanating from the cancer and its treatment. For example, to many Kenyans, the word "surgery" implies "cutting" and possibly the removal of some of those important sexual organs. This could imply a changed image for the woman who may feel like a "lesser woman". These could have direct impact on QOL, and hence the need to have them investigated.

Therefore this study intends to solicit evidence for interventions to manage affects of the issues in order to improve quality of life in cancer patients. Given the bulk of literature available detailing the efficacy of various types of interventions for patients at all points of the illness trajectory, it would seem ill considered not to provide these services to cancer patients at this point in their needs for holistic care. Indeed, undocumented information in Kenya indicates

that this aspect of management of the elderly woman with a gynaecological cancer is required.

It is on the bases of these that a study is deemed a necessary undertaking, for an assessment of the quality of life of women with gynaecological and breast cancers, identification of factors influencing their quality of life, and areas of life in which they need further support, as no study has been done locally in this area. This study is justifiable as the women with gynaecological and breast cancer should, continue to enjoy a valued and worthwhile life despite their disease.

1.6.2 Rationale

The manner in which women with gynaecological or breast cancer perceive their physical, psychological, social, and spiritual well-being, among others, has not been examined in Kenya. There is also no data on how women with gynaecological or breast cancer rate their quality of life. An understanding of these cancer patients' perceptions should result in a more holistic management of the women with these cancers and enhance a better quality of life for them, regardless of the stage of the cancer. This would also form a basis to help women with cancer live a valued life.

The guiding principle at the heart of the palliative care intervention is the notion of quality of life.⁷⁴ The Kenya Health service sector has embraced palliative care since 1990. However, this care activity of QOL is not well inscribed in the Kenyan health provision setting. Furthermore, patients and the general public interpret health state descriptions differently.⁷⁵ Thus through experience;

patients know better the full scope of the health state they experience than anyone else. As the burden of cancer increases, there is an overwhelming demand for quality care of the cancer patients. Since survival, in especially breast and cervical cancer, is poor in sufficient depth, quality of life should be considered an important critical factor in patients who develop these diseases.

How important is quality of life assessment in the era of increasing optimism in the effectiveness of combination therapy? For the moment, because it has been missing, it is perhaps a little less in our situation, but in the near future more people will be aware of real cure. It is obvious that more people are living with cancers than before, as there have been subtle shifts in the importance of quality of life in cancers. In conversation with the past and as recently as the 1990's, cancers were accepted as being a terminal disease. Despite suffering, treatment side effects could be justified in hopes of 'being around when we have better medications'. Much of treatment was palliative care, for which quality of life should be primary. Since 1980, the availability of life-prolonging treatments has made durable suppression of cancer the primary goal of treatment.⁷⁶ However, an important secondary objective is to identify strategies that maximize quality of life.⁷⁷ In addition, since today's symptoms often trump the logic of future gains for individuals, quality of life is important in choosing regimens that are tolerable as well as effective. In the long term, when there are many effective treatments, maximizing quality-adjusted survival will arguably be the ultimate goal of therapy. It is hoped that there will emerge a new woman who has the ability to put into perspective her physical, psychological social and spiritual changes and existential issues in the pursuit of health.

In the coming years, quality of life assessment can be used to answer questions in clinical care and health policy. At the level of the individual care giver, optimising quality of life among patients will be essential to improving adherence with treatment regimens, and hence with prolonging overall quality survival. More attention needs to be paid to incorporating patient-reported data into the clinical encounter so that it can be used to help direct treatment.

Understanding the nature and prevalence of cancer-related disability, will help policy makers to plan for accessible, comprehensive and effective cancer care services. An important area will be development of policies that encourage people with cancer to return to work. Health-related quality of life measures can also serve as important tools in the evaluation of cancer programs and services. Periodic surveys will help to establish the extent of disability in people living with cancer, and help the health-care community design beneficial plans and care. Vulnerable subgroups to target include families and individuals with low literacy and education.

When people with cancer live normal or near-normal life spans, the most important questions will be how to maximize their quality of life. In the meantime, quality of life will continue to be an important outcome in the evaluation of new and existing treatment strategies. Increased life expectancy dictates extending consideration to dimensions of quality of life in the physical, social, mental and spiritual domains. Research will be needed to evaluate the effectiveness of the many medical, psychological and social interventions that are available to patients. Indeed, quality of life research can improve the quality

of clinical cancer research and add to its value, thus helping to improve the lives of people with cancer.

Considering the patients illness process, it is important to assess the physical, psychological, social and spiritual domains. Assessment of these variables is necessary for more effective planning of care and application of nursing interventions such that if modelled, can provide a locally derived conceptual framework for the assessment and evaluation of QOL in cancer patients, and can help health professionals and nurses in particular, to develop their own assessment tools and plan care and or interventions based on such a holistic assessment.⁷⁸

1.6.3 Significance

This is a pioneering work in an aspect that is important to the persons sick with serious chronic diseases. The findings of the proposed study would generate new knowledge pertaining to the quality of life of women with gynaecological and breast cancer, as no local information, with regard to this area, is available. They would enhance the understanding of areas of need for improvement of quality life of the women by the service providers and caregivers. The results would help in identification of areas of life in which the women need more support, and hence, help in re-designing and planning for management of their care, for example, by inclusion of appropriate and adequate information and counselling.

The findings would also help in drawing policy guidelines regarding gynaecological and breast cancer prevention and treatment, since this problem

is on the increase. They may also point out areas for further research on quality of life of cancer patients in Kenya.

The present work will come up with knowledge, which gives explanations for events or phenomena of QOL in the section of this population. Thus it will present a systematic approach, which aims at an overall understanding of particular issues of QOL. Such understanding could assist nurses to improve practice and the provision of care through assessment, nursing diagnoses, planning for interventions and evaluation of care. That is, research will come up with an assessment model of QOL based on a process influenced by physical, psychological, social and spiritual domains. This clearly is an assumption based on bio-psychosocial model of adaptation⁷⁹ and the systems model.^{80, 81} The model will have been tested in our situation for possible adoption.

At the moment there is no documentary interventional guidelines on issues regarding QOL in our health care systems. Several developed countries, particularly America and other agencies, have developed guidelines for instance, psychosocial care based upon results obtained through research like this proposal. The Canadian Association of Psychosocial oncology has published a book of standards, which details principles of practice, professional issues, and organisational structure of psychosocial oncology programmes.⁸² Guidelines regarding treatment of physical symptoms such as pain, fatigue are also developed. Effective management of a wide variety of these types of physical symptoms contribute greatly to improving QOL and ultimately reducing the development of psychosocial distress.

There are several hospices scattered about in Kenya providing services related to QOL, however, there are no specific interventional guidelines on handling of QOL issues. This will further enhance the team's efforts to put life into their days rather than just days into their life. In advanced cancers, the primary goal is improved comfort. In less severe cases intervention can be an essential component of anti tumour therapy. Appropriate and timely interventional measures can help maintain body features, reduce fatigue and stress in the areas of emotional, social and familial life to enhance well-being. Lifestyle changes can be part of preventive care strategies for recovered cancer patients. Care areas in this multidisciplinary background, can be best identified in studies such as this that involves QOL. The ability to improve the overall QOL should be a major objective of integrated cancer care. If the need for intervention is detected, the entire cancer team should work together, to devise a management plan that will both maintain the patients overall status and improve the patients quality of life.

Unfortunately the state of the knowledge in terms of identifying, for example, psychosocial problems and developing practice guidelines in Kenya has been outpaced. Similarly, the capacity of health care system to deliver services in this key area needs to be developed and recommended. While primary care staff are also overburdened and often overlook QOL issues, information and knowledge for the local scene is greatly deserved. So far, the result is that the proportion of patients who receive some care to improve their QOL is negligible, and cannot stand to be counted. The Kenya health care system faces significant delivery challenges in the future, and may have to consider alternative service delivery models, such as large group psycho-education and other distress alleviation

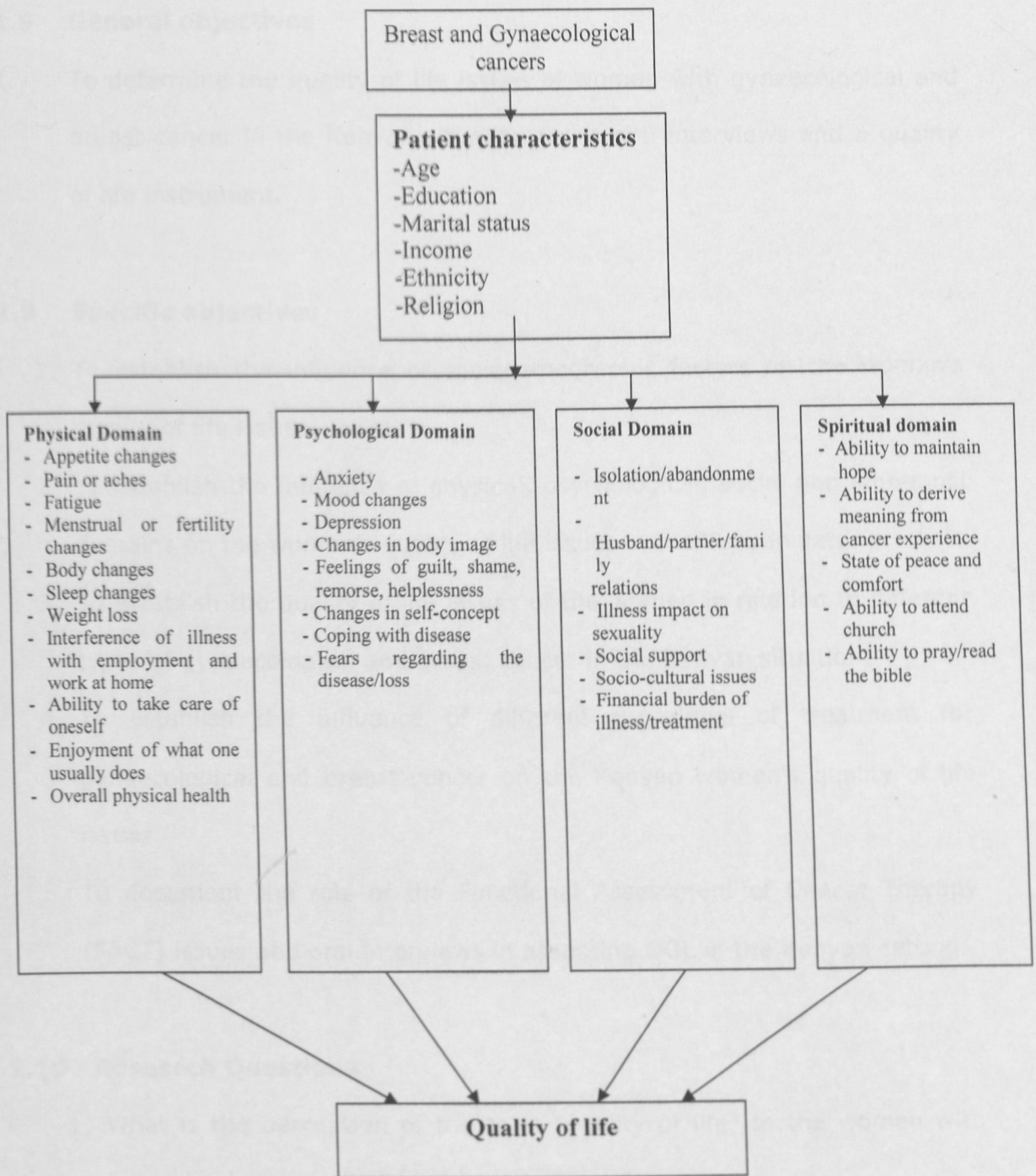
means, so as to comprehensively provide meaningful care to people afflicted by cancer.

It is the job of decision makers to allocate resources for treatment for different health states. Also it seems equally clear that uncritical use of patients unresearched information, as the basis of determining the public's value for allocating public resources, is not the answer. For the quality of life research community, the challenge is how to move beyond asking the public to value telegraphic health profile descriptions. For them, there is a strong need to define the QOL paradigm to make realistic use of patients percepts and values in their own language and use them to provide satisfactory services.

1.7 CONCEPTUAL FRAMEWORK OF QOL ISSUES

The basis of this framework is that QOL researchers have shown that there is no "gold-standard" instrument to measure QOL; hence one should carefully examine the underlying theoretical framework that supports the questionnaire in order to select "an appropriate and relevant questionnaire".⁸³

For purposes of this study, the following framework has been selected as a guide.



1.8 General objectives

1. To determine the quality of life issues of women with gynaecological and breast cancer in the Kenyan situation using oral interviews and a quality of life instrument.

1.9 Specific objectives

1. To establish the influence of sociodemographic factors on the woman's quality of life issues.
2. To establish the influence of physical, psychological, social and emotional domains on the woman's quality of life issues in the Kenyan setting.
3. To establish the quality of life issues of the women in relation to different types of gynaecological and breast cancer in the Kenyan situation.
4. To establish the influence of different modalities of treatment for gynaecological and breast cancer on the Kenyan women's quality of life issues.
5. To document the role of the Functional Assessment of Cancer Therapy (FACT) issues and oral interviews in assessing QOL in the Kenyan setting.

1.10 Research Questions

1. What is the perception of the term "quality of life" to the women with breast and gynaecological cancer in Kenya?
2. What are the quality of life issues of women with gynaecological and breast cancer?
3. What demographic factors influence the quality of life of females with breast or gynaecological cancer?

4. What is the influence of the physical, psychological, social, and spiritual well being on the woman's quality of life?
5. Are there differences in the quality of life of women suffering from the various types of gynaecological and breast cancers?
6. How do various modalities of treatment influence QOL of women with breast and gynaecological cancer?
7. In this setting, how is the information and data gathered through an oral interview different from that gathered using the FACT subscales in determining QOL issues?

CHAPTER 2

LITERATURE REVIEW

2.1 The burden of cancer

2.1.1 Cancer as worldwide problem

The burden of cancer worldwide is significant and growing. Regardless of the site, cancer is a major disease burden. It is known to be causing increasing numbers of new cases and deaths each year.⁶⁰

According to the cancer incidence and mortality data for the year 2012, there were well over 14.1 million new cases, over 8.2 million deaths and over 32.6 million people over the age of 15 years living with cancer in that year.⁶⁰ Among the female population worldwide, in the year 2012, cancer of the breast and cancer of the cervix were the most prevalent cancers with 1,676,633 and 527,624 new cases of women being diagnosed with the two cancers during the year.⁶⁰ Thus breast cancer takes the lead among female cancers with cervical cancer taking the second position.

2.1.2 Cancer in developing countries including Africa

In sub-Saharan Africa, the incidence of cancer of the breast and that of the cervix is significant with a recorded age standardized rate of 30/100,000 and 34.8/100,000 population respectively.⁶⁰

Approximately 70% of the over 266,000 deaths that occur from cervical cancer every year, occur in developing countries.⁶⁰ These deaths from cervical cancer, are known to occur due to lack of or inadequate screening services in most developing countries in comparison to the developed world where screening services are known to have contributed to a reduction in cervical cancer.

2.1.3 Women's cancer in Kenya

Cancer epidemiology in Kenya does not differ from regional estimates in Sub-Saharan Africa or other developing countries. While population based registries provide accurate estimates of cancer burden these are rarely found in developed countries due to resource constraints and competing demands within health systems. Where they exist the data are updated periodically. For example the most recent publication from the Nairobi cancer registry is from 2006 and 2009 for the Eldoret cancer registry.^{84, 85} Hospital based estimates are therefore commonly used in Kenya, where such data show that among all cancers, which accounted for 2% of all hospitalised cases, cancers of the uterus, the cervix and the breast were among the leading cancers by site.⁶⁵

The data from Nairobi Cancer Registry on common cancers in females, indicate that breast cancer incidence was the highest followed by cancer of the cervix, cancer of the uterus and cancer of ovary.⁸⁴

In a review of Nairobi Hospice data over a 10-year period, 1991-2000, it was found that breast cancer was the commonest followed by cervical cancer.⁸⁶ Earlier reports had however shown, that cervical cancer was the commonest of all cancers of the genital tract, accounting for 70-80%.⁸⁷ In a retrospective review of cancers of the female genital tract and cancer of the female breast, for the period 1969 – 1984, it was found that, out of 4305 histologically proven cancers, cervical cancer accounted for 59.2%, cancer of the breast 24.9%, ovarian cancer 5.9%, carcinoma of the vulva 3.6%, carcinoma of the endometrium and corpus uteri 2.1% and 1.4% respectively, and carcinoma of the vagina 1.1%.⁸⁸ Thus while in earlier days cervical cancer seems to have

taken the lead; breast cancer has become the leading cause of female cancer more lately. This may be because of a greater awareness on the part of both the patients and the health care providers.

Some studies conducted locally had revealed that cervical cancer, the commonest gynaecological cancer, is usually diagnosed late and is associated with a high mortality.^{73, 89} This sad picture of late presentation for diagnosis also applies generally to all cancers. Godia,⁸⁶ found that patients who were attending the Nairobi Hospice, suffering from various cancers, were not aware of the initial signs of cancer hence ignored them and only sought health care when the signs persisted or worsened. This study, although based on in-depth interviews with eleven patients suffering from various cancers, generally supports the lack of awareness about the signs and symptoms and preventative action for cervical cancer, as shown by other locally conducted studies.⁹⁰⁻⁹²

2.2 Cancer and the Quality of Life Issues

Cancer, being associated with a poor prognosis is usually considered a terminal disease and hence triggers a lot of reactions particularly psychological distress. The quality of life of women with gynaecological and breast cancer is likely to be influenced by the type and degree of the cancer they have, and the treatment modalities used. In turn, the effects of the treatments are likely also to have an impact on the women's physical, psychological, social and spiritual domains hence their QOL.

The issues that affect the quality of life of a person with a disease are mainly the disease itself and patient's reactions to that disease.⁹³ In the case of cancer

usually it is not just having cancer that elicits problems, it is also the implied connotations that may be attached to the disease such as pain, disfiguration, hospitalisation, loss of work ability, disability and fear of death.²⁴ The ensuing responses depend on how the individual deals with stressful situations and the nature of the stresses imposed by the manifestations and course of the cancer.^{24, 94, 95} It is possible that patients' reactions to cancer may vary remarkably in different parts of the world depending on age group, cultural, ethnic, social, economic and educational factors.⁴³ In most countries, the word cancer is a recent concept and many local languages do not have the equivalent words for cancer.

Previously, physicians avoided telling the patients their diagnosis because of the admonition that "he will kill himself if he knows he has cancer".^{96, 97} However, accurate data on these issues including declaration of the diagnosis are scarce, and the risk of suicide as a result of discussing the patient's diagnosis with him seems to be exaggerated.

Furthermore, there are other aspects of cancer that impact on the quality of life differently from other diseases. These aspects relate to the histological type, anatomical sites and the treatment of cancer, which may entail various combinations of surgery, radiotherapy, chemotherapy and supportive.^{45, 46, 98, 99} All these have been shown to demand extensive psychological and physical adaptation to maintain good adjustment.^{96, 97} For instance, it is envisaged that surgical loss of the body part and functions impact serious concerns transiently or permanently. Other corrective and rehabilitative measures are also of relevance as some patients, due to adverse psychological reactions just never

attain full return to the expected function and occasionally, a patient becomes a psychological invalid despite cure of cancer.¹⁰⁰ The interpretation, for instance, that one is being given radiotherapy, to many people means that the outlook is poor. To many people, chemotherapy demands a high level of patient cooperation and commitment with its established complications and uncertain outcome. These would impose further, particularly, psychological reactions to the patient.¹⁰¹

Also a patient who has had a prior history of psychiatric illness may experience an exacerbation of mental symptoms in the course of cancer. Indeed the most common of emotional distresses is anxiety and depressive symptoms.^{102, 103}

It is also recognised that patients' attitudes to the medical staff particularly doctors, have an influence in their coping and psychological impact. The patient must have, not only a personal involvement, but also full acceptance of the sick role.¹⁰⁴

It is mandatory that as soon as the diagnosis of cancer is made and before a cancer patient is commenced on any modality of treatment for the cancer, an in-depth counselling be done. The potential issues that will affect the quality of life particularly psychological ones should be addressed in a systematic manner for the proper total management of the cancer patient. Just as appropriate history and laboratory data are assembled while prescribing medication, collection of data to determine the quality of life issues should be assessed.

The significance of social support for well being and social functioning is often stressed in cancer patients and most studies conclude that satisfaction with family life and marriage is one of the most important precipitators of QOL.^{105, 106} However social relationships can also be an additional source of distress because the disease can provoke physical aversion and avoidance behaviour.¹⁰⁵

These should enable, in the majority of patients, honest discussions about the subsequent management of events. However, it is desirable to have local dimensions of some of the ensuing issues of cancer patients against a unique background of knowledge, regional, cultural, ethnic, social, economic and educational diversity some of which are known to influence the reactions to cancer.⁷⁵ Indeed it is widely recognised that there is no gold standard to estimate people's subjective quality of life. However, whatever makes up the quality of life, an illness may have a variable impact that can be predicted by instruments or scales from different societies. Quality of life encompasses a broad spectrum of issues in cancer care including physical, cognitive, emotional and psychological aspects. It is documented that emotional distress is very common in cancer patients. Research has revealed a high prevalence of psychiatric illness in a variety of populations of cancer patients.^{24, 43, 94, 95} Adjustment disorders are also reported to be common.⁹⁵

Results of studies from other parts of the world attest to these. For instance, a Turkish cancer patients' study found no association between QOL and the disease duration but did find that those diagnosed at a later disease duration had lower QOL than those with earlier stage disease.¹⁰⁷ In another study, younger women with breast cancer (those who were pre menopausal), reported

lower QOL than older women following cancer treatment.¹⁰⁸ These studies have identified groups of patients at higher risk for low QOL diseases namely those with late disease, poor prognosis, greater disease burden and perhaps younger age.

Indeed, in other parts of the world where such QOL issues have been identified, there has been a growing proliferation of studies of different types of intervention, designed to help people cope with cancer, from the time of initial biopsy, through diagnosis, treatment, adjustment to post treatment, metastatic disease or recurrence, to palliation and death.

Quality of life in women with gynaecological cancer

As found out by Bodurka-Bevers et al,¹⁰⁹ on assessed aspects of QOL factors in 246 women diagnosed with ovarian cancer, results suggested that 21% met criteria for depression and 29% scored above the 75th percentile for anxiety.

Miller et al,¹¹⁰ observed that there is need for assessment of quality of life and emotional functioning. In this study 57% of patients required help to enable them handle emotional issues.

While Capelli et al.¹¹¹ studied 115 women between the ages of 21 and 83 years diagnosed with ovarian, endometrial and cervical cancer. Results of this research suggested that women with primary cancer were similar overall to healthy women. On the other hand, patients with recurrent disease scored an average of 10 points lower on each scale of the SF-36. Patients undergoing palliative chemotherapy treatment had the lowest scores overall.

Wenzel et al.⁷¹ on the QOL of long-term survivors of ovarian cancer assessed 49 women. The results indicated that this disease-free sample enjoyed as good QOL compared to other cancer survivors and non-cancer cohorts.

Predictors of quality of life in women with gynaecologic cancer

In their work Eisemann et al⁷⁰ assessed well-being in women with endometrial and cervical cancer at pre-treatment and also at 6 months and 1 year post-treatment. His conclusion was that that cervical cancer patients reported significantly more symptoms at all time points.

It was therefore noted that overall, extensively treated women reported substantial, lasting decrements in physical, functional and emotional well-being. There were no differences between groups in depressed or anxious mood.

Given the challenges and changes that women must face after a diagnosis of gynaecologic cancer, QOL is an especially pertinent issue on which to focus⁶⁹⁻⁷¹.

Due to the relatively small number of gynaecologic cancer patients seen at any cancer centre, most of the research studies have grouped gynaecologic cancer patients into one group, as opposed to separating out by diagnosis. As such, any interpretation of the impact of treatment type on QOL should also be done cautiously and in the context of disease stage.

Most of the literature suggests that QOL in women with gynaecological cancer is varied from high to low^{18, 112}.

In addition, pain also limits daily functioning, which can have an impact on psychological status, increasing distress¹¹³.

In the other domains, the psychological was also compromised, with the main issue areas being anger, depression and tension^{114, 115}.

Spiritual issues have also been raised as concerns as patients search for meaning in their lives. Appropriate support is necessary in this frequently neglected domain of QOL, and group therapies have also been used in this area successfully^{116, 117}. QOL reports from Western countries for example, tends to define QOL in relation to being healthy and independent, reclaiming life, psychological well-being or social relationships, and they place little emphasis on material support or having money^{118, 119, 120}.

Further, one of the main issues affecting negatively QOL in most studies was "finances", depicted both in the qualitative and quantitative analyses of the data. This probably reflects a rather materialistic view of life.

Sexual relationships were found to be affected by the cancer diagnosis or its treatments. The unwillingness of many subjects to complete this section of the study may be related to the cultural view that sex is a taboo topic which is rarely discussed in public, as Tang et al.¹²¹ have commented. Nevertheless, sexual functioning was considerably more affected in many studies. For example, in a study of 73 patients with haematological malignancies receiving maintenance chemotherapy in the UK using the same scale, Molassiotis et al.³⁸ reported a mean score of 4.65 (D 3.86). Andersen et al.¹²² stress that half the women treated for gynaecological cancers have sexual dysfunctions, and this proportion

is close to the findings from the descriptive analysis of the current study, especially with regard to the phase of interest in sex and sexual satisfaction^{123-125, 126}

There are a number of interventions available for these problems, such as sex counselling, prevention of sexual dysfunction at the time of treatment, hormone replacement therapy and procreative alternatives^{10, 123, 124}. Sexual/psychosexual functioning and care have received little attention, partly because of the intimate nature of the topic, the perception of the patients that this is "part of the deal", or the inadequate training of health professionals in assessment of such problems and intervention where necessary.

Outcomes generally assessed include psychological functioning, primarily anxiety and depression, and overall quality of life. Interventions themselves usually assume one of four common forms: psycho-education, cognitive-behavioural training (group or individual), group supportive therapy, or individual supportive therapy. They are as well, usually targeted to one of three points on the illness trajectory: diagnosis/pre-treatment, immediately post-treatment or during extended treatment (such as radiotherapy or chemotherapy), and disseminated disease or death.¹²⁷ Certain modalities of treatment have been shown to be more efficacious at one or more of these time periods. For example, psycho education may be most effective during the diagnosis/pre-treatment time period, when patient information needs are high. However, for later stage adjustment with more advanced disease, group support may be more effective,¹²⁸ while cognitive behaviour techniques such as relaxation, stress management and cognitive coping may be most useful during extended treatments^{129, 130}. In fact, relaxation and imagery have been shown to be useful in controlling nausea and

vomiting, associated with chemotherapy treatment, in several early studies.¹³¹ These can also help patients decrease pain medication use.¹³² Cunningham has identified a hierarchy of different types of therapy, based on increasingly active participation by the recipient. These five types are: providing information, emotional support, behavioural training in coping skills, psychotherapy, and finally spiritual/existential therapy.¹³³ All of these five levels of therapy are supported by research demonstrating their efficacy, although the bulk of the research is in the area of supportive and cognitive behavioural interventions.

Breast cancer patients have historically been the most common patient group studied,¹³⁴⁻¹³⁶ although there is now ample research in other populations and mixed groups, demonstrating therapeutic efficacy to confidently generalise outcomes beyond breast cancer. Some authors have repeatedly suggested that the evidence of the efficacy of psychosocial therapy, is strong enough that it should be considered on the same footing as adjunctive medical therapies such as chemotherapy,¹³⁷ particularly using brief, professionally led support groups, with cognitive behavioural training in active coping strategies. Cunningham¹³⁷ suggests a model wherein every cancer patient receives at least minimal group adjunctive therapy, as a routine part of cancer treatment. Some have suggested that the evidence is so compelling that there is no need to further test this proposition.¹³⁸ In their meta analysis of 45 randomised controlled trials in the area (14 in breast cancer, the remainder with other cancers of mixed groups), Meyer et al¹³⁸ found effect sizes on measures of emotional adjustment, functional adjustment, treatment and disease related symptoms, and global quality of life in the same range as psychotherapy in general, at par with other psychological interventions that are known to work. In percentage terms, the

differential success rates for participants in intervention versus control conditions were 56% versus 44% for measures of emotional adjustment, and similar for the other outcomes. These effects are considered to be clinically significant for patients.

Also, many reviews have focussed on the efficacy of group interventions,^{128, 129, 133, 139-142} and it seems to be more the trend to offer group, rather than individual, therapy. Group therapies have repeatedly been shown to be as effective, if not more effective, than individual treatment. Given the reduced cost of group therapies, and the greater number of patients who can be treated using this modality, it is not surprising that many researchers identify group therapy as the preferred route for treating distress in cancer patients.

Furthermore, it is recommended that QOL is addressed at a variety of levels in order to give information about as many relevant dimensions as possible. In spite of the value of global approaches, important information about the patients can be masked if one only uses a global approach.¹⁴³

2.2.1 Women's Cancer by Site

2.2.1.1 Cancer of the cervix

Of the two most common cancers, cancer of the breast and cancer of the cervix, it probably takes long for cancer of the cervix, being a genital cancer, to be diagnosed and treated among Kenyan women. This could be related to the fact that it is taboo to talk about issues pertaining to reproduction and the genital tract to other people. The social stigma of having a genital cancer can result in feelings of guilt in the patient as it may be connected to an "immoral act".

Consequently, many women tend to seek medical help late with serious symptoms such as those listed below:

- Irregular vaginal bleeding from the cauliflower-like growth. In late stages, this growth bleeds vigorously on touch;
- Vaginal discharge which may be watery at first for the post-menopausal woman, changing to a blood stained discharge with a characteristic offensive odour;
- The woman may become cachexic due to loss of appetite and loss of weight with the resultant anaemia and general weakness;
- The woman may experience pain that occurs due to infiltration with the cancer causing nerve involvement, or pain from a pyometra resulting from a stenosed cervical canal.
- She may experience other symptoms related to the late stages of cervical cancer such as pruritus and disorders with micturition and/or defaecation.¹⁴⁴

Various modalities of treatment may be undertaken on the basis of the stage of cancer, when the woman presents herself.

Treatment modalities include:

- Surgery for patients classified as having FIGO stage I and IIa disease, for which a modified radical hysterectomy is performed. It is useful for young women for whom ovarian conservation is required;
- Radiation can be used in all stages of the disease. It could be intracavity in early disease to treat the primary lesion or external radiotherapy to shrink the tumour. Postoperatively, radiotherapy can sterilize cancer in

pelvic lymph nodes that may not have been removed. However, post radiotherapy bowel and urinary tract complications could occur;

- o Chemotherapy use is limited by success with surgery and radiotherapy, however, trials have shown concurrent chemoradiation to be beneficial.¹⁴⁵

With cervical cancer being the second most common cancer, the investigator assumes that women suffering from this type of cancer, mostly in their 40s and above, experience not only a lot of physical distress, but also extensive emotional distress. It is documented that emotional distress, which may be evidently displayed by anxiety and depressive symptoms, is very common among cancer patients.¹⁰³

2.2.1.2 Cancer of the breast

Breast cancer is known to be the most common malignant tumour among women in Kenya. It is considered to be a stressful life event first, because of the role of the breast in reproduction, and secondly, the preservation of the woman's image. As it commonly is with malignant diseases, the aetiology is not known. However, there are associated risk factors such as childlessness, genetic, endocrine and environmental influences. It is however documented that 70 – 80% of all breast cancers occur in patients without identifiable risk factors, while the risk is greatest after age 50 years.¹⁴⁶

With regard to genetic influences, first degree relatives like siblings and children are known to have a higher risk of developing breast cancer; while the endocrine influences are shown by an early age at menarche, late onset of menopause, null parity and late age (after 30 years) at first pregnancy. Radiation like what

occurred after the exposure to radioactive substances in the Hiroshima bomb blast, contributed to breast cancer in women who were aged 10-14 years at the time.¹⁴⁶ This is documented as one of the examples of environmental influences increasing the risk of developing breast cancer. Although conditions related to the latter are not common in Kenya, we nevertheless experience a high incidence of breast cancer. Questions like the effect of dumping of industrial and agricultural wastes in the environment, as well as the diets consumed in the contemporary society in Kenya, would cause concern. It is documented that a high fat diet is a specific risk factor to breast cancer, in addition to obesity and alcohol consumption, and that lactation does not affect the incidence of breast cancer.¹⁴⁵

Breast cancer commonly arises in the upper outer quadrant, where there is more breast tissue,¹⁴⁵ and performance of Breast Self Examination (BSE) monthly for detection of any abnormality, as well as examination by a clinician, are recommended measures. Through BSE or clinician's examination, the distinguishing signs for breast cancer are: abnormal hard masses or lumps that feel fixed, dimpling of the overlying skin or nipple retraction. Although radiological examination is advocated, it is not within the affordability and accessibility of most women in Kenya, for that more accurate early detection of abnormalities required, if the incidence of breast cancer is to be reduced.

Of concern with regard to breast cancer is that, by the time these signs are present, the cancer is likely to have metastasized.¹⁴⁶ It is a known fact that breast carcinoma is prone to metastasize fairly early to the regional lymph nodes and from there spread to other structures like the bone, lungs or liver in 85% of

women with metastatic breast cancer.¹⁴⁵ Other than the lymphatic spread, blood borne metastases are also known to occur, with a predilection for ovaries, adrenals and pituitary gland. Ganz et al.,¹⁴⁷ found only a weak positive relationship between age and QOL in women with breast cancer.

Treatment modalities

Treatment for breast cancer could entail surgery with adjuvant radiotherapy after mastectomy or with adjuvant systemic therapy. The side effects of chemotherapy are however notable for compliance purposes.¹⁴⁶ Among the notable side effects of chemotherapy are nausea, vomiting, bone marrow suppression, alopecia, stomatitis, cystitis, diarrhoea, conjunctivitis and amenorrhoea. In the long term, early menopause, osteoporosis and leukaemia, may occur. Psychosocial effects include change in mood, depression, anxiety, and change in sexual relationships and work related activity.¹⁴⁸

Although in most cases breast cancer occurs in the older woman who has completed child bearing, it probably is difficult for her to imagine herself without a breast after a mastectomy is done. The permanent loss of a breast could bring along with it many psychological and emotional reactions. Locally, women have been known to keep away after surgery only to return when recurrence of the cancer or other complications have arisen.

It is difficult to imagine the degree of psychological distress the woman goes through as some women allege that "as soon as the diagnosis of breast cancer is made and treatment commenced, the health of the woman with cancer

deteriorates fast and she dies." Consequently, these women advise others against medical treatment.

2.2.1.3 Cancer of the Endometrium

Most patients with endometrial cancer are diagnosed between the ages of 55 – 60 years.¹⁴⁹ Its most common symptom is abnormal spotting and bleeding. The common risk factors include obesity, null parity, diabetes mellitus, hypertension and late menopause (after 52 years).¹⁵⁰

An endometrial aspiration smear or scrapings of the endometrium are more effective diagnostic measures than a Pap smear, which detects just about 50 – 60% of the endometrial cancers. It is noted that delays for diagnosis and treatment are likely to occur as women in the perimenopausal period may assume that the irregular bleeding is physiologic in nature.¹⁴⁹ However, 75% of all endometrial cancers occur in postmenopausal women.¹⁵⁰

Treatment Modalities

The method of treatment is determined by the extend of the tumour at diagnosis, and include surgery, irradiation and a combination of both surgery and irradiation.¹⁴⁹ Often, total abdominal hysterectomy and bilateral salpingo-oophorectomy with preoperative radiation in advanced cases, and post operative radiation if the tumour had deeply invaded the uterus, or spread to the pelvic lymph nodes, is done.¹⁵⁰

2.2.1.4 Cancer of the ovary

Epithelial cancers are the most common ovarian malignancies. Most women have no symptoms for long periods.¹⁴⁵ Early and insidious symptoms include – an abnormal girth enlargement, vague abdominal discomfort, dyspepsia, flatulence, and a feeling of fullness after a light meal.^{150, 151} In advanced stages, the woman may have abdominal distension, bloating, constipation, nausea and anorexia. Irregular or heavy menses in the premenopausal woman or vaginal bleeding in the postmenopausal woman may be reported. On examination, a solid, irregular, fixed pelvic mass and ascites may be noted.¹⁴⁵

Ovarian cancer has no known specific risk factors,¹⁵⁰ however, it is associated with low parity and infertility, while early menarche and late menopause increase the risk of ovarian cancer.¹⁴⁵ This cancer may give rise to many primary cancers, and the ovary may also be the recipient of metastases from other cancers.¹⁵⁰

Treatment modalities

Treatment is surgical – total abdominal hysterectomy with bilateral salpingo-oophorectomy, radiation therapy as an adjunct to surgery, and chemotherapy.¹²⁵ Whole abdominal radiation therapy has been shown to be associated with increased morbidity such as intestinal obstruction.¹⁴⁵

2.2.1.5 Carcinoma of the vulva

Squamous cell carcinoma of the vulva is reported to be the most common, and most patients are menopausal, with age 62 years being the average age for

diagnosis. It is reported that patients may delay seeking attention because this is a "personal problem" as vulva pruritis is the most common symptom, with others like ulceration, bleeding, pain and the presence of a mass, a cauliflower-like growth. Treatment entails chemosurgery.¹⁵²

2.2.1.6 Carcinoma of the vagina

The average age of occurrence is 60 years, while the most common presenting complaint is vaginal bleeding or bloody discharge. In the advanced disease, pain or symptoms related to the urinary tract or bowels, may be reported. Treatment entails both radical surgery and radiation therapy, on the basis of FIGO classification.¹⁵²

2.3 The threat of cancer on the patient

The onset of a life threatening or terminal illness like cancer, is a critical life event involving the physical, psychological, social and spiritual dimensions of the patient. Cancer is a major health threat that has a long-term impact on the quality of life of the patient. Gynaecological carcinomas and carcinoma of the breast are some of the most stressful life events for women. They are often followed by depressive reactions, fears and doubts on the individual's worth. In the Kenyan setting, these characteristics may be worsened by some of the socio-cultural beliefs connected to disease causality. Examples of these were noted in studies where women associated irregular vaginal bleeding with a curse by mother or co-wives, eating eggs, husband's crossing over wife in bed or having extra marital affairs.^{91, 153} Although these are indicative of knowledge

deficits, the disease occurrence can result in high distress levels that would affect the woman's quality of life.

2.4 Models of Quality of Life:

There are numerous concepts offered in the literature about quality of life (QOL) as it is perceived as a differing concept by different individuals reflecting their own particular point of view.²⁵ The Greek philosopher Aristotle in his book 'Ethics' recognized this fact almost 2500 years ago.

When it comes to saying in what happiness consists, opinions differ, and the account given by the generality of mankind is not at all like that of the wise. The former take it to be something obvious and familiar, like pleasure or money or eminence, and there are various other views and often the same person actually changes his opinion. When he falls ill, he says that it is his health, and when he is hard up he says that it is money.¹⁵⁴

This citation shows very graphically the subjectivity of the issue, which does not differ from the definitions of quality of life in the current literature. Neugrarter et al¹⁵⁵ indicated the subjectivity of this concept and pointed out that only the individual himself is the proper judge of his well-being. Dubos,¹⁵⁶ defined QOL as a concept, which 'involves value judgements that are highly subjective and associated with profound satisfaction from the activities of daily living'. Hornquist³⁴ defined QOL as satisfaction with areas such as physical, psychological, social, activity, material and structural. Similarly, Szalai,³⁵ pointed out that QOL is a global evaluation of an individual's description of satisfaction with life.

In a recent qualitative research study, Bertero et al¹⁵⁷ asked their leukaemia patients to describe what quality of life meant for them. Most of the patients commented that QOL meant a positive attitude to life, which is dependent of interpersonal relationships and autonomy; security, support, respect, information and conversation were themes interrelated with both interpersonal relationships and autonomy. In another qualitative study among 119 bone marrow transplant (BMT) long-term survivors,¹⁵⁸ the authors tried to conceptualise the meaning of QOL for BMT survivors. Eight theme-core concepts emerged: having family and relationships, being independent, being able to work/financial success, having a heightened appreciation for life, being alive, being satisfied and fulfilled with life, and being normal (healthy). In a review of the QOL literature, De Haes et al¹⁵⁹ pointed out that some authors like Szalai,³⁵ view QOL as a global and overall concept, while some others like to believe that components of life are important for defining and evaluating QOL.³⁴

DOMAINS OF QUALITY OF LIFE

2.4.1 Physical

This includes the physical symptoms of the disease, outcomes and toxicities of the treatment. Pain is a common feature in cancer and affects the QOL in advanced cancer.⁴⁰ Though a physical symptom, pain influences all domains. The patient with cancer may experience intractable pain that is both humiliating and frightening.¹⁶⁰ Pain is the most feared symptom for patients with advanced cancer and effective pain relief is critical to preservation of quality of life for such patients but despite this, the incidence of uncontrolled pain is high.¹⁶¹ Studies done locally have shown that most patients are diagnosed in advanced stages of cancer,^{73, 89} hence the likelihood to suffer from pain.

Other studies have also supported these short falls in the care for the terminally ill. In Uganda, Kikule,⁴⁰ in a study of patients most of whom were terminally ill with AIDS while a smaller proportion had cancer, identified three main needs for the terminally ill to be the control or relief of pain and other symptoms like diarrhoea and vomiting, counselling and financial assistance for basic needs such as food and shelter.

Common to these findings in Kikule's study,⁴⁰ Murray¹⁶² in Kenya, identified physical pain and financial worries to be major needs while analgesia, essential equipment, suitable food and assistance in care, were often inaccessible and unaffordable to patients, hence unmet physical needs. Other than pain, the patient with cancer may also experience problems with mobility and sleep in addition to having a poor appetite as well as experiencing nausea.¹⁶⁰

Murray¹⁶² found that meeting patients' physical needs at home was also difficult and patient-family relationships were strained where patients were vomiting, incontinent, or had offensive smelling wounds. Cultural traditions also tend to hinder physical care provision at home. However, families, local community and religious groups were found to provide support in meeting patients' psychological, social and spiritual needs.¹⁶²

2.4.2 Psychological

Under this domain fall the psychological symptoms such as anxiety, and mood changes associated with the change in the body image.²⁵ Other than pain management, psychiatrists and psychologists are needed in cancer care for management of morbidity that arises as a consequence of cancer and its

treatment. The fear of loss of a body part in an anticipated surgery, could lead to grief-like responses, and the patient may experience feelings of guilt, shame and remorse. This can arise as the patient could worry about the effect the loss of a body part will have on the family, such as child-bearing, and sexual relations.¹⁶³ Difficulties related to sexual activity and sexual satisfaction post-treatment have been reported in a small qualitative study of 20 women.¹⁶⁴

Nosarti et al., found that a significant proportion of breast cancer patients experience psychiatric morbidity in the first year after a breast cancer diagnosis and beginning treatment.¹⁶⁵ It is noted that some 20% of cancer patients may need to see a psychiatrist for treatment of major depression or anxiety as well as a psychologist for treatment of distress through counselling.²³

Patients suffering from cancer require a caring attitude that shows an understanding of their problems. Attention paid by health care providers to psychosocial issues concerning patients with cancer, such as: how a patient was coping, the support services available and common emotional reactions to cancer, were found to possibly enhance patients' satisfaction with treatment.⁴⁶ Such concern by the staff can give hope and also enhance the cancer patients "will to live" through channelling all their energy "into a tenacious fight for life".¹⁶⁶

Loss of a body part such as the breast, brings about a range of emotional and behavioural reactions; hence the health care provider should treat not only the disease itself "but the individual suffering from the disease, thus the total person approach to patient problems".⁶¹

Advanced cancer raises psychological issues such as a state of "learned helplessness and loss of control".¹⁶⁷ Controversially, this reaction has also been noted among 359 early-stage breast cancer patients where a significant association was observed between anger control and a helpless attitude.¹⁶⁸ Anxiety, depression, emotional reactions and a fatalistic attitude toward cancer were also found among those patients.¹⁶⁸ In addition to these, adjustment to illness is necessary and man has the ability to adapt, adjust and cope with life events, if given support.¹⁶⁰ Individual or group supportive therapies are some of the interventions that may also help patients' adjustment especially in advanced disease,^{23, 128} while cognitive behaviour techniques may be useful during extended treatments like radiotherapy or chemotherapy.¹²⁹

The efficacy of different types of therapy, with active patient participation, that have also been supported by research include – providing information, emotional support, behavioural training in coping skills, psychotherapy and spiritual/existential therapy.¹⁶⁹ There is little, if any, studies done in Kenya among cancer patients, to show the efficacy of group therapy even though this therapy could be in place, for example, for breast cancer patients.

Intervention studies done in other countries on various cancers have produced positive psychosocial outcomes such as less demand on health care utilization, and consequently, medical cost offset.^{45, 170}

2.4.3 Social

This includes the interests and relationships and social support as well as the financial issues of the treatment process.²⁵ Cancer, especially if advanced, may interfere with the patient's patterns of relationships. The patient may experience fears of abandonment by family and friends. Due to the physical impairment by the cancer or the mutilating surgery, which contribute to emotional trauma, sexual problems are likely to arise, leading to increased fears of being rejected and anxiety.¹⁶⁰ On the other hand, some people may feel uncomfortable with a patient diagnosed to have cancer hence avoid social contacts thus socially isolating the patient. The change in roles formally undertaken by the patient, may affect family members making them feel insecure, resentful and angry. This can result in feelings of guilt.¹⁶³

Cancer treatment may also affect the socio-economic status of the patient and her family. Montazeri et al,¹⁷¹ found that most patients of lower socio-economic status had more health problems, less functioning and more symptoms compared to the more affluent patients. This led them to conclude, quality of life is not only the outcome of the disease and its treatment, but is also highly dependent on each patients' socio economic characteristics.¹⁷¹ In studies in Kenya¹⁶² and Uganda,⁴⁰ financial constraints were found to contribute to patient's unmet physical needs.

In order to help cancer patients adjust to their situation and avoid intrusive thoughts, social support is needed to act as a buffer.²⁶ Norsarti et al ¹⁶⁸ found that social support was associated with successful adjustment following a breast cancer diagnosis. It is therefore essential to assess the patients' perceptions of

social support and develop patients' supportive networks if lacking. Family and friends support and involvement of the patient in social activities can be a basis for such support.

2.4.4 Spiritual

While providing care for the terminally ill patient, it is essential to keep in mind that the human being incorporates the concept of the body, mind and soul. Therefore, not only the physical and psychosocial needs should be met but also the spiritual needs for the achievement of holistic care. Murray et al¹⁶² found that attention to the patients' religious beliefs provided peace and comfort resulting in the patients' acceptance of their prognosis and inevitable death. However, spiritual and emotional support was better met at home than in hospital.

METHODS OF ASSESSMENT OF QOL

Questionnaires and interview schedules

Although quality of life assessments are less time consuming and less invasive than many clinical assessments, obtaining answers from patients poses its own challenges. Data collection requires adequate preparation of study personnel to assure uniformity. Since patient expectations can affect their responses, blinded designs are preferable. Protocols are needed to reduce missing data, which are more likely to occur when patients' quality of life is worse.

Questionnaire administration may need to be tailored for patients with lower literacy and educational levels. This is where open interviews may help and analytic strategies (qualitative measures of analysis) deployed to handle missing data so as to get more data needed to aid interpretation of what scores mean.

In many studies the researchers have adopted the head-to-head comparison of two questionnaires: an open interview schedule and a widely used measure of health-related quality of life, FACT-G.

The two methods are usually adopted because of their responsiveness in a particular environment. Responsiveness can be defined as the ability of a measurement instrument to detect change. In some studies, both patient reports of changes in clinical parameters are utilized to define change, making the results easier to interpret. For researchers selecting a measure to use in a study, or performing sample size calculations, the specific results of the study are useful since greater responsiveness means more power. No two questionnaires aim to measure exactly the same things. Indeed, the results should provide ammunition to both camps to support the clinical utility of their methods. It is certainly an indicator of the field's growing maturity that excellent methodologic work is being done by groups other than the initial developers of questionnaires.¹⁷²⁻¹⁷⁷

Varied instruments are preferred due to the subjective character of quality of life encompassing both positive and negative aspects and its multidimensional nature that is a fundamental characteristic. Such interest is justified by the fact that it is not possible to assume that instruments that are suitable for assessing the field of physical health among young adults, for example, are the same or appropriate for populations of elderly adults. Specific matters probably need to be addressed for each age group. In addition to this, the magnitude of the

aging phenomenon, together with the scarcity of instruments for evaluating such questions, strengthens such interest.

The way QOL is assessed determines not only the extent but also the impact of the issues. In research 'quality of life', usually mean health-related quality of life (HrQOL). At a minimum, this includes several dimensions: physical functioning and symptoms, performance of social roles, psychological status, spiritual and cognitive functioning, and how the patient feels about her health.¹⁷⁸ All of these concepts can be measured adequately using sets of questions, which are deployed in standardized questionnaires. In this context therefore questionnaires for assessment of QOL are referred to as 'instruments'. Such questionnaires are in fact measurement for assessment of QOL is therefore tools, with coefficients of variation that compare favourably to those for parameters such as physical and emotional reactions. As with all tools, quality of life instruments are important to the extent that they provide precise and unbiased answers to some research questions.

By nature, a human being is within the process of an interaction between the environment and the self. The individual, family, society, customs and practices, all influence ones QOL in some ways. Therefore there may be questions about the management of gynaecological and breast cancer that can only be answered by asking the patient. Some of the questions, such as those relating to cultural and customary behaviours and practices, are clinically important, as they are likely to affect the outcome. The tolerability of therapies in the identification of unsuspected symptoms, and other questions such as: what is the extent of need in communities, and what is the natural history of disability, are important to

policy makers. Answering these questions requires collecting patient-reported data on quality of life.

It may be relevant to note that in cancers, the applications of quality of life assessment coincided with the advent of holistic care management. Quality of life data add useful information to treatment trials, sometimes in support of clinical findings,¹⁷⁹⁻¹⁸³ sometimes at odds,¹⁸⁴ sometimes revealing the only difference among treatment modalities.¹⁸⁵ Clearly some of the results make more sense today than they did in the past, such as the finding that spiritual, social and customary aspects decreased quality of life in patients with early disease.^{186, 187}

Oral Interviews

In addition to using questionnaires as is the standard practice in measurement of HRQoL, and in line with other QOL studies,^{117, 119} the current study used narrative interviews that have gained new momentum in recent years due to the ability of narratives to overcome the criticism of question-response schema of questionnaire interviews.¹⁸⁸ Additional attractiveness of narration derives from its richness in detail with reference to concrete events in place and time, the relative independence of story-telling skills from education and language competence of interviewees and inclusion of an evaluation of outcome.^{188, 189} Separately, social and cultural differences to a large extent preclude the direct application of QOL questionnaires developed in Western countries to African population and adopting mixed methods in QOL studies has been used to verify validity of claims of indirectness of HRQoL tools.¹⁹⁰

QOL studies adopting qualitative approaches

In reviewing literature on quality of life in cancer patients it is apparent that narratives related to experiences of patients living with cancer, like other social phenomena, are infinite in their variety.^{188, 190} In general reviewed studies utilised deductive analysis to code qualitative data into pre-determined categories most often based on literature or well established HRQoL domains for example physical, psychological and social domains.^{119, 190, 191}

Previous studies in gynaecological cancer patients utilising either qualitative approaches only or mixed approaches (both qualitative and quantitative) report that cancers and cancer treatment may result in quality of life issues and in general negatively impact on quality of life.^{119, 190, 191}

Perception of quality of life

Perception of quality of life has cultural and context specific aspects.¹¹⁹ For example in all seventeen Hispanic patients participating in in-depth interviews, religious beliefs and family support were important aspects of quality of life in addition to the more general domains of QOL including physical, psychological, spiritual and social wellbeing.¹¹⁹ Themes under the physical domain in this study included: functional limitations, decreased appetite, dyspnoea, personal grooming, fatigue, and loss of hair. The psychological wellbeing of the participants was composed of patient responses indicating: anxiety, sadness, mood changes, cognitive effects, delayed diagnosis, coping with pain, feeling useless and uncertainty.¹¹⁹ Social support, a prominent feature of Hispanic culture, was defined by eight themes: need for family support, family help with pain management, spouse support, isolation, financial burden, loss of freedom, support from friends and neighbours, and past experience with cancer in family.

Finally, in the spiritual domain patients responses corresponded to nine themes reflecting coping with illness and these included: going to church, prayer and reading the Bible, faith, pain as redemption, religious rituals, negotiating or asking God to take cancer / pain away, awareness of death, resignation to God's will and positive effect.¹¹⁹

Quality of life issues

Sexual function impairment is among the main quality of life issues in gynaecological cancer following cancer treatment procedures particular when surgical treatment modalities are applied.¹⁹⁰ Turkish patients interviewed following surgery reported that loss of body parts and sexual organs impacted on four areas of sexual health: damaged body image, feminine identity or gender role, sexual functioning, and reproductive ability. Similar concerns related to role functioning, and self-image have been reported from lived experience of patients with metastatic breast cancer.¹⁹²

Further, Mosher and colleagues,¹⁹¹ have elucidated quality of life issues in distressed breast cancer patients. The study reported, based on analysis of focus group discussion data, that patient non-disclosure of cancer related concerns (issues) due to social constraints patients' distress worsens underlining the importance of sociocultural context in patient quality of life issues. Distress related to gynaecologic cancer diagnosis coupled with reduced social support can feed into each other to create a vicious circle.¹⁹³

From the foregoing review of qualitative analysis guided by deductive methodology it could be argued that quality of life issues that emerge from studies that allow themes to emerge from data as opposed to using pre-determined themes may identify different quality of life issues. Qualitative

studies guided by grounded theory methodology report that the main issues confronting female cancer patients particularly during disease progression relates to adjusting to recurrent nature of cancer disease and living with a persistent life-threatening illness.^{194, 195} In the pre-treatment period the main issues for women with breast cancer is threatened self-integrity and the patients adjustment to this situation was defined in three stages: surveying the situation, taking action and emerging self.¹⁹⁵

1.2 Study Area

The study was carried out at the Kenyatta National Hospital, Moi Kariakoo and Teaching Hospital, and in three provincial hospitals, namely: Provincial General Hospital, Nakuru in Rift Valley Province, Quya General Provincial Hospital, Muramba East Province, and Nyaruga General Hospital, Kisumu in coastal Province.

Kenya has the largest referral and teaching hospital situated within Nairobi the capital of Kenya, as the first specialized national referral and teaching hospital. It has to have a large population of women on breast to have the specialized services being referred to the more specialized treatment since it is also a university based hospital. However, it has more resources for use in diagnosis and treatment procedures of common cancers. It also receives patients referred from all other cancer centres. It is expected that this capacity will be further strengthened by being

METHODS AND MATERIALS

3.1 Study Design

This was a cross-sectional study, conducted using both quantitative and qualitative approaches for data collection and analysis.

3.2 Study Area

The study was carried out at the Kenyatta National Hospital, Moi Referral and Teaching Hospital, and in three provincial hospitals, namely: Provincial General Hospital, Nakuru in Rift Valley Province, Coast General Provincial Hospital, Mombasa in Coast Province, and Nyanza General Hospital, Kisumu in Nyanza Province.

Kenyatta Hospital, the oldest referral and teaching hospital situated within Nairobi the capital city in Kenya, as the most established national, referral and teaching hospital, is likely to have a large population of women diagnosed to have the specified cancers being referred for the more specialized treatment since it is also a university teaching hospital. As such, it has more resources for use in diagnostic and treatment procedures of complex ailments. It also receives patients referred from all over Kenya, hence it is expected that most subjects will be from this institution in Nairobi.

The three provincial hospitals, like other provincial hospitals, serve as referral hospitals for the district hospitals in the respective provinces. These three provincial hospitals also represent a cross-section of the major indigenous ethnic

groups in Kenya, as the hospitals are located in the cities of Mombasa and Kisumu, and in the urban areas of Nakuru and Eldoret.

Generally all these hospitals receive most of the cancer patients in Kenya as they are located in the major urban areas and cover large geographical regions of the country.

Furthermore, the Nairobi, Eldoret, Kisumu and Mombasa Hospices are chosen to represent patients in four major urban areas.

3.3 Target Population

The target population were women diagnosed to have gynaecological cancer or breast cancer. This included patients admitted in the wards or those attending outpatient clinics with a confirmed diagnosis of the specified cancers, and the specified Hospices, at the time of the study.

3.4 Study Sample

A consecutive series of 384 women with documented histological diagnosis of gynaecological cancer or breast cancer, were serially recruited from Kenyatta National Hospital, Moi Hospital Eldoret, and the three provincial hospitals.

3.4.1 Sample Size Determination

A 50% proportion was used since there is no previous study done in this area.

Fisher's formula,¹⁹⁶ $n = \frac{Z^2 p (1-p)}{d^2}$, was used to estimate sample size,

d^2

where n = sample size desired

Z = Z value of 1.96

p = 50% prevalence

d² = 95% confidence level (the level of statistical significance)

hence

$$\begin{aligned}n &= \frac{1.96^2 \times 0.50 (0.50)}{0.05^2} \\&= \frac{3.8416 \times 0.25}{0.0025} \\&= \frac{0.9604}{0.0025} \\&= 384.16 \\&= 384 \text{ patients}\end{aligned}$$

3.4.2 Sampling Technique

The sampling strategy involved sequential enrolment of patients with histologically proven cancer and included patients with gynaecological cancer and those with breast cancer as they became available. It was expected that most subjects would be recruited at the Kenyatta National referral hospital, with fewer subjects being recruited at Moi referral hospital, Coast, Rift Valley and Nyanza general provincial hospitals. In addition, it was expected that the subjects from these five major hospitals would give a relatively good representation of all the Kenyan ethnic groups as Nairobi, Mombasa and Kisumu are large metropolises.

3.5 Inclusion Criteria

Women aged 18 years and above, who had a documented histological proof of the cancers under study (gynaecological and breast cancer), and consented were included.

ECOG Performance scale, 0 -3 (Full description of scale in Appendix VII)

3.6 Exclusion Criteria

Women less than 18 years of age

Women with a histologically diagnosed gynaecological and breast cancer who refused to consent to participate in the study

Non-Kenyans

ECOG Performance scale, stage 4 (Full description of scale in Appendix VII)

PROCEDURES

3.7 Data Collection

The researcher collected data with the help of Research Assistants. Data were collected during a two calendar-year period between 2006 and 2008 with intention of interviewing all cancer patients who met the inclusion criteria and were attending the specified Provincial and National Hospitals.

For patients meeting study eligibility criteria study information was provided and informed consent sought prior to recruitment or collection of any information. Upon consenting the eligible subjects were assessed at whatever stage of their treatment. Self-administered questionnaires were used to collect data. The FACT subscales were self-administered but assistance in marking the subscales was offered to those unable to complete the tool by themselves. For the oral

interview, subjects were requested to talk about their life in the immediate two weeks' period while living with cancer.

Measurement tools

The Functional Assessment for Cancer Therapy (FACT) subscales was applied to each patient, the details of which are given in the Appendix III. A brief description of the subscales is as follows.

Considering the subjectivity of the result, whichever tool or instrument of evaluation of QOL is used, Neugarten¹⁵⁵ pointed out that only the individual himself is the proper judge of his well being, and therefore a wide leeway is necessary to enable an individual tell and divulge self views on concepts of QOL. However some standardized instrument is always necessary. For this reason therefore, FACT subscales contained in FACT-G were used and oral interviews conducted using an interview guide (Appendix II). The FACT scales (Appendix III) and the oral interview were selected for this study because they are considered to represent important dimensions of the QOL domains and attending theoretical framework contributing to adaptation, and also because they have a close similitude to African culture.

Furthermore the FACT and oral interview have been shown to be powerful means for assessment of quality of life of patients, by several authors.⁷² The oral interview takes cognisance of the fact that QOL being a subjective matter, the most appropriate method for collecting data relies on self-reporting by the patients themselves typically using self-administered scales.¹⁴³ The researcher with the help of research assistants trained on the application of the instruments, assisted patients to complete the FACT subscales and conducted the oral interview for the patients.

3.8 Training of interviewers

The researcher collected the data with the help of one research assistant per site. The research assistants were trained by the researcher during data collection on the first five subjects at each site or until acceptable agreement was achieved between the researcher and research assistant. Thereafter the research assistant proceeded with data collection with supervision from the researcher and inspection of completed questionnaires. The training entailed both the use of the standardized tool – (FACT) and the interview guide.

An interview guide was used for reference by the interviewers as the patient was expected to talk freely and openly about her life experiences while suffering from the disease in the previous two weeks prior to the interview. Probing for clarification was considered necessary.

3.9 Data management

The data were screened and entered in IBM SPSS® statistics program, for data cleaning. The screening of questionnaires was conducted by the researcher with the intention of confirming that all recruited participants met the inclusion criteria and also ensuring completion of the required response items. For questionnaires where item non response was noted the research assistants were required to follow up and obtain the missing data. On the other hand, only five questionnaires were determined not to have met the inclusion criteria and were excluded from analysis. Data entry was conducted by a research assistant using a database designed in SPSS with inbuilt range and consistency checks to minimize data entry errors by flagging up database entries outside the allowable ranges for example ineligible age. The database had codes for categorical

variable types and value labels associated with each code. Data cleaning was conducted by exploring each variable in turn and checking for invalid entries. When such entries were noted validation was done by referring back to the questionnaire responses and making appropriate corrections. A log of all the changes during data cleaning was maintained by the researcher along with a copy of the initial database entries. The cleaned database and project metadata were stored in a password protected directory on the researcher's personal computer with external backup, and the questionnaires and accompanying documentation were maintained in an archive in the University of Nairobi, School of Nursing Sciences.

3.10 Data Analysis

Data analysis was conducted using IBM SPSS® statistics program, version 19, ©IBM Corporation, Armonk, NY, USA. Descriptive statistics including means and SD for continuous variables and frequency distributions for categorical variables were used to summarize all data. Associations between patient characteristics and cancer diagnosis, and its staging were examined using cross tabulations. Multinomial regressions were used to identify significant association between patient characteristics and cancer diagnosis. Similar models were also used for examining patient characteristics and cancer staging, and finally patient characteristics and treatment modalities. The null model containing a particular cancer attribute only (e.g type of cancer diagnosis, staging or treatment modality) was initially run then compared to model containing the cancer attribute plus a specific patient characteristic for which association was being examined. Likelihood ratio tests (LRT) were then used to determine if the model with explanatory factor had a better fit than the null model. The p-value from

the LRT was used to determine statistical significance between the outcome and explanatory factor in the model. The quality of life issues were identified by calculating the percentage of patients giving each of the five possible Likert scale ratings. For each item the two response categories indicating the greatest impact of cancer on patient quality of life were combined. This combined proportion was used to rank all FACT G items within each domain. Based on this ranking, items that scored highly were reported as important quality of life issues. To identify patient factors (both demographic and socioeconomic) that were significantly associated with quality of life issues, bivariate ordinal logistic regressions were conducted relating each patient factor to each quality of life issue, in turn. A multivariable regression model was then run for each quality of life issue. Variable selection for the multivariable models was based on a cut off value of 0.05 for all associations examined in the bivariate analysis. All the patient factors that showed significant bivariate associations were included all at once in multivariable regressions models. Odds ratio and 95% CI were reported. Associations between quality of life issues and type of cancer and treatment modalities were also determined using a similar approach.

In addition, to identifying quality of life issues, an assessment of patient quality of life was conducted by calculating the FACT-G score based on the methods proposed by Cella and colleagues.⁵⁹ After conducting descriptive analysis of FACT-G scores using measures of locations (means) and variation (SD) the factors influencing quality of life (FACT-G score) were determined by comparing mean scores across different levels of patient factors using Analysis of Variance (ANOVA).

A deductive approach was adopted in the analysis of interview data following on the domains contained in the FACT-G tool namely physical issues, social well being, functional and emotional well being issues. The analysis was based on what the researcher understood the meaning of patient narratives to be. The stages of data analysis included a thorough reading of the entire transcription of the participant's description; identifying themes in the descriptions resulting in division of the transcription into domains; specifying significant domains in each theme; distillation of these domains to express the central meaning of all issues in the words of the participant, and final synthesis of the key issues that emerged¹⁹².

All transcripts were then given to another researcher familiar with qualitative data analysis to confirm the accuracy and appropriateness of the themes, domains and issues developed, in order to increase the validity of the findings¹⁹³. Disagreements were discussed and resolved through mutual agreement. Although 'bracketing' for instance, putting aside preconceived ideas about a phenomenon is advocated in the analysis of data deriving from phenomenological inquiry, this was not attempted in the present data. This is because it is recognized that it is difficult for researchers to avoid or put aside their own social and cultural biases, which influences their judgement when they are interpreting data.¹⁹⁷

3.11 Ethical Considerations

Approval to carry out the study was sought from the Ethics and Research committee of Kenyatta National Hospital and the University of Nairobi. After approval was given, permission was thereafter sought from the Ministry of

Education, Science and Technology and with the Medical Superintendent at each of the Institutions involved in the study.

Furthermore, an informed consent was sought from all the patients before involvement in the study (Appendix IV). Assurance for privacy and confidentiality of the data gathered was given.

The researcher or a research assistant not directly involved in patient care, individually approached each patient. After explanations about the study objectives, the patients' participation was sought. Patients were guaranteed confidentiality of their responses (Appendix IV). Also, the research assistants had no oncology background and no previous experience working with gynaecological or breast cancer patients. This reduced the possibility of the interviewer's preconceived ideas influencing the results. However, the researcher / research assistant used probing questions and asked for clarifications on issues that were not clear.

For those patients who would benefit from other services for instance, hospice services; arrangements for referral to hospice care were made following the established referral system of the institution. The patients were advised to attend hospice care if they were willing after being given information on available hospice services.

CHAPTER 4

SOCIODEMOGRAPHIC FACTORS AND CANCER

The study targeted to recruit 384 patients with gynaecological and breast cancer but 394 patients were actually recruited. The distribution of the patients across the five study sites was as follows: Nairobi (75.1%), Mombasa (9.1%), Eldoret (7.6%), Nakuru (4.6%) and Kisumu (3.6%). The analysis of the characteristics of these patients presented in this chapter showed the following:

4.1 Demographic factors

Patient age

The average age (SD) of patients was 48.6 years (SD 12.7), with a range from 18 to 86 years. Most patients 115 (29.2%) were aged 45-54 years and 102 (25.9%) were aged 35-44 years (Table 4.1).

Table 4.1: Age distribution of female patients with breast and gynaecological cancer

Age group	Frequency	(%)
18-24 years	9	2.3
25-34 years	40	10.2
35-44 years	102	25.9
45-54 years	115	29.2
55-64 years	75	19.0
65-74 years	36	9.1
75 years and above	14	3.6
Not stated	3	0.76
Total	394	100

Marital status

Figure 4.1 shows that 66.2% of patients presenting with breast and gynaecological cancer were married. Fifty-eight (14.7%) patients were widowed and the remaining were either single (11.9%) or divorced (6.1%).

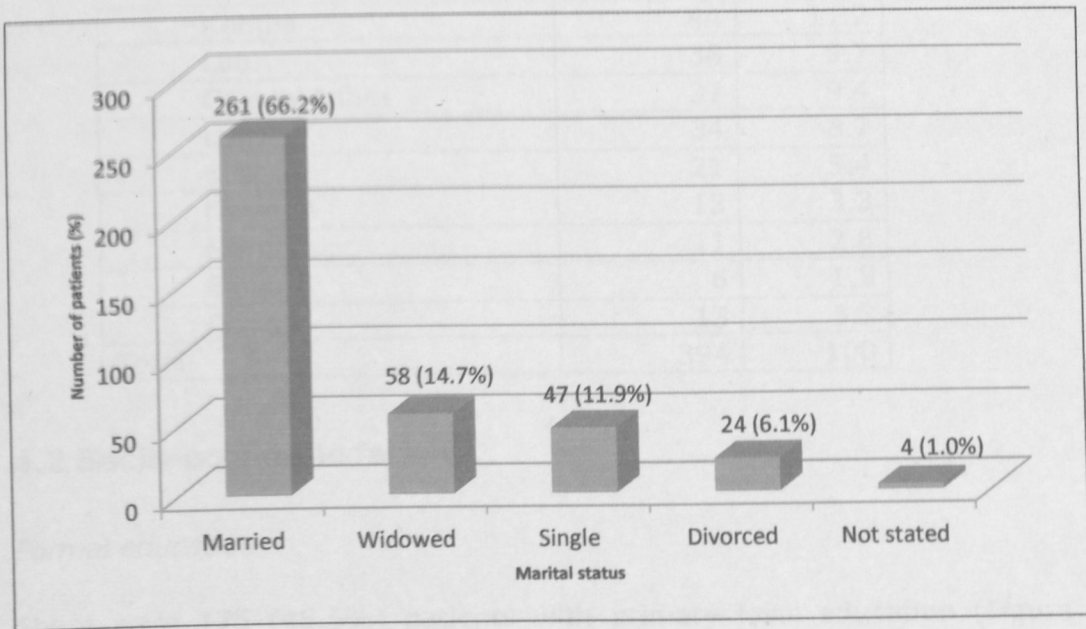


Figure 4.1: Marital status of patients with breast and gynaecological cancer

Religion

Ninety three percent of the patients were Christians while Muslims and others accounted for the rest.

Tribe

One hundred and seventy-five (44.6%) patients were Kikuyus (Table 4.2). The other tribes accounting for significant patient numbers were Kamba 44 (11.2%), Luo 38 (9.7%), Coastal tribes 37 (9.4%) and Luhya 34 (8.7%).

Table 4.2: Distribution of breast and gynaecologic cancer patients according to tribe

Patient's tribe	Frequency	(%)
Kikuyu	175	44.6
Kamba	44	11.2
Luo	38	9.7
Coastal tribes	37	9.4
Luhya	34	8.7
Kisii	21	5.4
Kalenjin	13	3.3
Meru	11	2.8
Embu	6	1.5
Others	13	3.3
Total	394	100

4.2 Socio-economic factors

Formal education

There were 175 (45.5%) patients with primary level education (Figure 4.2). Twenty-seven percent of patients reported not having attended any formal education and 20.7% had attained secondary level education.

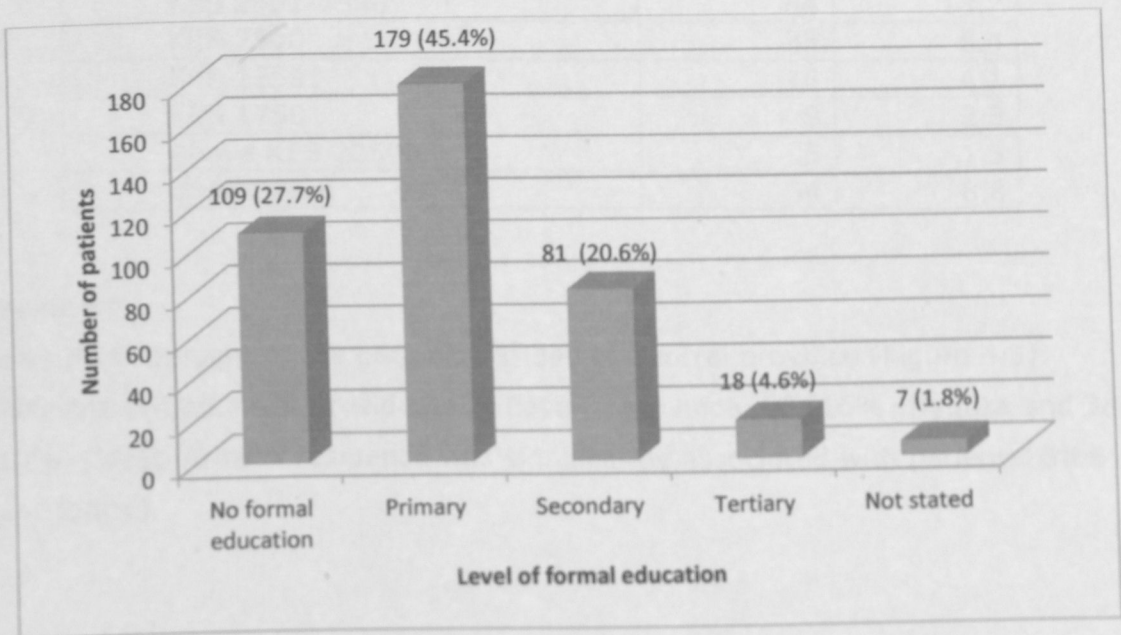


Figure 4.2: Formal education attainment by breast and gynaecologic cancer patients

Occupation and income

Most patients reported engaging in some occupational activity with the most common activities being either small scale farming 134 (34%) or household chores performed by housewives 130 (33%), Table 4.3. Only 34 (8.6%) of patients were employed in professional jobs. Household incomes varied from patients reporting no regular income to those earning over KES 22500 per month. Most patients 251 (63.7%), however reported monthly incomes less than KES 2500.

Table 4.3: Occupations of breast and gynaecologic cancer patients

Occupation	Frequency	(%)
Small scale farmer	134	34.0
Housewife	130	33.0
Small scale business	44	11.1
Professional	34	8.6
Skilled employment	9	2.3
Other	13	3.3
Not stated	30	7.6
Monthly income		
Less than KES 2500	251	63.7
KES 2501-7500	54	13.7
KES 7500	25	6.4
KES 12501	16	4.1
KES 17501	9	2.3
Above KES 22500	5	1.3
Undisclosed	34	8.6

Residence

Forty three percent of the patients resided in Central province (Figure 4.3). Sixty-two patients were residents of Eastern province, 58 (15%) Nyanza and 38 (10%) Coast. Area of residence was significantly associated with patients' tribe ($p < 0.001$).

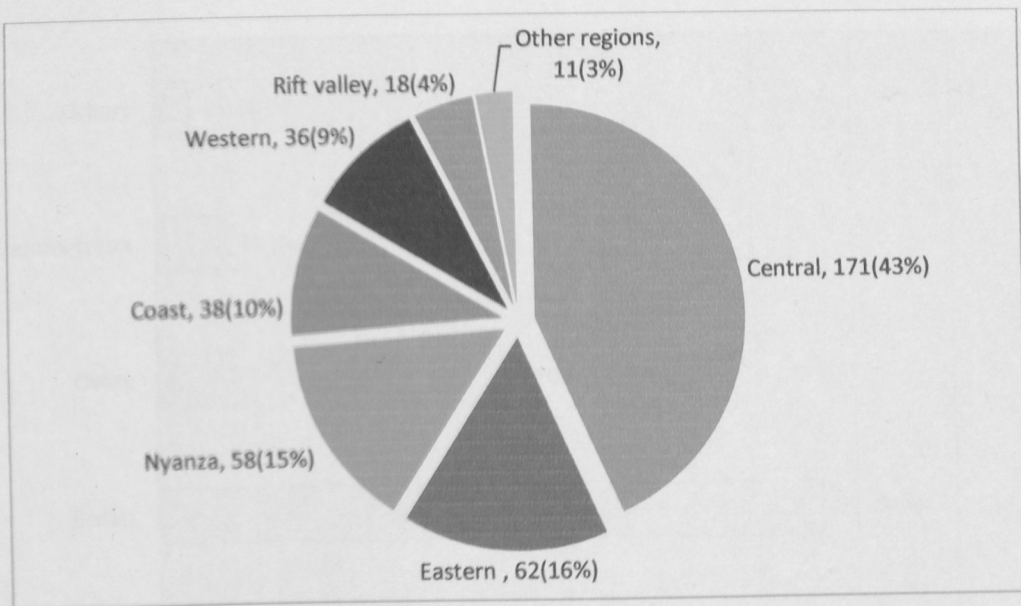


Figure 4.3: Residence of patients participating in study

4.3 Cancer diagnosis

Five main types of cancers namely, cancer of the cervix, breast, ovary, endometrium and other gynaecologic cancers were diagnosed among patients in this study (Figure 4.4). The most common types of cancer were cancer of the cervix and breast cancer diagnosed in 170 (43.2%) and 133 (33.8%) patients, respectively.

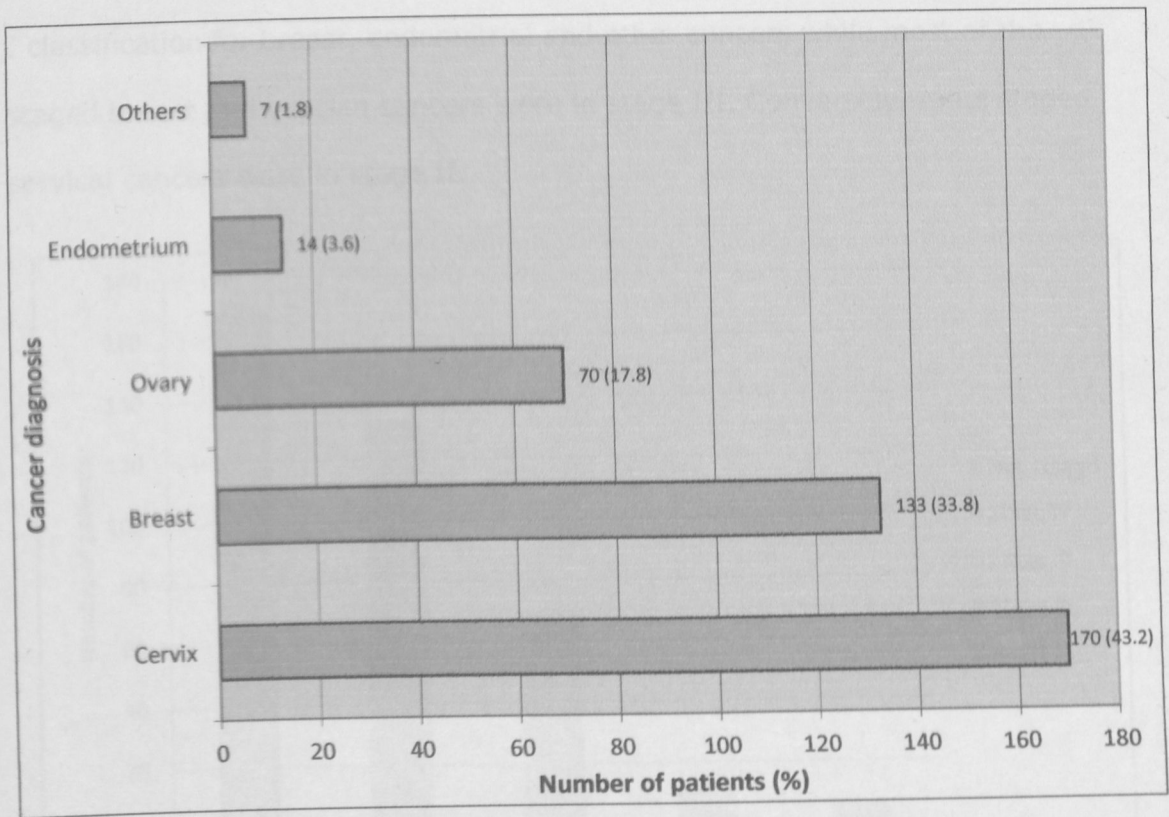


Figure 4.4: Cancer diagnoses among breast and gynaecologic cancer patients

4.4 Clinical staging

Most (44.7%) cancers diagnosed in the study were not staged (Table 4.4).

Among the cancer diagnoses with a clinical staging, the most frequently reported staging was stage III, 82 (20.8%).

Table 4.4: Clinical staging of breast and gynaecologic cancers

Clinical staging of cancer	Frequency	(%)
I	16	4.1
II	63	16.0
III	82	20.8
IV	57	14.5
Not staged	176	44.7
Total	394	100

There was a statistically significant association between type of cancer and clinical staging (LRT p value = 0.003). Figure 4.5 shows that there was no stage

I classification for breast, endometrial and other cancers while most of the staged breast and ovarian cancers were in stage III. Conversely, most staged cervical cancers were in stage II.

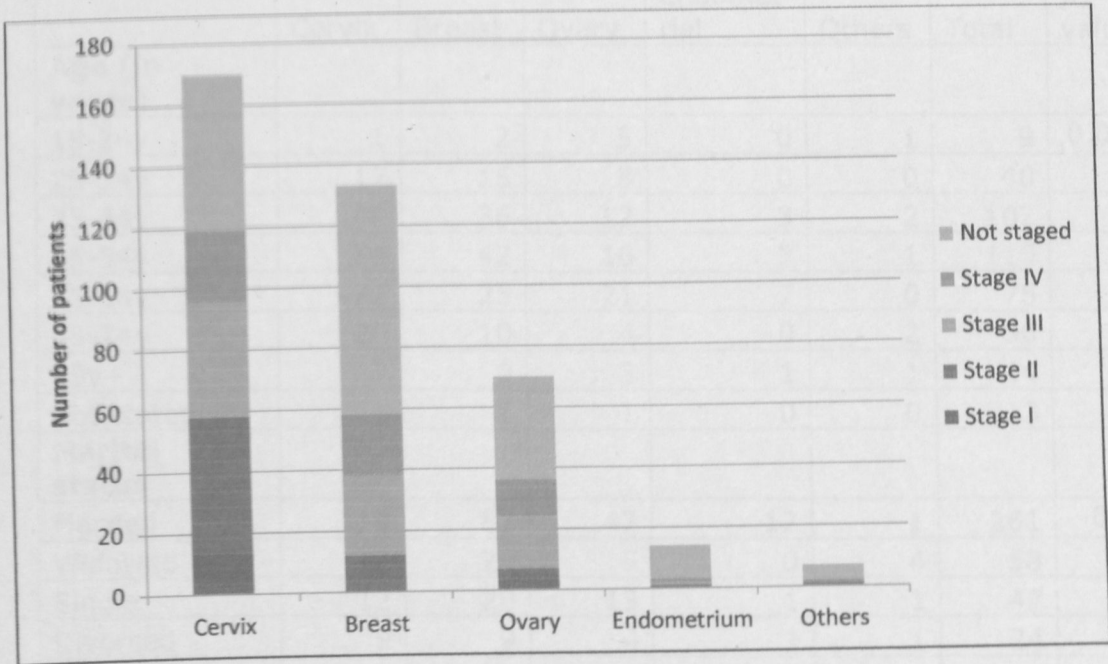


Figure 4.5: Clinical staging of cancer according to cancer diagnosis

4.5 Cancer diagnosis versus patient characteristics

There was a statistically significant association between cancer diagnosis and both patient age (LRT p value = 0.004) and marital status (LRT p value = 0.03) but not with religion (LRT p value = 0.27), Table 4.5.

Cancer of the cervix was the predominant diagnosis between 25 and 54 years. Similarly, cancer of the cervix was the main diagnosis in married women but it had a similar prevalence to breast cancer in single and widowed patients.

Table 4.5: Distribution of cancer diagnoses according to patient age, marital status and religion

	Type of cancer					Total	LR test p value
	Cervix	Breast	Ovary	Endometrial	Others		
Age (in years)							
18-24y	1	2	5	0	1	9	0.004
25-34y	17	15	8	0	0	40	
35-44y	49	36	12	3	2	102	
45-54y	53	42	16	3	1	115	
55-64y	22	25	21	7	0	75	
65-74y	20	10	4	0	2	36	
75y+	7	2	3	1	1	14	
Not stated	1	1	1	0	0	3	
Marital status							
Married	119	82	47	12	1	261	0.03
Widowed	29	20	5	0	4	58	
Single	12	20	13	1	1	47	
Divorced	9	9	4	1	1	24	
Not stated	1	2	1	0	0	4	
Religion							
Protestant	113	96	50	13	6	278	0.27
Catholic	39	33	16	1	1	90	
Muslim	16	3	3	0	0	22	
Other	2	1	1	0	0	4	

4.5.1 Patient age and cancer diagnosis

As shown in table 4.6, the relative risk for cancer of the ovary compared to cancer of the cervix was 10.6 higher for patients aged 18-24 years relative to patients 25-34 years.

Table 4.6: Multinomial logistic regression of cancer diagnosis and patient age

Age group	Type of cancer			
	Breast RRR(95% CI)	Ovary RRR(95% CI)	Endometrial RRR(95% CI)	Other RRR(95% CI)
18-24 years	2.3(0.2- 27.6)	10.6(1.1- 106.6)*	***	***
25-34 years	Ref	Ref	Ref	Ref
35-44 years	0.8(0.4-1.9)	0.5(0.2-1.5)	***	***
45-54 years	0.9(0.4-2)	0.6(0.2-1.8)	***	***
55-64 years	1.3(0.5-3.2)	2(0.7-5.7)	***	***
65-74 years	0.6(0.2-1.6)	0.4(0.1-1.7)	***	***
75 years+	0.3(0.1-1.8)	0.9(0.2-4.5)	***	***
Not stated	1.1(0.1- 19.7)	2.1(0.1-38.5)	***	***
N	133	70	14	7

Note: Reference category for multinomial regression equation is cancer of the cervix (*p <0.05, *** Not determined)

4.5.2 Marital status and cancer diagnosis

The relative risk of breast cancer over cancer of the cervix was 2.4 for single patients relative to married patients (Table 4.7). Single patients had similarly higher relative risks of cancer of ovary (RRR = 2.7), and the relative risk of other cancers was 16.4 for widowed compared to married patients.

Table 4.7: Multinomial logistic regression of cancer diagnosis and marital status

Marital status	Type of cancer			
	Breast RRR(95% CI)	Ovary RRR(95% CI)	Endometrial RRR(95% CI)	Other RRR(95% CI)
Married	Ref	Ref	Ref	Ref
Widowed	1(0.5-1.9)	0.5(0.2-1.2)	***	16.4(1.8- 152.4)*
Single	2.4(1.1- 5.2)*	2.7(1.2- 6.4)*	0.8(0.1-6.9)	9.9(0.6-168.8)
Divorced	1.5(0.6-3.8)	1.1(0.3-3.8)	1.1(0.1-9.5)	13.2(0.8-229.4)
Not stated	2.9(0.3- 32.5)	2.5(0.2- 41.3)	***	***
N	133	70	14	7

Note: Reference category for multinomial regression equation is cancer of the cervix (*p <0.05, *** Not determined)

4.5.3 Religion and cancer diagnosis

Overall, religion was not significantly associated with cancer diagnosis (LRT $p = 0.27$, Table 4.5), but the relative risk for breast cancer over cancer of cervix was 0.2 for Muslims compared to Christians (Table 4.8).

Table 4.8: Multinomial logistic regression of cancer diagnosis and religion

Religion	Type of cancer			
	Breast RRR(95% CI)	Ovary RRR(95% CI)	Endometrial RRR(95% CI)	Other RRR(95% CI)
Protestant	Ref	Ref	Ref	Ref
Catholic	1(0.6-1.7) 0.2(0.1-0.8)	0.9(0.5-1.8)	0.2(0-1.8)	0.5(0.1-4.1)
Muslim	*	0.4(0.1-1.5)	***	***
Other	0.6(0.1-6.6)	1.1(0.1-12.8)	***	***
N	133	70	14	7

Note: Reference category for multinomial regression equation is cancer of the cervix (* $p < 0.05$, *** Not determined)

4.5.4 Patient's tribe and cancer diagnosis

Cancers of the cervix and breast were the most common diagnosis in patients within each of the tribes. These two diagnoses occurred in at least half of patients from each tribe (Figure 4.6).

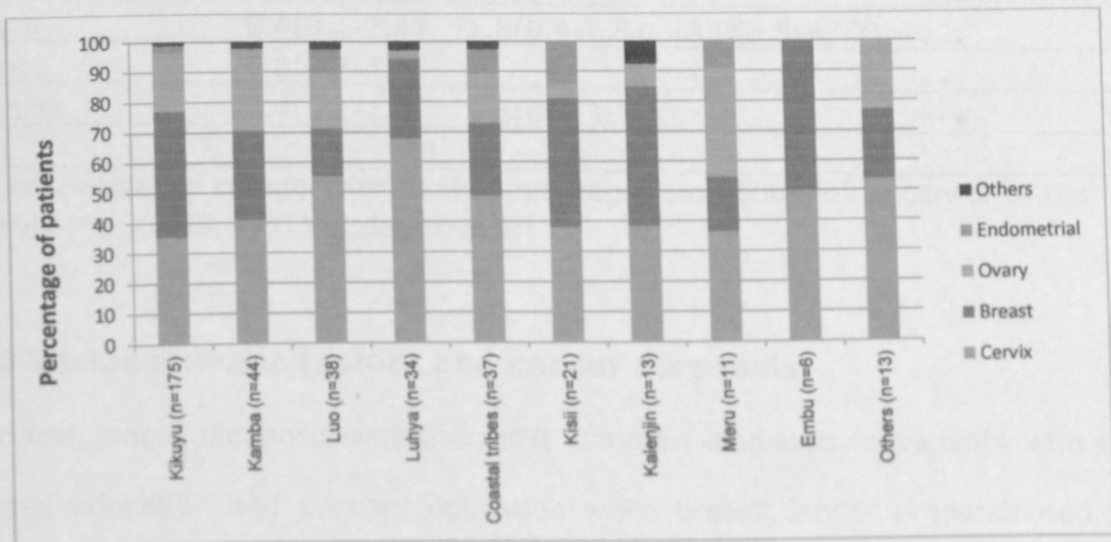


Figure 4.6: Distribution of cancer diagnosis among breast and gynaecologic cancer patients according to tribe

There was a statistically significant association between patient tribe and cancer diagnosis (LRT p value = 0.01). Table 4.9 shows that the relative risk of breast cancer over cancer of the cervix for Luo (0.2) and Luhya (0.3) patients was significantly lower relative to Kikuyu patients. Similarly, the relative risk of cancer of the ovary compared to cervix was 0.1 for Luhya patients. Compared to Kikuyu patients, Kisii patients had a significantly higher relative risk of endometrial cancer over cervical cancer (RRR = 5.8).

Table 4.9: Multinomial logistic regression of cancer diagnosis and tribe

Tribe	Type of cancer			
	Breast RRR(95% CI)	Ovary RRR(95% CI)	Endometrial RRR(95% CI)	Other RRR(95% CI)
Kikuyu	Ref	Ref	Ref	Ref
Kamba	0.6(0.3-1.4)	1.2(0.5-2.8)	***	1.7(0.1-20.1)
Luo	0.2(0.1-0.6)*	0.6(0.2-1.6)	2.2(0.5-10.7)	1.5(0.1-17.1)
Luhya	0.3(0.1-0.8)*	0.1(0-0.6)*	***	1.3(0.1-15.6)
Coastal tribes	0.4(0.2-1)	0.6(0.2-1.7)	2.6(0.5-12.6)	1.7(0.1-20.1)
Kisii	1(0.3-2.6)	0.2(0-1.9)	5.8(1.1-30.8)*	***
Kalenjin	1(0.3-3.5)	0.4(0-3.2)	***	6.2(0.5-80.8)
Meru	0.4(0.1-2.4)	1.8(0.4-7.8)	3.9(0.3-43.3)	***
Embu	0.8(0.2-4.4)	***	***	***
Others	0.4(0.1-1.5)	0.8(0.2-3.2)	***	***
N	133	70	14	7

Note: Reference category for multinomial regression equation is cancer of the cervix (*p < 0.05, *** Not determined)

4.6 Socioeconomic factors and cancer diagnosis

Cervical cancer diagnosis was the most common diagnosis in patients with no formal education and primary education while breast cancer predominated in secondary or tertiary level (LRT p = 0.005), Table 4.10. Diagnosis was also significantly associated with occupation (LRT p = 0.001) and household income

(LRT $p = 0.0001$). Cancer of the cervix dominated among farmers and housewives and in patients in the lowest income group.

Table 4.10: Distribution of cancer diagnosis according to patients' socio-economic characteristics

	Type of cancer					Total	LRT p value
	Cervix	Breast	Ovary	Endometrial	Others		
Formal education							
None	58	22	20	5	4	109	0.005
Primary	82	57	33	6	1	179	
Secondary	22	45	11	2	1	81	
Tertiary	5	7	4	1	1	18	
Unclassified	3	2	2	0	0	7	
Patient occupation							
Farmer	63	44	24	2	1	134	0.001
Housewife	67	26	30	4	3	130	
Business	14	25	3	2	0	44	
Professional	8	18	5	2	1	34	
Skilled employment	5	3	1	0	0	9	
Other	4	7	0	1	1	13	
Not stated	9	10	7	3	1	30	
Household income							
Less than 2500	124	64	50	9	4	251	0.0001
2501 -7500	13	29	8	2	2	54	
7501 - 12500	5	16	3	1	0	25	
12501 - 17500	2	11	2	1	0	16	
17501 - 22500	1	7	1	0	0	9	
Above 22500	3	1	1	0	0	5	
Undisclosed	22	5	5	1	1	34	

4.6.1 Formal education and cancer diagnosis

The relative risk of breast cancer diagnosis over cervical cancer diagnosis is 1.8 for patients with primary education relative to no formal education (Table 4.11) and 5.4 and 3.7 for patients with secondary and tertiary education relative to no formal education.

Table 4.11: Multinomial logistic regression of cancer diagnosis and formal education

Formal education	Type of cancer			
	Breast	Ovary	Endometrial	Other
	RRR(95% CI)	RRR(95% CI)	RRR(95% CI)	RRR(95% CI)
None	Ref	Ref	Ref	Ref
Primary	1.8(1-3.3)*	1.2(0.6-2.2)	0.8(0.2-2.9)	0.2(0-1.6)
Secondary	5.4(2.7-10.9)*	1.5(0.6-3.5)	1.1(0.2-5.8)	0.7(0.1-6.2)
Tertiary	3.7(1.1-12.9)*	2.3(0.6-9.5)	2.3(0.2-23.9)	2.9(0.3-31.2)
Unclassified	1.8(0.3-11.2)	1.9(0.3-12.4)	***	***
N	133	70	14	7

Note: Reference category for multinomial regression equation is cancer of the cervix (*p <0.05,*** Not determined)

4.6.2 Patient occupation and cancer diagnosis

Table 4.12 shows that the relative risk of breast cancer relative to cervical cancer was 2.6 and 3.2 for patients engaged in business and professional employment compared to farmers. Significantly higher relative risks for endometrial relative to cervical cancer (10.5) was also seen in patients who did not state their occupation compared to farmers.

Table 4.12: Multinomial logistic regression of cancer diagnosis and occupation

Occupation	Type of cancer			
	Breast	Ovary	Endometrial	Other
	RRR(95% CI)	RRR(95% CI)	RRR(95% CI)	RRR(95% CI)
Farmer	Ref	Ref	Ref	Ref
Housewife	0.6(0.3-1)	1.2(0.6-2.2)	1.9(0.3-10.6)	2.8(0.3-27.8)
Business	2.6(1.2-5.5)*	0.6(0.1-2.1)	4.5(0.6-34.7)	***
Professional	3.2(1.3-8.1)*	1.6(0.5-5.5)	7.9(1-63.9)	7.9(0.4-138.5)
Skilled employment	0.9(0.2-3.8)	0.5(0.1-4.7)	***	***
Other	2.5(0.7-9.1)	***	7.9(0.6-106.5)	15.7(0.8-300.9)
Not stated	1.6(0.6-4.2)	2(0.7-6.1)	10.5(1.5-71.7)	7(0.4-122)
N	133	70	14	7

Note: Reference category for multinomial regression equation is cancer of the cervix (*p <0.05, *** Not determined)

4.6.3 Household income and cancer diagnosis

The relative risk of breast cancer compared to cancer of cervix was 4.3, 6.2, 10.7 and 13.6 for patients with incomes of Kshs 2501 -7500, 7501 – 12500, 12501 – 17500 and 17501 – 22500, respectively, relative to patients earning less than Kshs 2500 (Table 4.13).

Table 4.13: Multinomial logistic regression of cancer diagnosis and income

	Type of cancer			
	Breast	Ovary	Endometrial	Other
Formal education	RRR(95% CI)	RRR(95% CI)	RRR(95% CI)	RRR(95% CI)
Less than 2500	Ref	Ref	Ref	Ref
2501 -7500	4.3(2.1-8.9)*	1.5(0.6-3.9)	2.1(0.4-10.9)	4.8(0.8-28.6)
7501 - 12500	6.2(2.2-17.7)*	1.5(0.3-6.5)	2.8(0.3-26.2)	***
12501 - 17500	10.7(2.3-49.5)*	2.5(0.3-18.1)	6.9(0.6-83.4)	***
17501 - 22500	13.6(1.6-112.6)*	2.5(0.2-40.4)	***	***
Above 22500	0.6(0.1-6.3)	0.8(0.1-8.1)	***	***
Undisclosed	0.4(0.2-1.2)	0.6(0.2-1.6)	0.6(0.1-5.2)	1.4(0.2-13.2)
N	133	70	14	7

Note: Reference category for multinomial regression equation is cancer of the cervix (*p <0.05, *** Not determined)

4.7 Cancer staging and patient characteristics

4.7.1 Demographic characteristics of patients in different cancer stages

The staging of cancers was significantly associated with marital status. Cancer was often not staged for single (63.8%) or divorced (54.2%) women and most of the widowed (41.4%) women had stage III or IV cancers (Table 4.14). The remaining demographic characteristic namely, age, religion and tribe did not show significant association with cancer staging.

Table 4.14: Associations between cancer staging and demographic characteristics of patients attending care in Kenyan facilities

	Cancer staging			LRT P value
	Stage I/ II	Stage III/ IV	Not staged	
	N = 79	N = 139	N = 176	
Age category				
18-24 years	1(11.1%)	2(22.2%)	6(66.7%)	0.40
25-34 years	13(32.5%)	13(32.5%)	14(35.0%)	
35-44 years	21(20.6%)	35(34.3%)	46(45.1%)	
45-54 years	24(20.9%)	35(30.4%)	56(48.7%)	
55-64 years	11(14.7%)	32(42.7%)	32(42.7%)	
65-74 years	5(13.9%)	17(47.2%)	14(38.9%)	
75 years and above	4(28.6%)	3(21.4%)	7(50.0%)	
Not stated	0(0.0%)	2(66.7%)	1(33.3%)	
Marital status				
Married	49(18.8%)	98(37.5%)	114(43.7%)	< 0.001
Widowed	15(25.9%)	24(41.4%)	19(32.8%)	
Single	5(10.6%)	12(25.5%)	30(63.8%)	
Divorced	9(37.5%)	2(8.3%)	13(54.2%)	
Not stated	1(25.0%)	3(75.0%)	0(0.0%)	
Tribe				
Kikuyu	40(22.9%)	54(30.9%)	81(46.3%)	0.53
Kamba	8(18.2%)	18(40.9%)	18(40.9%)	
Luo	7(18.4%)	9(23.7%)	22(57.9%)	
Coastal tribes	7(18.9%)	13(35.1%)	17(45.9%)	
Luhya	6(17.6%)	19(55.9%)	9(26.5%)	
Kisii	4(19.0%)	7(33.3%)	10(47.6%)	
Kalenjin	1(7.7%)	5(38.5%)	7(53.8%)	
Meru	2(18.2%)	6(54.5%)	3(27.3%)	
Embu	2(33.3%)	1(16.7%)	3(50.0%)	
Others	40(22.9%)	54(30.9%)	81(46.3%)	
Religion				
Protestant	47(16.9%)	102(36.7%)	129(46.4%)	0.17
Catholic	25(27.8%)	27(30.0%)	38(42.2%)	
Muslim	7(31.8%)	8(36.4%)	7(31.8%)	
Other	0(0.0%)	2(50.0%)	2(50.0%)	

4.7.2 Socioeconomic characteristics of patients and cancer stages

Among the four social economic factors shown in Table 4.15 namely formal education, occupation, monthly income or residence, none showed a significant association with whether a patient's disease staging was done or whether the patients had advanced stages of cancer.

Table 4.15: Associations between cancer staging and socioeconomic characteristics of patients attending care in Kenyan facilities

	Cancer staging			LRT P value
	Stage I/ II	Stage III/ IV	Not staged	
	N = 79	N = 139	N = 176	
Level of formal education				
No formal education	23(21.1%)	41(37.6%)	45(41.3%)	0.44
Primary education	41(22.9%)	58(32.4%)	80(44.7%)	
Secondary education	10(12.3%)	32(39.5%)	39(48.1%)	
Tertiary education	4(22.2%)	4(22.2%)	10(55.6%)	
Not stated	1(14.3%)	4(57.1%)	2(28.6%)	
Occupation				
Small scale farmer	32(23.9%)	50(37.3%)	52(38.8%)	0.85
Housewife	25(19.2%)	42(32.3%)	63(48.5%)	
Small scale business	8(18.2%)	16(36.4%)	20(45.5%)	
Professional	6(17.6%)	11(32.4%)	17(50.0%)	
Skilled employment	1(11.1%)	5(55.6%)	3(33.3%)	
Other	1(7.7%)	6(46.2%)	6(46.2%)	
Not stated	6(20.0%)	9(30.0%)	15(50.0%)	
Monthly income				
Less than KES 2500	56(22.3%)	83(33.1%)	112(44.6%)	0.46
KES 2501-7500	6(11.1%)	24(44.4%)	24(44.4%)	
KES 7500	5(20.0%)	11(44.0%)	9(36.0%)	
KES 12501	1(6.3%)	4(25.0%)	11(68.8%)	
KES 17501	3(33.3%)	3(33.3%)	3(33.3%)	
Above KES 22500	1(20.0%)	1(20.0%)	3(60.0%)	
Undisclosed	7(20.6%)	13(38.2%)	14(41.2%)	
Permanent residence				
Central	40(23.4%)	53(31.0%)	78(45.6%)	0.46
Eastern	12(19.4%)	25(40.3%)	25(40.3%)	
Nyanza	11(19.0%)	16(27.6%)	31(53.4%)	
Coast	7(18.4%)	13(34.2%)	18(47.4%)	
Western	6(16.7%)	19(52.8%)	11(30.6%)	
Rift valley	2(11.1%)	8(44.4%)	8(44.4%)	
Other regions	1(9.1%)	5(45.5%)	5(45.5%)	

4.8 Cancer treatment modalities

Surgery conducted in combination with either radiotherapy or chemotherapy was the most commonly (41%) employed mode of treatment for breast and gynaecological cancers in this study (Figure 4.7). A total of 126 (32%) patients were treated using surgery alone and the remaining patients were most commonly on palliative care.

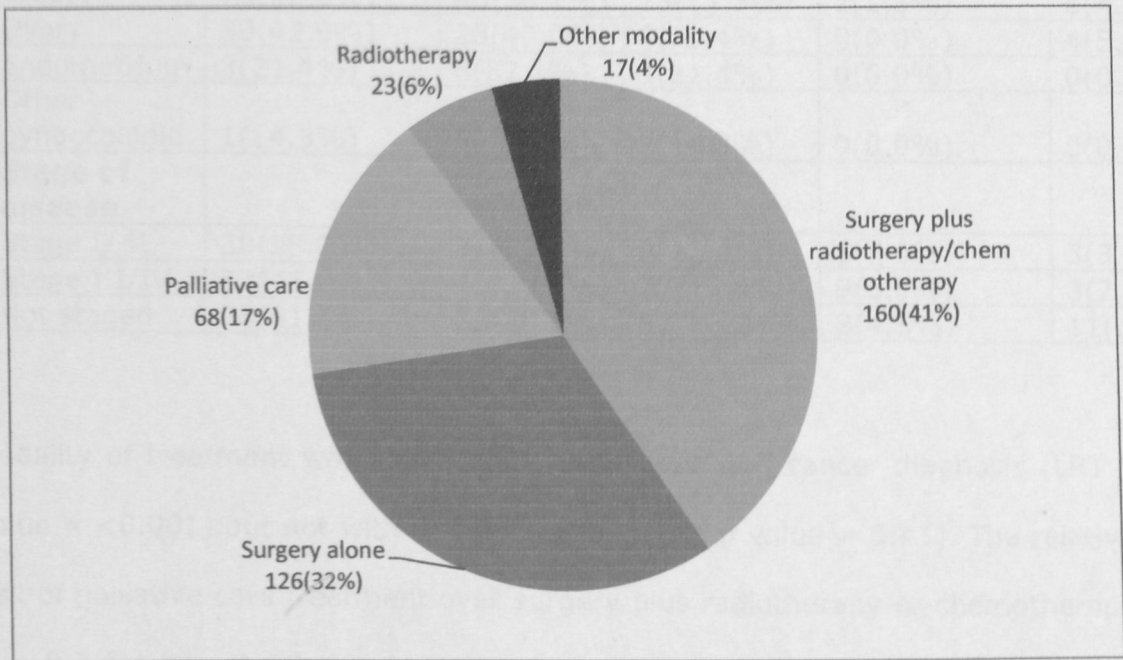


Figure 4.7: Modalities of cancer treatment used among female patients at Kenyan facilities

Treatment modality versus cancer staging and diagnosis

Table 4.16 shows the distribution of cancer treatment modalities according to cancer diagnosis and clinical staging of cancer. Endometrial cancer (57.1%) and other cancers (71.4%) were commonly managed using surgery alone. Most cases of breast cancer, and cancers of the cervix and ovary were managed using combined modalities most commonly surgery plus radiotherapy or chemotherapy.

Table 4.16: Treatment mode and illness characteristics of women with breast and gynaecologic cancers

	Treatment modality				
	Surgery plus radiotherapy/ chemotherapy	Surgery alone	Palliative care	Radiotherapy	Other modality
	N = 160	N = 126	N = 68	N = 23	N = 17
Cancer diagnosis					
Cervix	56(32.9%)	45(26.5%)	41(24.1%)	21(12.4%)	7(4.1%)
Breast	70(52.6%)	40(30.1%)	15(11.3%)	2(1.5%)	6(4.5%)
Ovary	30(42.9%)	28(40.0%)	8(11.4%)	0(0.0%)	4(5.7%)
Endometrium	3(21.4%)	8(57.1%)	3(21.4%)	0(0.0%)	0(0.0%)
Other gynaecologic	1(14.3%)	5(71.4%)	1(14.3%)	0(0.0%)	0(0.0%)
Stage of disease					
Stage I/ II	30(38.0%)	31(39.2%)	9(11.4%)	6(7.6%)	3(3.8%)
Stage III/IV	57(41.0%)	43(30.9%)	27(19.4%)	9(6.5%)	3(2.2%)
Not staged	73(41.5%)	52(29.5%)	32(18.2%)	8(4.5%)	11(6.3%)

Modality of treatment was significantly associated with cancer diagnosis (LRT p value = <0.001) but not with disease staging (LRT p value = 0.41). The relative risk of palliative care treatment over surgery plus radiotherapy or chemotherapy was 0.3 for breast relative to cervical cancer and 0.4 for cancer of the ovary relative to cancer of the cervix (Table 4.17). The relative risk of radiotherapy was 0.1 for breast relative to cervical cancer.

Table 4.17: Univariate multinomial logistic regression of treatment mode and illness characteristics of women with breast and gynaecologic cancers

	Surgery alone	Palliative care	Radiotherapy	Other modality
	N = 126	N = 68	N = 23	N = 17
Cancer diagnosis	RRR (95% CI)	RRR (95% CI)	RRR (95% CI)	RRR (95% CI)
Cervix	1.0	1.0	1.0	1.0
Breast	0.7(0.4-1.2)	0.3(0.1-0.6)*	0.1(0.01-0.3)	0.7(0.2-2.2)
Ovary	1.2(0.6-2.2)	0.4(0.2-0.9)*	*	1.1(0.3-3.9)
Endometrium	3.3(0.8-13.2)	1.4(0.3-7.1)	***	***
Other gynaecologic	6.2(0.7-55.2)	1.4(0.1-22.5)	***	***
Stage of disease				
Stage I/ II	1.0	1.0	1.0	1.0
Stage III/IV	0.7(0.4-1.4)	1.6(0.7-3.7)	0.8(0.3-2.4)	0.5(0.1-2.8)
Not staged	0.7(0.4-1.3)	1.5(0.6-3.4)	0.5(0.2-1.7)	1.5(0.4-5.8)

Note: Reference category for multinomial regression equation is surgery plus chemotherapy or radiotherapy (*p <0.05, *** Not determined)

4.9 DISCUSSION

The descriptive data presented in this chapter was intended to summarise the characteristics of a sample of Kenyan women with breast and gynaecological cancers presenting for treatment at the main cancer treatment centres in the country. The results of the analysis of patients' characteristics reveal two main findings. First, the epidemiology of female cancers in the present study agrees with existing reports of cancer epidemiology both at the national and regional levels.^{84, 85} Second, cancer diagnosis shows significant associations with several patient demographic and socio-economic characteristics. There was a particularly strong association between type of cancer diagnosis and age among other characteristics.

Concerning cancer epidemiology, the main features of women with breast and gynaecologic cancers were: an average age of 48.6 years with 50% of patients being between 35 and 54 years, most were married (66.2%), Christians (93.4%), had no (27.7%) or basic (45.4%) education and resided in Central or Eastern provinces. The mean age of presentation with breast and gynaecological cancer in other studies among Kenyan females ranged from 47 to 49.4 years. It was similar to that reported in the present study and also most patients in the previous series were also married.^{85, 198} While the data for most demographic variables were comparable to national estimates, the observation in the current study that Christians comprised 93.4% of the sample and Kikuyu tribe accounted for 44% of patients are above the estimates of the religious and ethnic distribution of the Kenyan population. This is explained by the fact that the KNH contributed the greatest proportion of participants in this study. This national referral facility is located in the capital which is predominantly inhabited by Christians and accessible to ethnic groups like the Kikuyu and Kamba who reside close to the Capital city.

In addition, the main cancers in the present study were cancer of the cervix (43.2%) and breast cancer (33.8%). These cancers are also the leading female cancers in the Nairobi cancer registry,⁸⁴ and the Eldoret cancer registry,¹⁹⁸ which are the main cancer registries in Kenya. National cancer registries maintained in other sub-saharan Africa countries including Zimbabwe, Malawi, Congo and Cote d'Ivoire report similar cancer epidemiology.¹⁹⁹⁻²⁰³

A few of the associations between patient characteristics and cancer diagnosis are noteworthy. Firstly, among the various marital status, the risk of breast and ovarian cancer compared to cervical cancer was higher in single patients relative to married patients. There are limited data comparing cancer diagnoses in

Kenyan patients by marital status, but reports from MTRH show that current marriage and particularly being in a polygamous marriage is a common trait of patients with cancer of the cervix.⁷³

In common with reports from previous studies most genital tract cancers occurred in the fifth and sixth decades. Cancer of ovary and breast were more common in 18-24 year age group, relative to 25-34 year olds. The mean age of presentation with cancer of the cervix is significantly higher compared to age for presentation with cancer of the ovary (52 years compared to 46.4 years).²⁰⁴ Cancer of the ovary and choriocarcinoma have been noted to be more prevalent in younger age groups in other African studies.²⁰⁴

There was some evidence of association between different ethnic groups and cancer types. These associations should be interpreted with caution because some ethnic groups had minimal representation as evidenced by the wide confidence intervals where significant associations were reported. Larger studies with adequate nationwide representation of different tribes are required in future. This notwithstanding, such associations could be plausibly explained by the fact that different ethnic groups inhabit different geographic areas in Kenya. Wide geographic variations in cancer epidemiology even within the same country have been reported before.²⁰⁵ In addition, the epidemiology of cancers in general and particularly genital tract cancers, has been significantly altered by HIV/AIDS which also shows wide geographic variations in Kenya.²⁰⁶

CHAPTER 5

QUALITY OF LIFE ISSUES

5.1 General QoL issues

Fourteen general issues were identified as important quality of life issues among Kenyan women with breast and gynaecologic cancer (Table 5.1). These issues were identified from among the 27 items in FACT-G tool. The four leading quality of life issues among patients were: worrying that their condition will deteriorate, lack of satisfaction with sex life, losing hope in the fight against illness and worrying about death. These issues caused concern among 93.9%, 84.1%, 83.7% and 83.1% of patients, respectively.

The other important issues reported to in more than two-thirds (66%) of patients were: lack of fulfilment in work, feeling nervous, inability to work, lack of enjoyment in things usually done for fun and discontent with quality of life (Table 5.1).

Table 5.1: Important quality of life issues among Kenyan women with breast and gynaecologic cancer

Quality of life issue	Not at all	A little bit	A little bit/Somewhat	Quite a bit	Very much	%
I worry that my condition will get worse	10(2.8)	5(1.4)	7(1.9)	16(4.4)	323(89.5)	93.9
I am satisfied with my sex life	238(79.1)	15(5.0)	13(4.3)	20(6.6)	15(5.0)	84.1
I am losing hope in the fight against my illness	12(3.3)	20(5.5)	27(7.5)	31(8.6)	271(75.1)	83.7
I worry about dying	20(5.6)	20(5.6)	21(5.8)	31(8.6)	268(74.4)	83.1
My work (include at home) is fulfilling	143(37.4)	154(40.3)	29(7.6)	35(9.2)	21(5.5)	77.7
I feel nervous	24(6.6)	27(7.5)	31(8.6)	59(16.3)	221(61.0)	77.4
I am able to work (include work at home)	128(33.3)	162(42.1)	36(9.4)	42(10.9)	17(4.4)	75.3
I am enjoying the things I usually do for fun	112(29.4)	165(43.3)	38(10.0)	32(8.4)	34(8.9)	72.7
I am content with the quality of my life right now	100(26.1)	157(41.0)	44(11.5)	45(11.8)	37(9.7)	67.1
I am able to enjoy life	80(20.9)	175(45.7)	40(10.4)	29(7.6)	59(15.4)	66.6
I feel sad	33(9.1)	43(11.9)	55(15.2)	155(42.8)	76(21.0)	63.8
I am sleeping well	70(18.2)	159(41.4)	52(13.5)	52(13.5)	51(13.3)	59.6
I am bothered by the side effects of treatment	44(11.8)	58(15.6)	80(21.5)	88(23.7)	102(27.4)	51.1
I am satisfied with how I am coping with my illness	35(9.8)	146(40.7)	58(16.2)	62(17.3)	58(16.2)	50.4

The issues presented in table 5.2 were rated as a source of quite a bit or very much concern by less than 50% of patients and thus were categorised as unimportant issues among Kenyan women with breast and other gynaecologic cancers. The patients reported that the issues that least bothered them were lack of emotional support from their families (4.0%), lack of satisfaction with family communication about illness (6.6%) and not feeling close to friends (7.0%).

Less than 15% of patients reported that they were bothered by the level of support they got from friends, not feeling close to their partner and the lack of family acceptance of illness.

Table 5.2: Quality of life issues scored low among Kenyan women with breast and gynaecologic cancer

Quality of life issue	Not at all	A little bit	A little bit/ Somewhat	Quite a bit	Very much	%
I have nausea	35(9.4)	57(15.4)	99(26.7)	94(25.3)	86(23.2)	48.5
I am forced to spend time in bed	69(18.5)	82(22.0)	58(15.6)	92(24.7)	71(19.1)	43.8
I have a lack of energy	47(12.6)	117(31.5)	72(19.4)	109(29.3)	27(7.3)	36.6
I have pain	70(18.8)	112(30.1)	82(22.0)	70(18.8)	38(10.2)	29.0
I feel ill	71(19.1)	120(32.3)	84(22.6)	60(16.2)	36(9.7)	25.9
Because of my condition, I have trouble meeting the needs of my family	105(28.5)	146(39.7)	43(11.7)	36(9.8)	38(10.3)	20.1
I have accepted my illness	29(7.6)	29(7.6)	27(7.1)	57(14.9)	240(62.8)	15.2
I get support from my friends	30(8.1)	24(6.5)	28(7.6)	55(14.8)	234(63.1)	14.6
I feel close to my partner (or the person who is my main support)	30(8.4)	7(2.0)	11(3.1)	53(14.9)	256(71.7)	10.4
My family has accepted my illness	14(3.8)	20(5.4)	32(8.7)	53(14.4)	250(67.8)	9.2
I feel close to my friends	7(1.9)	19(5.1)	23(6.2)	52(14.0)	271(72.8)	7.0
I am satisfied with family communication about my illness	11(3.0)	13(3.5)	33(9.0)	60(16.4)	249(68.0)	6.6
I get emotional support from my family	7(1.9)	8(2.2)	16(4.3)	46(12.4)	295(79.3)	4.0

5.2 Influence of domains on QoL issues

There was evidence of significant differences in patient ranking of quality of life issues across four domains namely: physical, social, emotional and functional domains ($p = 0.0034$). The average response to the six emotional well being items and seven functional domain items were significantly higher than those of

the physical and social well being domains. The social well being domain had the least influence on quality of life issues.

5.3 Influence of demographic and socioeconomic factors on QoL issues

5.3.1 Physical issues

5.3.1.1 Patient perception of physical well being

Among all the seven physical well being items, only one item namely treatment side effects was considered an important issue by more than 50% of the patients with breast and gynaecologic cancer (Figure 5.1)

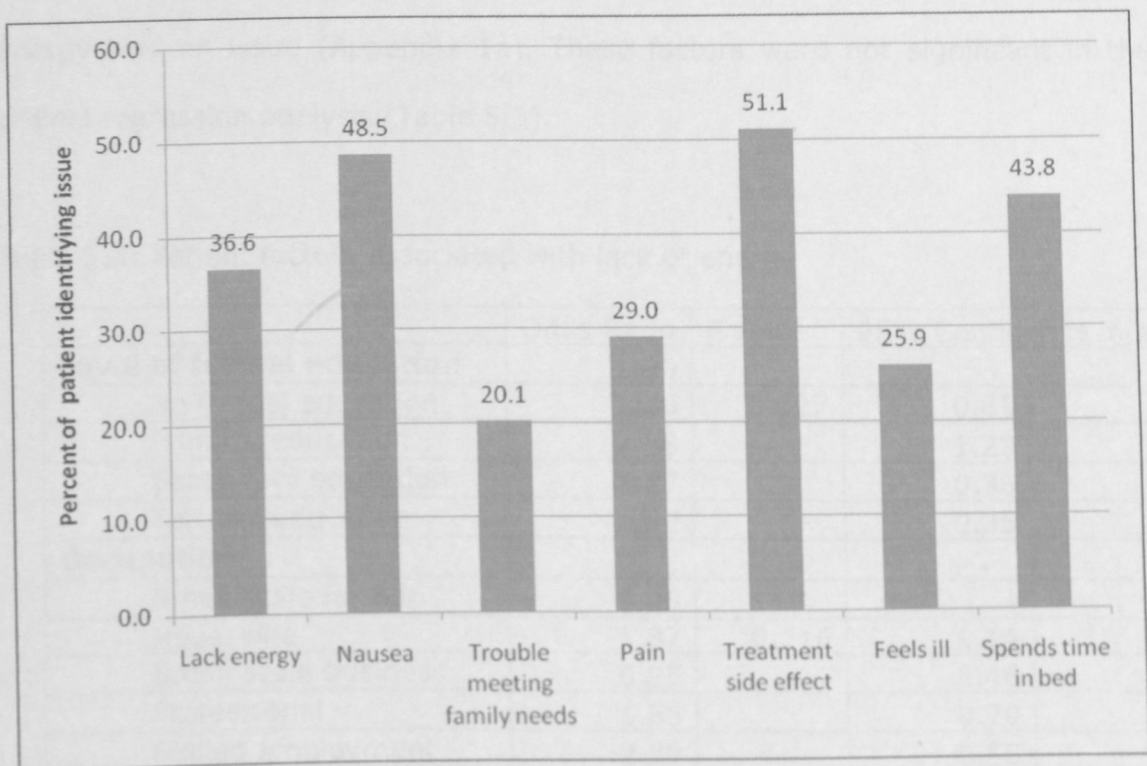


Figure 5.1: Importance of physical domain issues among Kenyan women with breast and gynaecologic cancers

5.3.1.2 Patient characteristics and physical well being

Details of the univariate analysis of each of the demographic and socioeconomic patient factor and physical well being issues are presented in Appendix 1a. Results of adjusted ordinal logistic regression between these issues and demographic and socioeconomic factors are shown in table 5.3 to 5.8.

a) I have a lack of energy

Lack of energy was significantly associated with patients level of formal education and occupation. Lack of energy was common among professionals, skilled employees and patients in "other" occupations. Patients with higher education levels namely secondary and tertiary were likely to report that lack of energy was an issue (Appendix 1a). These factors were not significant in the ordinal regression analysis (Table 5.3).

Table 5.3: Patient factors associated with lack of energy

	Odds Ratio	P value	95% Confidence interval	
Level of formal education	1.00			
No formal education	1.30	0.127	0.81	2.10
Primary education	2.38		1.23	4.61
Secondary education	1.27		0.36	4.46
Tertiary education	1.59		0.35	7.18
Occupation				
Small scale farmer	1.00			
Housewife	1.87	0.116	1.14	3.04
Small scale business	0.95		0.46	1.95
Professional	1.86		0.70	4.95
Skilled employment	2.28		0.55	9.52
Other	2.77		0.82	9.43
Not stated	1.64		0.78	3.44

b) I have nausea

None of the demographic or socioeconomic factors explored were significantly associated with experiencing nausea in the univariate associations (Appendix 1a)

c) I have trouble meeting the needs of my family

Higher levels of education were associated with trouble meeting family needs in the unadjusted analysis (Appendix 1a). The patients in income category KES 17501-22500 also considered trouble meeting family needs as an issue. In the adjusted analysis this group was four times more likely to report this issue compared to patients in the lowest income category (Table 5.4). Patients in other occupations were also more likely to consider trouble meeting family needs as a quality of life issue (Table 5.4).

Table 5.4: Patient factors associated with trouble meeting family needs

	Odds Ratio	P value	[95% Conf.	Interval]
Level of formal education				
No formal education	1.00			
Primary education	1.27	0.343	0.78	2.07
Secondary education	2.01		1.02	3.97
Tertiary education	1.39		0.38	5.08
Not stated	0.79		0.18	3.51
Occupation				
Small scale farmer	1.00			
Housewife	1.01	0.040	0.62	1.66
Small scale business	0.62		0.30	1.27
Professional	1.31		0.45	3.85
Skilled employment	0.64		0.15	2.85
Other	3.15		0.88	11.25
Not stated	2.62		1.19	5.77
Monthly income				
Less than KES 2500	1.00			
KES 2501-7500	1.49	0.027	0.79	2.80
KES 7500	1.59		0.64	3.94
KES 12501	0.51		0.18	1.50
KES 17501	4.25		0.90	20.16
Above KES 22500	0.28		0.04	2.24
Undisclosed	0.50		0.22	1.13

d) I have pain

Level of education, religion and residence showed significant association with pain as a quality of life issue (Table 5.5). Pain was a significant issue in patients with high levels of formal education compared to those with no formal education. Pain was less of an issue among Catholics compared to Protestants and Muslims. Patients in Nyanza and Coast considered pain less of an issue compared to those in Central, while those in Rift valley reported pain to be a major issue.

Table 5.5: Patient factors associated with self reported pain as an issue

	Odds Ratio	P value	[95% Conf.	Interval]
Level of formal education				
No formal education	1.00			
Primary education	1.59	0.003	0.97	2.60
Secondary education	3.18		1.73	5.85
Tertiary education	3.15		1.17	8.44
Not stated	1.23		0.25	5.91
Religion				
Protestant	1.00			
Catholic	0.49	0.041	0.30	0.80
Muslim	1.08		0.40	2.95
Other	0.72		0.07	7.39
Permanent residence				
Central	1.00			
Eastern	1.53	0.0006	0.84	2.81
Nyanza	0.39		0.21	0.72
Coast	0.39		0.18	0.83
Western	0.62		0.31	1.26
Rift valley	2.38		0.90	6.32
Other regions	0.70		0.18	2.69

e) I am bothered by side effects of treatment

The patients tribe or region in which they resided, and education showed a significant association with whether they considered side effects of treatment as an issue or not. Side effects of treatment were less of a concern among patients

with secondary or tertiary education (Table 5.6). Patients in Central province were less likely to reported side effects of treatment as a major issue compared to patients in the other regions.

Table 5.6: Patient factors associated with side effects of treatment as an issue in cancer

	Odds Ratio	P value	[95% Conf.	Interval]
Level of formal education				
No formal education	1.00			
Primary education	1.53	0.015	0.91	2.58
Secondary education	0.71		0.35	1.45
Tertiary education	0.22		0.06	0.80
Not stated	1.18		0.24	5.82
Occupation				
Small scale farmer	1.00			
Housewife	1.05	0.407	0.62	1.78
Small scale business	0.68		0.33	1.43
Professional	0.66		0.21	2.07
Skilled employment	3.50		0.62	19.85
Other	0.82		0.24	2.81
Not stated	0.57		0.25	1.29
Permanent residence				
Central	1.00			
Eastern	1.55	0.0002	0.83	2.88
Nyanza	2.96		1.49	5.89
Coast	3.09		1.39	6.84
Western	3.44		1.51	7.81
Rift valley	1.81		0.68	4.86
Other regions	0.27		0.07	0.98
Monthly income				
Less than KES 2500	1.00			
KES 2501-7500	0.76	0.557	0.40	1.46
KES 7500	1.05		0.41	2.72
KES 12501	1.48		0.45	4.89
KES 17501	0.65		0.12	3.51
Above KES 22500	0.42		0.06	3.04
Undisclosed	1.98		0.81	4.84

f) I feel ill

The younger patient age groups (below 34 years) considered feeling ill to be a major issue and the association between age and feeling ill was significant in the univariate analysis (Appendix 1a). In the adjusted analysis only region was significantly associated with feeling ill with patients in the Rift valley being thrice more likely to report feeling ill as an issue compared to those in Central (Table 5.7).

Table 5.7: Patient factors associated with reports of feeling ill as an issue in cancer

	Odds Ratio	P value	[95% Conf. Interval]	
Age category				
18-24 years	1.00			
25-34 years	0.83	0.053	0.18	3.70
35-44 years	0.44		0.11	1.84
45-54 years	0.24		0.06	1.01
55-64 years	0.44		0.10	1.96
65-74 years	0.46		0.09	2.29
75 years and above	0.39		0.07	2.27
Not stated	0.29		0.01	7.99
Level of formal education				
No formal education	1.00			
Primary education	1.71	0.052	1.00	2.94
Secondary education	2.27		1.14	4.53
Tertiary education	3.92		1.31	11.69
Not stated	0.84		0.18	4.00
Marital status				
Married				
Widowed	0.61	0.068	0.33	1.13
Single	0.71		0.36	1.43
Divorced	0.40		0.16	0.99
Not stated	0.10		0.01	1.31
Permanent residence				
Central	1.00			
Eastern	1.01	0.0016	0.55	1.86
Nyanza	0.35		0.18	0.66
Coast	0.62		0.30	1.27
Western	0.55		0.26	1.16
Rift valley	3.60		1.29	10.01
Other regions	0.71		0.19	2.68

g) I am forced to spend time in bed

Higher levels of formal education and tribe (Luhya or Coastal) were associated patient perception of time spent in bed as an issue among Kenyan women with breast and Gynaecologic cancers (Appendix 1a). Table 5.8 shows that in the adjusted regression model perception of this issue as an important issue increased with higher levels of formal education and was also high in Central province compared to other regions.

Table 5.8: Patient factors associated with time spent in bed as an issue in cancer

	Odds Ratio	P value	[95% Conf.	Interval]
Level of formal education				
No formal education	1.00			
Primary education	1.65	0.03	0.041	2.63
Secondary education	2.44	0.00		4.44
Tertiary education	1.56	0.38		4.21
Not stated	3.34	0.18		19.21
Permanent residence				
Central	1.00			
Eastern	0.71	0.23	0.012	1.25
Nyanza	0.43	0.01		0.77
Coast	0.34	0.00		0.66
Western	0.52	0.07		1.06
Rift valley	0.49	0.16		1.32
Other regions	0.38	0.13		1.33

5.3.2 Emotional issues

5.3.2.1 Patient perception of emotional well being

The emotional well being domain made an important contribution to the quality of life issues reported among Kenyan women with cancer. Each of the items in this domain was reported to cause concern in at least 50% of all patients (Figure 5.2).

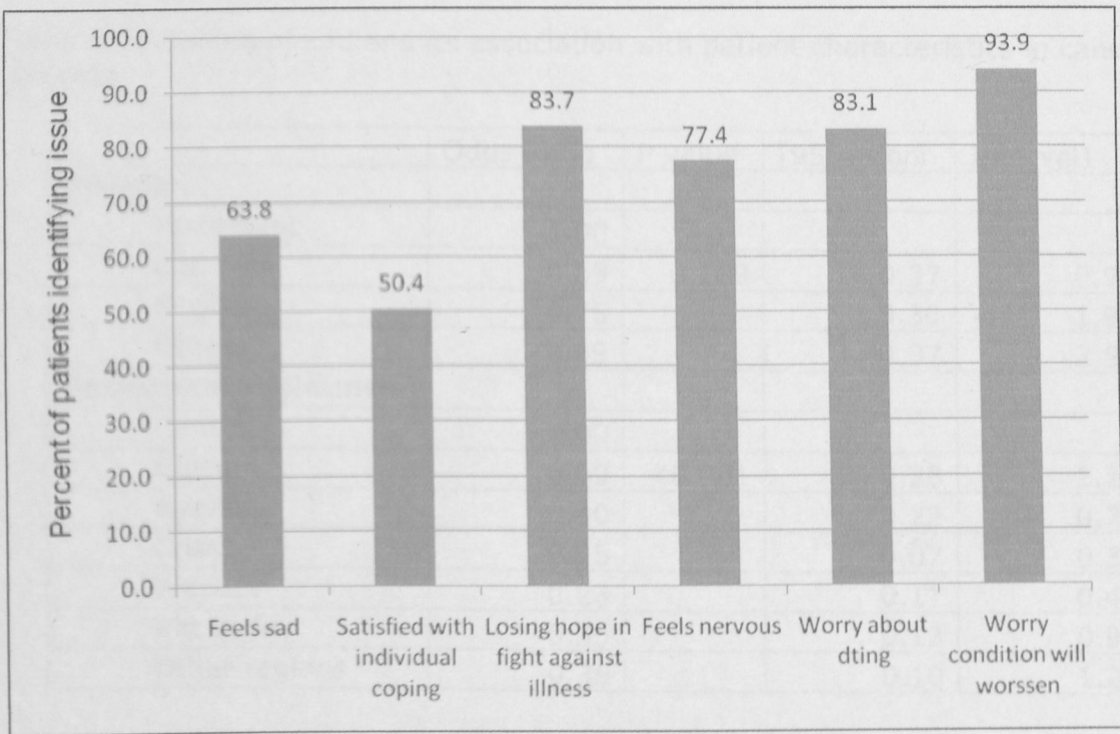


Figure 5.2: Importance of emotional domain issues among Kenyan women with breast and other gynaecologic cancers

5.3.2.2 Patient characteristics and emotional well being

Details of the univariate analysis of each of the demographic and socioeconomic patient factors and emotional well being issues are presented in Appendix 1c. Results of adjusted ordinal logistic regression between these issues and demographic and socioeconomic factors are shown in tables 5.9- 5.13.

a) I feel sad

Most patient factors did not show significant association with patient report of sadness as most patients in all groups reported feeling sad (Appendix 1a). However, residence was significantly associated with feeling sad with patients in Central being likely to feel sad compared to other provinces (Table 5.9).

Table 5.9: Feeling of sad and its association with patient characteristics in cancer patients

	Odds Ratio	P value	[95% Conf.	Interval]
Religion				
Protestant	1.00			
Catholic	0.59	0.159	0.37	0.95
Muslim	0.75		0.30	1.90
Other	0.49		0.07	3.51
Permanent residence				
Central	1.00			
Eastern	0.69	<0.001	0.38	1.26
Nyanza	0.40		0.22	0.74
Coast	0.15		0.07	0.30
Western	0.23		0.11	0.47
Rift valley	0.35		0.13	0.93
Other regions	0.35		0.10	1.27

b) I am satisfied with how I am coping with my illness

Individual satisfaction with coping with cancer was a major issue among small scale farmers, housewives and patients in other occupations(Appendix 1c) This was also considered a significant issue among patients with incomes between KES 17501 and KES 22500 (Table 5.10).

Table 5.10: Individual satisfaction with coping with illness and its association with patient characteristics in cancer patients

	Odds Ratio	P value	[95% Conf.	Interval]
Level of formal education				
No formal education	1.00			
Primary education	0.87	0.275	0.54	1.41
Secondary education	1.58		0.82	3.08
Tertiary education	0.95		0.29	3.08
Not stated	2.01		0.46	8.73
Occupation				
Small scale farmer	1.00			
Housewife	0.55	0.007	0.33	0.90
Small scale business	1.00		0.50	2.01
Professional	1.21		0.46	3.20
Skilled employment	2.62		0.77	8.93
Other	1.71		0.55	5.28
Not stated	0.30		0.13	0.69
Monthly income				
Less than KES 2500	1.00			
KES 2501-7500	1.84	0.065	1.01	3.37
KES 7500	0.59		0.24	1.42
KES 12501	1.40		0.49	4.01
KES 17501	1.63		0.41	6.54
Above KES 22500	1.39		0.21	9.12
Undisclosed	2.26		1.11	4.61

c) I am losing hope in the fight against my illness

Patients commonly reported that they were losing hope in their fight against cancer (Appendix 1c). Among the patient factors considered only residence showed a statistically significant association with responses to this issue. Patients in Coast province were least likely to report that they were losing hope in their fight against cancer (Table 5.11)

Table 5.11: Losing hope in the fight against cancer and its association with patients' residences

	Odds Ratio	P value	[95% Conf.	Interval]
Permanent residence				
Central				
Eastern	1.76	0.012	0.63	4.90
Nyanza	1.62		0.58	4.53
Coast	0.28		0.13	0.62
Western	0.73		0.28	1.85
Rift valley	0.84		0.22	3.14
Other regions	0.73		0.15	3.60

d) I feel nervous

Religion and residence were significantly associated with feeling of nervousness in the univariate analysis in Appendix 1c. Muslims were least likely to report feeling nervous compared to Protestants and Catholics. Similarly, patients in Coast province and Rift Valley did not consider nervousness to be a major quality of life issue (Table 5.12).

Table 5.12: Patient characteristics and association with nervousness in female cancer patients

	Odds Ratio	P value	[95% Conf.	Interval]
Religion				
Protestant	1.00			
Catholic	0.72	0.354	0.43	1.23
Muslim	0.50		0.19	1.30
Other	0.56		0.07	4.68
Permanent residence				
Central	1.00			
Eastern	0.99	<0.001	0.50	1.96
Nyanza	0.49		0.24	0.98
Coast	0.16		0.07	0.33
Western	0.32		0.15	0.69
Rift valley	0.23		0.08	0.63
Other regions	0.51		0.12	2.15

e) I worry about dying

Patients responses on worry about dying was significantly associated with their residence ($p < 0.001$), table 5.13. Patients in Coast province were least likely to report being worried about dying, followed by Western and Rift valley provinces.

Table 5.13: Female cancer patient self reported worry about death and its association with patient characteristics

	Odds Ratio	P value	[95% Conf.	Interval]
Religion				
Protestant	1.00			
Catholic	0.65	0.387	0.37	1.14
Muslim	0.61		0.21	1.72
Other	0.48		0.05	4.33
Permanent residence				
Central	1.00			
Eastern	0.91	<0.001	0.44	1.88
Nyanza	0.94		0.44	2.00
Coast	0.16		0.07	0.35
Western	0.19		0.09	0.43
Rift valley	0.51		0.16	1.62
Other regions	0.63		0.13	2.96

f) I worry that my condition will get worse

Most female cancer patients were worried that their condition will get worse. There were, however, no significant associations between patient characteristics and self reported worry that the condition will get worse (Appendix 1b)

5.3.3 Social issues

5.3.3.1 Patient perception of social well being

In the social domain, only one issue – satisfaction with sexual life, was reported to be important by at least 50% of the patients (Figure 5.3).

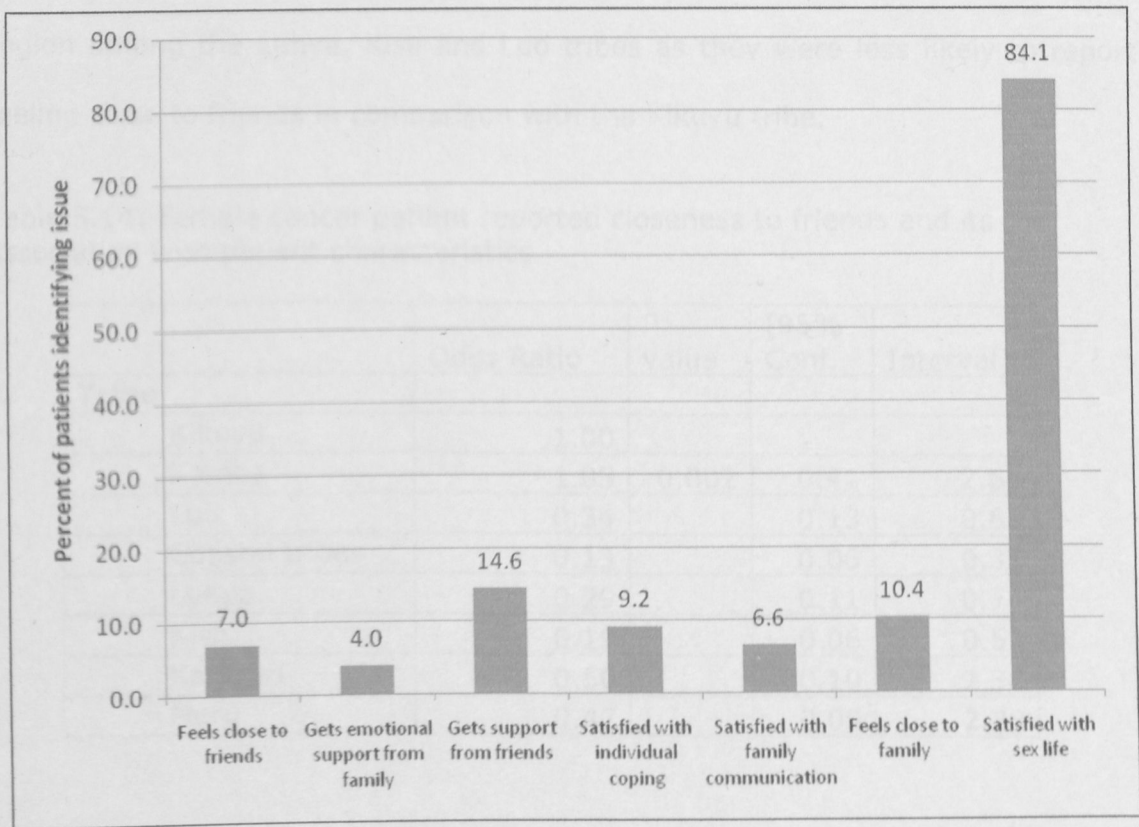


Figure 5.3: Importance of social domain issues among Kenyan women with breast and other gynaecologic cancers

5.3.3.2 Patient characteristics and social well being

Details of the univariate analysis of each of the demographic and socioeconomic patient factors and social well being issues are presented in Appendix 1c. Results of adjusted ordinal logistic regression between these issues and demographic and socioeconomic factors are shown in tables 5.14 – 5.19.

a) I feel close to my friends

Most patients felt close to their friend and this feeling was not influenced by most of the demographic or socioeconomic characteristic (Appendix 1b). Table 5.14 shows a significant association between patient's tribe and feeling close to friends with this being more of an issue among the Coastal tribes and in Western

region among the Luhya, Kisii and Luo tribes as they were less likely to report feeling close to friends in comparison with the Kikuyu tribe.

Table 5.14: Female cancer patient reported closeness to friends and its association with patient characteristics

	Odds Ratio	P value	[95% Conf.	Interval]
Tribe				
Kikuyu	1.00			
Kamba	1.05	0.002	0.41	2.68
Luo	0.34		0.13	0.88
Coastal tribes	0.13		0.06	0.32
Luhya	0.29		0.11	0.74
Kisii	0.19		0.06	0.57
Kalenjin	0.50		0.10	2.38
Meru	0.47		0.09	2.38

b) I get emotional support from my family

Appendix 1b shows that none of the patient demographic or socioeconomic characteristics examined in this study was significantly associated with patient perception of the level of emotional support they received from family.

c) I get support from my friends

The level of support provided to patients by friends was not an important issue but it showed a significant association with income and tribe (Table 5.15). Kisii, Luo, Luhya and Coastal patients reported receiving less support compared to the Kikuyu tribe and level of support from friends (in families) generally increased with increasing incomes.

Table 5.15: Female cancer patient self reported of levels of emotional support from family and its association with patient characteristics

	Odds Ratio	P value	[95% Conf.	Interval]
Monthly income				
Less than KES 2500	1.00			
KES 2501-7500	1.02	0.023	0.51	2.07
KES 7500	0.23		0.10	0.56
KES 12501	1.12		0.37	3.41
KES 17501	0.63		0.13	3.12
Above KES 22500	1.01		0.14	7.02
Undisclosed	0.41		0.18	0.91
Tribe				
Kikuyu	1.00			
Kamba	0.96	0.006	0.43	2.14
Luo	0.26		0.12	0.59
Coastal tribes	0.33		0.15	0.74
Luhya	0.33		0.15	0.75
Kisii	0.29		0.11	0.80
Kalenjin	0.59		0.16	2.15
Meru	1.83		0.43	7.68
Embu	1.76		0.27	11.56
Others	0.35		0.10	1.15

d) My family has accepted my illness

Most families had accepted patient's illness hence this was not an important emotional issue (Appendix 1b). The level of acceptance was however, lower in Rift valley and Coast, Western and Nyanza regions (Table 5.16).

Table 5.16: Family acceptance of illness and its association with cancer patient characteristics

	Odds Ratio	P value	[95% Conf.	Interval]
Permanent residence				
Central				
Eastern	1.03	0.001	0.38	2.74
Nyanza	0.42		0.18	0.94
Coast	0.19		0.08	0.42
Western	0.40		0.16	1.02
Rift valley	0.25		0.08	0.74
Other regions	0.35		0.09	1.40

e) I am satisfied with family communication about my illness

Patients were likely to report that they were satisfied with family communication about their illness and this was not influenced by their demographic or socioeconomic characteristics (Appendix 1b). Patient residence however influences their perception of family communication as shown in Table 5.17.

Table 5.17: Influence of patient residence on their perception on family communication about their illness

	Odds Ratio	P value	[95% Conf.	Interval]
Permanent residence				
Central	1.00			
Eastern	1.16	0.003	0.36	3.73
Nyanza	0.33		0.14	0.79
Coast	0.21		0.09	0.50
Western	0.19		0.08	0.47
Rift valley	0.17		0.05	0.53
Other regions				

f) I feel close to my partner

The tribe of patients was associated with their perception of closeness to partners as an issue among cancer patients (Table 5.18). Embu and Coastal patients reported that feeling close to partners was a major issue while this was not the case among patients in other tribes.

Table 5.18: Female cancer patient characteristics and association with feeling close to partners

	Odds Ratio	P value	[95% Conf.	Interval]
Tribe				
Kikuyu				
Kamba	1.75	0.007	0.77	3.97
Luo	0.46		0.19	1.14
Coastal tribes	0.25		0.10	0.62
Luhya	1.09		0.43	2.77
Kisii	0.95		0.28	3.17
Kalenjin	1.41		0.34	5.88
Meru	0.54		0.12	2.38
Embu	0.10		0.02	0.61
Others	0.23		0.06	0.86
Marital status				
Married				
Widowed	0.76	0.803	0.36	1.60
Single	0.68		0.30	1.57
Divorced	0.87		0.30	2.50
Not stated	0.35		0.03	4.77
Occupation				
Small scale farmer				
Housewife	1.58	0.061	0.85	2.93
Small scale business	0.71		0.30	1.68
Professional	1.34		0.51	3.52
Skilled employment	0.13		0.03	0.62
Other	0.76		0.18	3.12
Not stated	0.90		0.32	2.54

g) I am satisfied with my sex life

Satisfaction with sex life was a major issue among cancer patients in the study (Appendix 1b). The satisfaction with sex life was influenced by occupation, income and residence (Table 5.19).

Table 5.19: Patient satisfaction with sex life and association with patient characteristics

	Odds Ratio	P value	[95% Conf.	Interval]
Monthly income				
Less than KES 2500				
KES 2501-7500	3.43	0.0006	1.88	6.27
KES 7500	2.45		1.02	5.89
KES 12501	1.69		0.57	5.04
KES 17501	3.31		0.79	13.93
Above KES 22500	3.83		0.62	23.46
Undisclosed	3.46		1.67	7.17
Permanent residence				
Central				
Eastern	0.85	0.0008	0.45	1.58
Nyanza	0.91		0.48	1.70
Coast	1.04		0.47	2.27
Western	0.47		0.20	1.08
Rift valley	5.35		2.06	13.87
Other regions	0.99		0.30	3.25
Occupation				
Small scale farmer				
Housewife	0.54	0.037	0.32	0.92
Small scale business	0.40		0.19	0.83
Professional	1.00		0.39	2.60
Skilled employment	0.24		0.04	1.24
Other	1.09		0.36	3.30
Not stated	0.42		0.17	1.05

5.3.4 Functional issues

5.3.4.1 Patient perception of functional well being

Only 15.2% of patients reported that failure to accept their illness was major functional issue. More than half of the patients identified each of the remaining six functional well being issues as major quality of life issues (Figure 5.4).

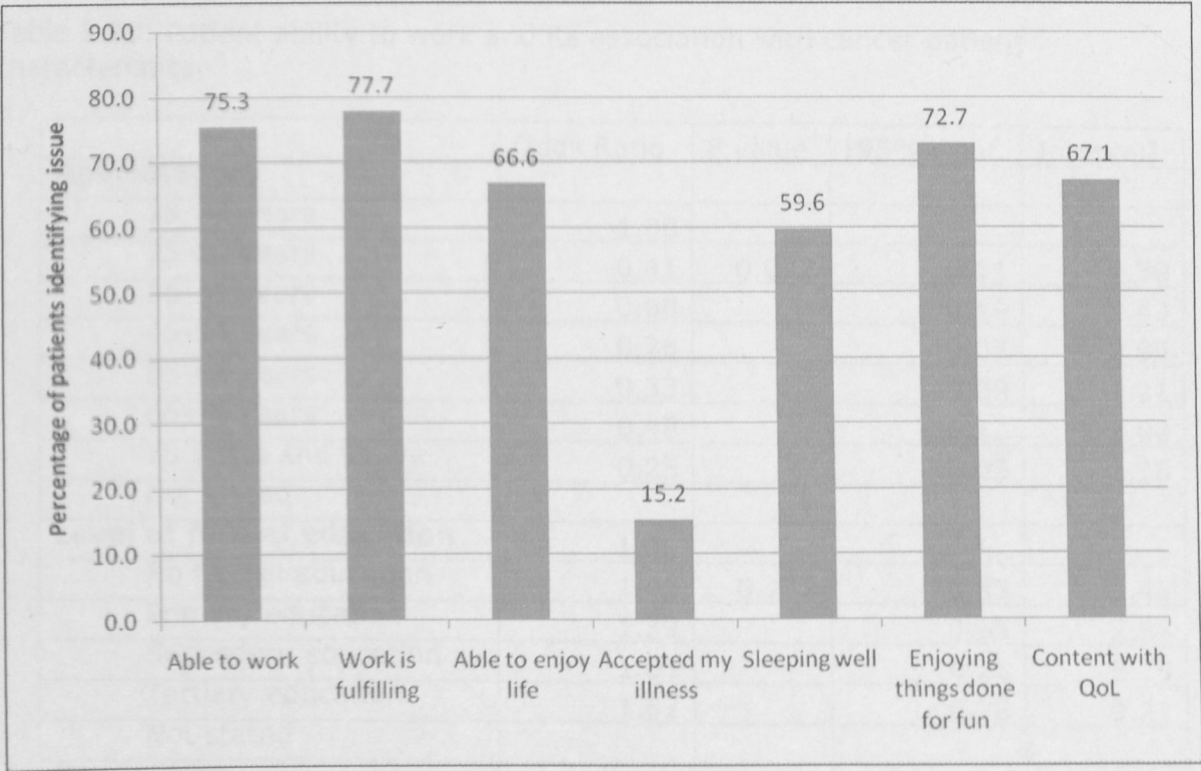


Figure 5.4: Importance of functional domain issues among Kenyan women with breast and other gynaecologic cancers

5.3.4.2 Patient characteristics and functional well being

Details of the univariate analysis of each of the demographic and socioeconomic patient factors and physical well being issues are presented in Appendix 1d. Results of adjusted ordinal logistic regression between these issues and demographic and socioeconomic factors are shown in tables 5.20 – 5.26.

a) I am able to work

The main factor influencing patient ability to work was age (Table 5.20). The ability to work as an issue in cancer increased with increasing age. The remaining patient factors did not influence patient ability to work.

Table 5.20: Patient ability to work and its association with cancer patient characteristics

	Odds Ratio	P value	[95% Conf.	Interval]
Age category				
18-24 years	1.00			
25-34 years	0.41	0.022	0.11	1.59
35-44 years	0.68		0.19	2.43
45-54 years	0.26		0.07	0.95
55-64 years	0.33		0.09	1.21
65-74 years	0.48		0.12	2.02
75 years and above	0.25		0.05	1.26
Not stated				
Level of formal education	1.00			
No formal education	1.42	0.732	0.83	2.43
Primary education	1.39		0.65	2.97
Secondary education	1.01		0.28	3.70
Tertiary education	1.62		0.28	9.27
Not stated				
Occupation				
Small scale farmer				
Housewife	0.90	0.606	0.54	1.48
Small scale business	1.26		0.61	2.62
Professional	1.51		0.51	4.43
Skilled employment	1.02		0.26	3.93
Other	2.32		0.67	8.04
Not stated	1.68		0.75	3.76
Monthly income				
Less than KES 2500				
KES 2501-7500	1.72	0.072	0.89	3.30
KES 7500	1.09		0.44	2.71
KES 12501	0.86		0.28	2.65
KES 17501	4.15		0.94	18.35
Above KES 22500	1.00		0.16	6.37
Undisclosed	2.81		1.25	6.33
Tribe				
Kikuyu				
Kamba	1.01	0.148	0.52	1.97
Luo	1.18		0.58	2.39
Coastal tribes	0.87		0.41	1.86
Luhya	0.48		0.22	1.02
Kisii	0.90		0.35	2.27
Kalenjin	1.02		0.32	3.23
Meru	4.31		1.35	13.72
Embu	0.43		0.07	2.60
Others	2.08		0.67	6.49

b) My work is fulfilling

In the univariate analysis (Appendix d) level of education, occupation, income and tribe were associated with patient perception of fulfilment from their work. Patient with higher education level were more fulfilled, while small scale farmers and housewives were less fulfilled. These associations were not significant in the adjusted analysis (Table 5.21)

Table 5.21: Fulfilment derived from work and its association with cancer patient characteristics

	Odds Ratio	P value	[95% Conf.	Interval]
Level of formal education				
No formal education	1.00			
Primary education	1.58	0.139	0.97	2.56
Secondary education	2.04		1.03	4.01
Tertiary education	0.91		0.26	3.18
Not stated	2.61		0.53	12.88
Occupation				
Small scale farmer	1.00			
Housewife	0.81	0.541	0.50	1.33
Small scale business	0.96		0.47	1.97
Professional	2.48		0.85	7.19
Skilled employment	1.76		0.47	6.62
Other	1.09		0.30	3.87
Not stated	0.97		0.44	2.15
Monthly income				
Less than KES 2500	1.00			
KES 2501-7500	0.99	0.183	0.52	1.88
KES 7500	1.02		0.42	2.46
KES 12501	1.17		0.39	3.51
KES 17501	2.79		0.65	11.90
Above KES 22500	0.83		0.13	5.32
Undisclosed	2.89		1.29	6.47
Tribe	1.00			
Kikuyu				
Kamba	0.79	0.20	0.42	1.50
Luo	0.78		0.38	1.57
Coastal tribes	0.59		0.29	1.23
Luhya	0.42		0.20	0.90
Kisii	0.69		0.28	1.68
Kalenjin	0.84		0.29	2.45
Meru	1.02		0.30	3.45
Embu	0.49		0.10	2.25
Others	2.64		0.92	7.59

Residence and monthly income influenced the patient's ability to enjoy life (Table 5.22). Ability to enjoy life was a significant issue among patients in the income category of KES 7501-12500. Patients from Coast, Western and Eastern provinces also identified ability to enjoy life as an important issue.

Table 5.22: Ability to enjoy life and its association with cancer patient characteristics

	Odds Ratio	P value	[95% Conf.	Interval]
Level of formal education				
No formal education				
Primary education	0.99	0.80	0.60	1.61
Secondary education	1.37		0.69	2.74
Tertiary education	0.92		0.25	3.39
Not stated	1.66		0.31	8.79
Occupation				
Small scale farmer				
Housewife	0.52	0.10	0.31	0.86
Small scale business	1.36		0.66	2.82
Professional	1.43		0.47	4.36
Skilled employment	0.71		0.18	2.73
Other	1.37		0.41	4.62
Not stated	0.81		0.36	1.82
Monthly income				
Less than KES 2500				
KES 2501-7500	1.83	0.021	0.96	3.48
KES 7500	0.50		0.19	1.30
KES 12501	1.00		0.32	3.15
KES 17501	2.35		0.53	10.33
Above KES 22500	1.38		0.20	9.44
Undisclosed	2.98		1.33	6.64
Permanent residence				
Central				
Eastern	0.76	0.002	0.42	1.37
Nyanza	1.28		0.70	2.35
Coast	0.20		0.09	0.44
Western	0.58		0.27	1.24
Rift valley	1.17		0.45	3.03
Other regions	1.16		0.32	4.22
Religion				
Protestant				
Catholic	0.86	0.512	0.53	1.37
Muslim	0.66		0.23	1.92
Other	0.24		0.03	2.16

c) I have accepted my illness

Acceptance of illness was generally high in the study and with the exception of residence it was not influenced by the remaining patient factors like age, education, occupation or income.

Table 5.23: Patient acceptance of illness and its association with cancer patient residence

	Odds Ratio	P value	[95% Conf.	Interval]
Permanent residence				
Central				
Eastern	1.03	0.0006	0.45	2.36
Nyanza	0.49		0.24	1.01
Coast	0.20		0.10	0.41
Western	0.58		0.25	1.37
Rift valley	0.62		0.19	2.04
Other regions	1.74		0.21	14.25

a) I am sleeping well

Sleeping well was an issue among most patients but was significantly influenced by reported monthly income only, Table 5.24. The ability to sleep well was more of an issue in the low compared to higher income groups. Sleep disturbance was common among patients who did not disclose income and those earning KES 2501-7500 and KES 12501-22500.

Table 5.24: Sleep disturbance and its association with cancer patient characteristics

	Odds Ratio	P value	[95% Conf.	Interval]
Level of formal education				
No formal education	1.00			
Primary education	0.87	0.288	0.54	1.40
Secondary education	1.43		0.73	2.81
Tertiary education	0.88		0.25	3.04
Not stated	3.02		0.67	13.68
Occupation				
Small scale farmer	1.00			
Housewife	0.54	0.178	0.33	0.88
Small scale business	1.11		0.55	2.26
Professional	0.98		0.35	2.72
Skilled employment	1.83		0.48	7.02
Other	0.87		0.25	2.96
Not stated	0.89		0.40	1.97
Monthly income				
Less than KES 2500	1.00			
KES 2501-7500	2.04	0.007	1.08	3.86
KES 7500	1.01		0.40	2.55
KES 12501	3.94		1.33	11.65
KES 17501	6.72		1.54	29.25
Above KES 22500	0.90		0.14	5.76
Undisclosed	2.43		1.10	5.37

b) I am enjoying the things I usually do for fun

Among the different patient factors explored (Appendix d) only the residence of patients influenced whether or not they enjoyed the things they usually did for fun. This was not a major issue for patients in Eastern and Rift valley while it was an issue in the other provinces, Table 5.25.

Table 5.25: Patient enjoyment of things done for fun and association with cancer patient characteristics

	Odds Ratio	P value	[95% Conf.	Interval]
Level of formal education				
No formal education	1.00			
Primary education	1.26	0.151	0.77	2.05
Secondary education	1.76		0.89	3.48
Tertiary education	1.09		0.31	3.85
Not stated	5.11		1.17	22.33
Occupation				
Small scale farmer	1.00			
Housewife	0.56	0.299	0.34	0.92
Small scale business	0.85		0.41	1.78
Professional	0.68		0.23	1.95
Skilled employment	1.01		0.27	3.74
Other	0.78		0.23	2.68
Not stated	1.22		0.55	2.70
Monthly income				
Less than KES 2500	1.00			
KES 2501-7500	2.15	0.169	1.14	4.06
KES 7500	1.18		0.47	2.99
KES 12501	1.99		0.66	5.99
KES 17501	3.97		0.99	15.85
Above KES 22500	0.94		0.14	6.49
Undisclosed	1.28		0.57	2.89
Permanent residence				
Central	1.00			
Eastern	1.23	0.0002	0.69	2.19
Nyanza	0.59		0.32	1.09
Coast	0.16		0.07	0.35
Western	0.60		0.29	1.22
Rift valley	1.32		0.52	3.37
Other regions	0.79		0.24	2.62

c) I am content with the quality of my life right now

Patient occupation and residence showed significant association with contentment with quality of life. Patients from Coast and Western province reported the lowest levels of satisfaction with quality of life followed by those in

Nyanza. On the other hand Professionals and patients in 'other' occupations reported significantly high quality of life compared to the remaining occupations.

Table 5.26: Patient contentment with QoL and association with cancer patient characteristics

	Odds Ratio	P value	[95% Conf.	Interval]
Level of formal education				
No formal education	1.00			
Primary education	1.05	0.11	0.66	1.69
Secondary education	1.66		0.86	3.20
Tertiary education	0.75		0.23	2.47
Not stated	4.65		1.05	20.62
Occupation				
Small scale farmer	1.00			
Housewife	0.48	0.01	0.30	0.78
Small scale business	0.95		0.46	1.95
Professional	1.64		0.64	4.21
Skilled employment	0.81		0.22	2.96
Other	2.44		0.76	7.83
Not stated	0.62		0.29	1.32
Permanent residence				
Central	1.00			
Eastern	1.10	0.004	0.63	1.93
Nyanza	0.71		0.39	1.28
Coast	0.33		0.16	0.68
Western	0.35		0.17	0.70
Rift valley	1.27		0.50	3.23
Other regions	0.50		0.15	1.60

5.4 DISCUSSION

The data presented in this chapter identify the main quality of life issues among Kenyan female patients with cancer, the domains affected by these issues and also the factors that are associated with these quality of life issues.

The findings showed that the main quality of life issues in Kenyan females with breast and gynaecologic cancers were: worrying that condition will get worse,

lack of satisfaction with sexual life, losing hope, worry about dying, lack of fulfilment in work and feeling nervous. These factors were related to the emotional, social and functional well being of patients. It is apparent that the emotional well being is most commonly affected by cancer diagnosis and treatment in Kenyan patients. The prominent role of emotional issues on quality of life has been reported in other studies among females with breast cancer and other gynaecologic cancers.²⁰⁷ The functional and physical well being domains are moderately affected, with six of the seven issues in this domain having scores between 59.6% for inability to sleep well, to 77.7% for lack of fulfilment with work. Patient's residence is shown to have an influence on issues like – the ability to enjoy life, making it an important issue for especially Coast and Western region residents, who also together with Nyanza residents, report – lack of enjoyment in what they do, and discontent with the quality of life at the time. The least impact is seen in the social well being. In fact satisfaction with sexual life was the only social well being issue for which more than one-half of participants selected the two worst categories.

These findings are important in that all the six emotional issues were reported as significant quality of life issues: feeling sad, dissatisfaction with individual coping, losing hope in fight against illness, feeling nervous, worrying about dying and worrying condition will get worse. It is also noteworthy that as in previous studies, all the anxiety-related items (worry about death, deterioration of condition, and feeling nervous) were more important issues than depression (feeling sad).²⁰⁸ These anxiety-related issues are more likely to respond to simple psychosocial interventions like counselling that can be easily incorporated into nursing roles compared to the more severe depressive symptoms that are challenging to manage. Similar to previous studies we noted that worrying that

condition will get worse was the most bothersome emotional issue.²⁰⁹⁻²¹¹ However, negative feeling about sadness and uncertainty did not rank as high among emotional issues as previously reported among cohorts of American breast cancer survivors.²⁰⁹

It was interesting to note that the patient's residence had a contribution in emotional issues as Coast, Western, and Rift valley residents did not consider – feeling sad, losing hope in the fight against illness, feeling nervous and worrying about death, to be major concerns when compared with Central residents.

While the present study did not evaluate the availability and type of emotional support provided to cancer patients within the study sites, it can be argued that promoting better understanding about diagnosis and providing psychosocial interventions tailored specifically at addressing cancer-specific concerns, may have considerable impact on emotional well being thereby impacting on the leading quality of life issues.²¹⁰ On the other hand, although emotional items were important issues, the availability of good social support compensated for the otherwise poor quality of life in this study with only one social well being issue – sex life, being reported as a major quality of life issue. The predominance (>50%) of gynaecological cancers affecting the female genital tract and also impacting on sex hormones (in the case of ovarian cancer), could explain the lack of satisfaction with sex life.

Contrary to expectation, physical issues (particularly treatment side effects, nausea, lack of energy, feeling ill, and pain) were considered to be less important issues compared to emotional and functional issues. Despite the fact that most physical issues were not classified as main issues based on the study's

definition, the demonstration of between 36.6% and 51.1% of patients who were concerned about lack of energy, nausea, time spent in bed as a result of illness and treatment side effects, identifies potential areas for further intervention. Interventions aimed at relieving these physical symptoms will certainly contribute to improving overall quality of life of female cancer patients. Finally, analysis for identifying factors associated with quality of life issues was based on the assumption that patients with similar socio-demographic attributes would tend to identify specific issues that were significantly worse for them. The level of formal education showed an interesting association with quality of life issues with the adjusted analysis showing significant associations between level of education and physical well being issues but not emotional, social or functional well being issues. While patient reported pain increased with level of education, reported side effects of treatment was lower in higher education categories. These associations possibly reflect the potential role of patient knowledge related to cancer on the patient's physical well-being. There exists evidence in previous studies of an impact of formal education on measures of adjustment and quality of life among patients with a variety of cancers.²¹²

In addition, residence featured greatly on pain and treatment side effects. While patients from Coast, Nyanza and Western regions reported pain to be of a lesser concern, side effects of treatment was a major concern for them, when compared to patients from Central province. It appears that probably factors not clear from this study may have some part to play.

CHAPTER 6

QUALITY OF LIFE ISSUES AND TYPE OF CANCER

This chapter presents the associations between quality of life issues and cancer diagnosis according to quality of life domains.

6.1 Physical well being domain

The distribution of patient responses to physical issues according to cancer diagnosis is shown in Table 6.1. Lack of energy was not an important issue for any of the cancers (between 14% and 43% selected the two worst categories for this issue). Nausea was an important issue for ovarian (50%) and 'other' (57%) cancers. Except for breast cancer patients, the remaining patients identified treatment side effects as an important issue: cervix (52%), ovary (50%), endometrial (64%) and 'other' (71%). Pain, trouble meeting family needs, and feeling ill were not important issues for any of the cancers, while for cancer of ovary, being forced to spend time in bed (51%) was identified as an important issue.

Table 6.1: Physical well being issues among patients with breast and other gynaecologic cancers

	Cancer diagnosis				
	Cervix	Breast	Ovary	Endometrial	Others
Number of patients	170	133	70	14	7
I have a lack of energy (%)					
Not at all	14	13	7	0	14
A little bit / Somewhat	49	46	50	36	71
Quite a bit/Very much	31	38	37	43	14
No response	6	3	6	21	0
I have nausea (%)					
Not at all	9	11	4	0	29
A little bit / Somewhat	40	38	40	57	14
Quite a bit/Very much	45	47	50	21	57
No response	6	4	6	21	0
Because of my physical condition, I have trouble meeting the needs of my family (%)					
Not at all	31	29	17	14	14
A little bit / Somewhat	47	45	53	64	43
Quite a bit/Very much	16	21	23	0	43
No response	6	5	7	21	0
I have pain (%)					
Not at all	21	20	9	14	14
A little bit/ Somewhat	48	47	53	57	57
Quite a bit/Very much	25	30	33	7	29
No response	6	3	6	21	0
I am bothered by side effects of treatment (%)					
Not at all	7	18	10	0	14
A little bit/ Somewhat	34	40	34	14	14
Quite a bit/Very much	52	39	50	64	71
No response	6	3	6	21	0
I feel ill (%)					
Not at all	19	21	10	7	29
A little bit/ Somewhat	59	44	50	64	29
Quite a bit/Very much	15	32	34	7	43
No response	6	4	6	21	0
I am forced to spend time in bed (%)					
Not at all	18	25	4	7	29
A little bit/ Somewhat	38	29	39	50	43
Quite a bit/Very much	38	44	51	21	29
No response	6	3	6	21	0

Two out of the seven quality of life issues in the physical well being domain showed statistically significant association with cancer diagnosis (Table 6.2). Patients with endometrial cancer (9%) and cancer of the cervix (16%) reported feeling ill less frequently compared to breast (33%), ovary (36%) and 'other' cancer (43%). Side effects of treatment were more important issues in endometrial (82%), and 'other' (71%) cancers.

Table 6.2: Comparisons of physical quality of life issues according to cancer diagnosis

	Cancer diagnosis					P value
	Cervix	Breast	Ovary	Endometrial	Others	
I have a lack of energy	33%	40%	39%	55%	14%	0.312
I have nausea	48%	48%	53%	27%	57%	0.597
I have trouble meeting the needs of my family	26%	31%	35%	9%	29%	0.127
I have pain	17%	22%	25%	0%	43%	0.409
I am bothered by side effects of treatment	56%	40%	53%	82%	71%	0.012
I feel ill	16%	33%	36%	9%	43%	0.002
I am forced to spend time in bed	40%	45%	55%	27%	29%	0.21

6.2 Social well being issues

Out of the seven social well being issues, only lack of satisfaction with sexual life was identified as an important issue. Between 53% and 79% of patients with the different types of cancer selected the two worst categories for this issue- lack of sexual satisfaction.

Table 6.3: Social well being issues among patients with breast and other gynaecologic cancers

	Cancer diagnosis				
	Cervix	Breast	Ovary	Endometrial	Others
Number of patients	170	133	70	14	7
I feel close to my friends (%)					
Not at all	0	3	1	7	14
A little bit / Somewhat	15	8	4	14	0
Quite a bit/Very much	78	85	90	57	86
No response	6	4	4	21	0
I get emotional support from my family (%)					
Not at all	2	2	0	0	0
A little bit/ Somewhat	8	5	3	7	29
Quite a bit/Very much	84	89	93	71	71
No response	6	4	4	21	0
I get support from my friends (%)					
Not at all	6	9	6	14	14
A little bit/ Somewhat	18	10	9	7	29
Quite a bit/Very much	69	77	80	57	57
No response	6	4	6	21	0
My family has accepted my illness (%)					
Not at all	4	4	3	7	0
A little bit/ Somewhat	15	14	9	0	29
Quite a bit/Very much	74	78	83	71	71
No response	8	4	6	21	0
I am satisfied with family communication about my illness (%)					
Not at all	3	4	1	0	0
A little bit/ Somewhat	16	8	1	21	43
Quite a bit/Very much	72	83	90	57	57
No response	8	5	7	21	0
I feel close to my partner (%)					
Not at all	7	10	3	0	43
A little bit/ Somewhat	9	1	3	0	0
Quite a bit/Very much	75	80	84	79	57
No response	9	9	10	21	0
I am satisfied with my sex life (%)					
Not at all	71	44	63	79	57
A little bit/ Somewhat	6	9	6	0	14
Quite a bit/Very much	3	16	10	0	29
No response	20	31	21	21	0

There was a significant association between types of cancer and lack of sexual satisfaction as a quality of life issue (Table 6.4). All patients with endometrial cancer and 93% of cases of cancer of the cervix were not satisfied with their sexual life, $p < 0.001$.

Feeling close to a partner was also significantly associated with type of cancer (Table 6.4). This was an important issue in 'other' cancers (43%) compared to the remaining cancers (less than 15%), $p = 0.010$.

Table 6.4: Comparisons of social well being quality of life issues according to cancer diagnosis

	Cancer diagnosis					P value
	Cervix	Breast	Ovary	Endometrial	Others	
I feel close to my friends	8%	6%	3%	18%	14%	0.309
I get emotional support from my family	4%	5%	1%	0%	14%	0.451
I get support from my friends	15%	15%	11%	18%	29%	0.718
My family has accepted my illness	10%	9%	8%	9%	14%	0.956
I am satisfied with family communication about my illness	9%	7%	2%	0%	0%	0.241
I feel close to my partner	12%	12%	3%	0%	43%	0.010
I am satisfied with my sex life	93%	71%	84%	100%	71%	<0.001

6.3 Emotional well being issues

Feeling sad was an important issue for all cancers (50-67%) except 'other' cancers (Table 6.5). The remaining emotional well being issues were important for patients with all types of cancer: worry about dying (71-83%), worrying condition will get worse (79-100%), losing hope in fight against illness (57-83%), and feeling nervous (57-83%).

Table 6.5: Emotional well being issues among patients with breast and other gynaecologic cancers

	Cancer diagnosis				
	Cervix	Breast	Ovary	Endometrial	Others
Number of patients	170	133	70	14	7
I feel sad (%)					
Not at all	12	7	4	0	14
A little bit/ Somewhat	22	28	23	29	57
Quite a bit/Very much	58	58	67	50	29
No response	9	8	6	21	0
I am satisfied with how I am coping with my illness (%)					
Not at all	12	5	4	14	29
A little bit/ Somewhat	55	46	59	50	29
Quite a bit/Very much	23	41	31	14	43
No response	10	8	6	21	0
I am losing hope in the fight against my illness (%)					
Not at all	4	4	1	0	0
A little bit/ Somewhat	14	9	10	14	43
Quite a bit/Very much	74	79	83	64	57
No response	9	8	6	21	0
I feel nervous (%)					
Not at all	8	4	6	0	14
A little bit/ Somewhat	16	16	6	21	29
Quite a bit/Very much	66	73	83	57	57
No response	9	8	6	21	0
I worry about dying (%)					
Not at all	5	5	7	0	0
A little bit/ Somewhat	14	10	3	7	29
Quite a bit/Very much	72	77	83	71	71
No response	9	8	7	21	0
I worry that my condition will get worse (%)					
Not at all	2	4	1	0	0
A little bit/ Somewhat	3	5	1	0	0
Quite a bit/Very much	85	84	91	79	100
No response	9	8	6	21	0

Table 6.6 shows that satisfaction with individual illness coping was the only emotional quality of life issue that showed a statistically significant association with cancer diagnosis ($p = 0.024$). Thirty nine percent of breast cancer patient were not satisfied with their coping and this percentage was lower than the proportions reported in the remaining diagnoses.

Table 6.6: Comparisons of emotional well being quality of life issues according to cancer diagnosis

	Cancer diagnosis					P value
	Cervix	Breast	Ovary	Endometrial	Others	
I feel sad	63%	63%	71%	64%	29%	0.246
I am satisfied with how I am coping with my illness	59%	39%	50%	64%	43%	0.024
I am losing hope in the fight against my illness	81%	86%	88%	82%	57%	0.228
I feel nervous	73%	79%	88%	73%	57%	0.097
I worry about dying	80%	84%	89%	91%	71%	0.397
I worry that my condition will get worse	94%	91%	97%	100%	100%	0.404

6.4 Functional well being issues

As shown in Table 6.7, most patients had accepted their illness regardless of their cancer diagnosis and this item was not an important quality of life issue. For cervical, breast, ovarian and endometrial cancer, all the remaining functional items were identified as important quality of life issues.

Table 6.7: Functional well being issues among patients with breast and other gynaecologic cancers

	Cancer diagnosis				
	Cervix	Breast	Ovary	Endometrial	Others
Number of patients	170	133	70	14	7
I am able to work (%)					
Not at all	29	33	36	50	29
A little bit/ Somewhat	55	47	46	43	57
Quite a bit/Very much	13	18	17	0	14
No response	2	2	1	7	0
My work (include work at home) is fulfilling (%)					
Not at all	37	35	34	50	29
A little bit/ Somewhat	50	43	44	43	57
Quite a bit/Very much	10	20	17	0	14
No response	3	2	4	7	0
I am able to enjoy life (%)					
Not at all	24	18	13	29	29
A little bit/ Somewhat	57	50	60	50	43
Quite a bit/Very much	16	29	24	14	29
No response	2	3	3	7	0
I have accepted my illness (%)					
Not at all	10	5	4	14	0
A little bit/ Somewhat	16	12	11	29	14
Quite a bit/Very much	71	80	81	50	86
No response	3	3	3	7	0
I am sleeping well (%)					
Not at all	24	11	16	14	29
A little bit/ Somewhat	55	50	59	71	14
Quite a bit/Very much	19	37	24	7	57
No response	3	2	1	7	0
I am enjoying the things I usually do for fun (%)					
Not at all	32	27	19	43	43
A little bit/ Somewhat	55	47	56	50	29
Quite a bit/Very much	10	24	21	0	29
No response	4	2	4	7	0
I am content with the quality of my life right now (%)					
Not at all	29	23	17	36	29
A little bit/ Somewhat	53	48	53	57	29
Quite a bit/Very much	15	26	27	0	43
No response	3	2	3	7	0

There was a significant association between cancer diagnosis and five out of the seven issues contained in the functional well being domain (Table 6.8). Ability to work and fulfilment in work were consistently reported as important issues among patients with endometrial cancer and cancers of the cervix and breast with between 78 and 100% of cases reporting these as important issues. Content with quality of life and enjoying things done for fun were also important issues in at least 79% of patients with cancers of the cervix and endometrium.

Table 6.8: Comparisons of functional well being quality of life issues according to cancer diagnosis

	Cancer diagnosis					P value
	Cervix	Breast	Ovary	Endometrial	Others	
I am able to work	78%	69%	80%	100%	57%	0.017
My work (include work at home) is fulfilling	83%	69%	78%	100%	71%	0.017
I am able to enjoy life	72%	60%	65%	85%	57%	0.087
I have accepted my illness	18%	11%	13%	38%	14%	0.082
I am sleeping well	66%	48%	64%	85%	43%	0.004
I am enjoying the things I usually do for fun	82%	62%	69%	100%	57%	<0.001
I am content with the quality of my life right now	79%	55%	60%	85%	43%	<0.001

6.5 Comparison of quality of life in breast cancer and gynaecologic cancers

Table 6.9 presents the mean scores for quality of life among all patients and among patients with different cancer diagnoses. To interpret the results, we considered a two-point difference on the FACT-G subscale scores and a five-point difference on the FACT-G total score to be associated with meaningful differences on clinical and subjective indicators as described in previous studies. The mean quality of life score among the patients in this study was 64.52 (SD=15.49).

The sample of patients in this study had low scores for physical (mean=13.39) and functional (mean=11.09) wellbeing. These differed from normative data for FACT-G subscales by more than 2 points and could be considered clinically meaningful. Functional well being scores for patients with cervical (9.88) and endometrial (6.76) cancers were even lower and differed significantly (> 2 points) from the average scores for the entire sample of patients.

Table 6.9: Mean (SD) FACT-G scores among Kenyan female cancer patients

FACT domain	Range	Mean	SD
PWB (0-28), all patients	0-27	13.39	5.41
Cervix	0-27	12.83	5.07
Breast	0-26	13.46	5.82
Ovary	5-26	14.74	5.4
Endometrial	9-17	12	3.16
Others	9-26	14.28	6.31
FWB (0-28), all patients	0-28	11.09	6.41
Cervix	0-28	9.88	5.88
Breast	0-28	12.53	6.71
Ovary	0-28	11.84	6.2
Endometrial	0-12	6.76	4.2
Others	1-28	13.57	9.88
SWB (0-28), all patients	1-28	21.56	4.9
Cervix	2-28	20.72	5.05
Breast	1-28	22.32	5.01
Ovary	11-28	22.75	3.15
Endometrial	8-28	20.27	5.74
Others	6-25	17.57	6.9
EWB (0-24), all patients	2-24	18.27	4.58
Cervix	4-24	17.7	4.57
Breast	2-24	18.65	4.78
Ovary	6-24	19.14	3.97
Endometrial	10-22	18.18	4.23
Others	7-24	16.42	6.16

Patients diagnosed with endometrial cancer reported the lowest quality of life (mean=58.45) while those with cancer of the ovary had the highest score

(68.57). As shown in table 6.10, the findings of ANOVA showed that there were significant differences in overall quality of life as a function of diagnosis; FACT-G ($F(4,350) = 3.46, P=0.008$). The subscales for physical wellbeing and emotional wellbeing did not differ significantly in patients by cancer diagnosis.

Table 6.10: Mean FACT-G Total and subscale scores by diagnosis

Scale (Number of items)	Cancer diagnosis					ANOVA
	Cervix	Breast	Ovary	Endometrial	Other	
PWB* (7)	12.83 SD=5.08	13.47 SD=5.83	14.75 SD=5.40	12 SD=3.16	14.29 SD=6.32	$F(4,367) = 1.71$ $P=0.146$
FWB* (7)	9.89 SD=5.88	12.54 SD=6.72	11.84 SD=6.20	6.77 SD=4.21	13.57 SD=9.88	$F(4,378) = 5.30$ $P=0.004$
SWB* (7)	20.72 SD=5.06	22.32 SD=5.01	22.76 SD=3.16	20.27 SD=5.75	17.57 SD=6.90	$F(4,365) = 4.41$ $P=0.002$
EWB* (6)	17.7 SD=4.58	18.65 SD=4.79	19.14 SD=3.97	18.18 SD=4.24	16.43 SD=6.16	$F(4,356) = 1.70$ $P=0.149$
FACTG (27)	61.71 SD=14.88	66.64 SD=16.27	68.57 SD=13.29	58.45 SD=12.13	61.86 SD=25.59	$F(4,350) = 3.46$ $P=0.008$

*PWB=physical wellbeing; FWB=functional wellbeing; SWB=social wellbeing; EWB=emotional wellbeing

6.6 DISCUSSION

This chapter investigated quality of life issues of women in relation to different types of gynaecological cancers and breast cancer within the Kenyan context. Three significant findings emerged from the analysis presented above. Firstly, ten out of the twenty seven quality of life issues examined in this study showed significant association with the type of cancer diagnosis. Secondly, the quality of life issues in the functional well being domain were more likely to show associations with cancer diagnosis compared to the remaining three domains.

Finally, overall quality of life (FACT-G) was also significantly associated with the different cancer diagnosis.

QOL issues and cancer diagnosis

There were ten quality of life issues that showed significant associations with gynaecological cancers and breast cancer: treatment side effects, feeling ill, feeling close to partner, satisfaction with sex life, individual coping with illness, ability to work, fulfilment with work, sleeping well, enjoying things done for fun and satisfaction with current QOL. For all these issues, except feeling ill and feeling close to partner, higher percentages of patients with endometrial cancers experienced these issues compared to the percentages of patients with the remaining gynaecological cancers –ovary, cervix and “other”- or breast cancers who experienced the same issues.

Separately, regarding all examined QOL issues -whether significantly associated with cancer diagnosis or not- patients with endometrial and cervical cancers ranked most issues higher than patients with cancer of the ovary, breast and ‘other’ cancers. The higher ranking by these two diagnoses was exemplified in the reporting of functional and social well being issues. Patients with endometrial cancer were followed by those diagnosed with cancer of the cervix in the ranking of important issues.

QOL issues according to QOL domain

QOL issues in the functional domain were most commonly associated with cancer diagnosis with five of the seven items in this domain showing significant association with type of cancer. On the other hand two items within the physical domain and two items in the social domain were significantly associated with cancer diagnosis. Only sexual satisfaction showed significant association with cancer diagnosis in the social well being domain.

CHAPTER 7

QUALITY OF LIFE ISSUES AND CANCER TREATMENT

The analysis of the associations between the modalities of treatment and quality of life issues showed the following:

7.1 Physical well being issues

Being bothered by treatment side effects and nausea were the main quality of life issues in the analysis conducted according to treatment modality. Nausea was an important issue for patients managed using surgery (55%), radiotherapy (52%) and those on palliative care (51%), Table 7.1. Patients on these three treatment modalities reported that side effects of treatment were an important quality of life issue: surgery (60%), radiotherapy (61%) and palliative care (69%).

Table 7.1: PWB quality of life issues and associations with modality of treatment

	Surgery plus Radio/ chemotherapy	Surgery	Palliative	Radio- therapy	Other
Number, n	160	126	68	23	17
I have a lack of energy (%)					
Not at all	8	10	25	13	18
A little bit/ Somewhat	46	56	43	39	41
Quite a bit/Very much	39	29	32	35	41
No response	8	6	0	13	0
I have nausea (%)					
Not at all	7	6	13	9	29
A little bit/ Somewhat	49	33	34	26	35
Quite a bit/Very much	36	55	51	52	35
No response	8	6	1	13	0
Because of my physical condition, I have trouble meeting the needs of my family (%)					
Not at all	19	19	50	39	47
A little bit/ Somewhat	55	52	32	26	41
Quite a bit/Very much	18	22	16	22	12
No response	9	6	1	13	0
I have pain (%)					
Not at all	6	21	40	17	12
A little bit/ Somewhat	54	46	46	48	47
Quite a bit/Very much	33	27	15	22	41
No response	8	6	0	13	0
I am bothered by side effects of treatment (%)					
Not at all	14	6	7	13	29
A little bit/ Somewhat	48	28	24	13	47
Quite a bit/Very much	31	60	69	61	24
No response	8	6	0	13	0
I feel ill (%)					
Not at all	8	16	47	22	6
A little bit/ Somewhat	57	48	41	61	59
Quite a bit/Very much	28	29	12	4	35
No response	8	6	0	13	0
I am forced to spend time in bed (%)					
Not at all	9	16	37	30	12
A little bit/ Somewhat	32	43	35	17	41
Quite a bit/Very much	51	36	28	39	47
No response	8	6	0	13	0

Comparisons of women on different modalities of treatment demonstrated significant differences in the percentages of women selecting the two worst categories for pain ($p = 0.028$), nausea ($p = 0.017$), treatment side effects ($p < 0.001$), feeling ill ($p = 0.004$) and being forced to spend time in bed ($p = 0.002$), Table 7.2.

Table 7.2: Comparisons of physical quality of life issues according to treatment modality

	Treatment modality					P value
	Surgery plus Radio/chemotherapy	Surgery	Palliative	Radio-therapy	Other	
I have a lack of energy	43%	30%	32%	40%	41%	0.275
I have nausea	39%	58%	52%	60%	35%	0.017
I have trouble meeting the needs of my family	19%	24%	16%	25%	12%	0.619
I have pain	35%	29%	15%	25%	41%	0.028
I am bothered by side effects of treatment	33%	64%	69%	70%	24%	<0.001
I feel ill	30%	31%	12%	5%	35%	0.004
I am forced to spend time in bed	55%	38%	28%	45%	47%	0.002

7.2 Social well being issues

Patients on each of the five modalities of treatment identified lack of satisfaction with sex life as an important quality of life issue (49%-65%), Table 7.3. Patients on each treatment modality reported having no problem with the remaining six social well being issues.

Table 7.3: SWB quality of life issues and associations with modality of treatment

	Surgery plus Radio/ chemotherapy	Surgery	Palliative	Radio- therapy	Other
Number, n	160	126	68	23	17
I feel close to my friends (%)					
Not at all	1	2	3	0	0
A little bit/ Somewhat	4	13	26	4	6
Quite a bit/Very much	88	79	69	83	94
No response	7	6	1	13	0
I get emotional support from my family (%)					
Not at all	1	1	6	0	6
A little bit/ Somewhat	3	6	13	4	12
Quite a bit/Very much	89	88	79	83	82
No response	7	6	1	13	0
I get support from my friends (%)					
Not at all	3	9	16	13	6
A little bit/ Somewhat	8	16	24	9	6
Quite a bit/Very much	83	70	57	65	88
No response	7	6	3	13	0
My family has accepted my illness (%)					
Not at all	1	3	9	0	18
A little bit/ Somewhat	6	22	19	4	6
Quite a bit/Very much	87	68	68	83	76
No response	7	6	4	13	0
I am satisfied with family communication about my illness (%)					
Not at all	1	1	9	0	18
A little bit/ Somewhat	3	17	25	13	6
Quite a bit/Very much	90	76	59	70	76
No response	7	6	7	17	0
I feel close to my partner (%)					
Not at all	6	8	10	4	18
A little bit/ Somewhat	1	6	12	0	0
Quite a bit/Very much	83	78	71	78	71
No response	10	8	7	17	12
I am satisfied with my sex life (%)					
Not at all	64	61	49	65	59
A little bit/ Somewhat	5	11	7	4	0
Quite a bit/Very much	10	6	10	9	12
No response	21	21	34	22	29

The quality of life issues that differed significantly between women managed using different treatment modalities were feeling close to friends ($p = 0.01$), getting support from friends ($p = 0.014$), family acceptance of illness ($p = 0.023$) and patient satisfaction with family communication about illness ($p < 0.001$), Table 7.4.

Table 7.4: Comparisons of social well being quality of life issues according to treatment modality

	Treatment modality					P value
	Surgery plus Radio/chemotherapy	Surgery	Palliative	Radio-therapy	Other	
I feel close to my friends	3%	9%	15%	0%	6%	0.010
I get emotional support from my family	3%	3%	7%	0%	12%	0.175
I get support from my friends	8%	18%	24%	20%	6%	0.014
My family has accepted my illness	5%	10%	15%	5%	24%	0.023
I am satisfied with family communication about my illness	1%	5%	19%	5%	18%	<0.001
I feel close to my partner	7%	11%	16%	5%	20%	0.200
I am satisfied with my sex life	84%	85%	80%	89%	83%	0.922

7.3 Emotional well being issues

The quality of life issues identified by patients undergoing treatment in all the modalities were losing hope in fight against illness (65-85% for various modalities), feeling nervous (59%-88%), worry about dying (65-94%), and worrying that condition will get worse (83-100%), Table 7.5.

Table 7.5: EWB quality of life issues and associations with modality of treatment

	Surgery plus Radio/ chemotherapy	Surgery	Palliative	Radio- therapy	Other
Number, n	160	126	68	23	17
I feel sad (%)					
Not at all	3	9	19	13	6
A little bit / Somewhat	18	30	31	39	12
Quite a bit/ Very much	69	52	49	35	82
No response	10	10	1	13	0
I am satisfied with how I am coping with my illness (%)					
Not at all	6	10	16	4	12
A little bit/ A little bit/ Somewhat	54	54	47	48	35
Quite a bit/ Very much	30	27	35	26	47
No response	10	10	1	22	6
I am losing hope in the fight against my illness (%)					
Not at all	3	1	3	13	6
A little bit/ Somewhat	1	20	25	9	6
Quite a bit/Very much	85	70	71	65	88
No response	11	10	1	13	0
I feel nervous (%)					
Not at all	3	5	15	17	0
A little bit/ Somewhat	4	25	25	9	12
Quite a bit/Very much	84	61	59	61	88
No response	10	10	1	13	0
I worry about dying (%)					
Not at all	3	4	12	13	0
A little bit/ Somewhat	3	16	21	4	6
Quite a bit/Very much	84	71	66	65	94
No response	11	10	1	17	0
I worry that my condition will get worse (%)					
Not at all	3	2	6	0	0
A little bit/ Somewhat	1	6	4	0	0
Quite a bit/Very much	86	83	88	83	100
No response	10	10	1	17	0

Significant differences were observed in the percentages of women on different treatments selecting the two worst categories for several emotional well being items (feel sad, losing hope, feel nervous, worry about dying), Table 7.6.

Table 7.6: Comparisons of emotional well being quality of life issues according to treatment modality

	Treatment modality					P value
	Surgery plus Radio/ chemotherapy	Surgery	Palliative	Radio-therapy	Other	
I feel sad	77%	57%	49%	40%	82%	<0.001
I am satisfied with how I am coping with my illness	56%	49%	45%	44%	38%	0.378
I am losing hope in the fight against my illness	95%	77%	72%	75%	88%	<0.001
I feel nervous	93%	68%	60%	70%	88%	<0.001
I worry about dying	94%	78%	67%	79%	94%	<0.001
I worry that my condition will get worse	96%	92%	90%	100%	100%	0.189

7.4 Functional well being issues

The functional well being items were identified as important issues by patients in each treatment group except for a single issue – I have accepted my illness- which was not an important issue for any treatment group, Table 7.7.

Table 7.7: FWB quality of life issues and associations with modality of treatment

	Surgery plus Radio/ chemotherapy	Surgery	Palliative	Radio- therapy	Other
Number, n	160	126	68	23	17
I am able to work (%)					
Not at all	31	31	35	39	35
A little bit/ Somewhat	55	52	46	43	24
Quite a bit/Very much	12	13	18	17	41
No response	2	4	1	0	0
My work (include work at home) is fulfilling (%)					
Not at all	30	36	50	43	35
A little bit/ Somewhat	56	47	28	39	35
Quite a bit/Very much	12	13	18	13	29
No response	2	4	4	4	0
I am able to enjoy life (%)					
Not at all	14	22	29	26	18
A little bit/ Somewhat	61	60	40	43	35
Quite a bit/Very much	23	14	28	30	41
No response	2	4	3	0	6
I have accepted my illness (%)					
Not at all	7	6	7	13	12
A little bit/ Somewhat	4	20	31	13	0
Quite a bit/Very much	86	70	59	70	88
No response	3	4	3	4	0
I am sleeping well (%)					
Not at all	11	21	29	22	0
A little bit/ Somewhat	60	53	40	65	35
Quite a bit/Very much	27	22	26	13	65
No response	2	3	4	0	0
I am enjoying the things I usually do for fun (%)					
Not at all	18	32	46	39	24
A little bit/ Somewhat	64	47	37	43	35
Quite a bit/Very much	16	17	12	13	41
No response	2	4	6	4	0
I am content with the quality of my life right now (%)					
Not at all	16	29	41	26	24
A little bit/ Somewhat	62	50	37	39	29
Quite a bit/Very much	21	17	19	30	47
No response	2	4	3	4	0

Out of the seven FWB issues only one item showed a significant association with treatment modality. Significantly different proportions of women on different

treatments selected the two worst categories for sleeping well (range 24-74%), as shown in Table 7.8.

Table 7.8: Comparisons of functional well being quality of life issues according to treatment modality

	Treatment modality					P value
	Surgery plus Radio/ chemotherapy	Surgery	Palliative	Radio-therapy	Other	
I am able to work	80%	74%	70%	78%	53%	0.101
My work (include work at home) is fulfilling	82%	77%	74%	82%	59%	0.226
I am able to enjoy life	69%	69%	61%	65%	50%	0.428
I have accepted my illness	10%	17%	24%	23%	12%	0.055
I am sleeping well	62%	63%	51%	74%	24%	0.006
I am enjoying the things I usually do for fun	75%	73%	75%	68%	53%	0.405
I am content with the quality of my life right now	66%	72%	68%	64%	47%	0.323

7.5 Impact of treatment modalities on quality of life

As shown in table 7.9, the findings of ANOVA showed that there were significant differences in overall quality of life as a function of treatment modality; FACT-G ($F(4,350) = 10.05, P = 0.005$). These significant differences were also observed within each of the four domains –physical, functional, social and emotional- of the FACT-G scale.

Table 7.9: Mean FACT-G Total and subscale scores by treatment modality

Scale (Number of items)	Treatment modality					ANOVA
	Surgery plus Radio/chemotherapy	Surgery	Palliative	Radiotherapy	Other	
PWB* (7)	14.09 SD=5.0	13.92 SD=5.53	11.49 SD=5.51	12.5 SD=4.96	12.29 SD=6.68	F(4,367) =3.39 P=0.001
FWB* (7)	11.76 SD=6.19	10.37 SD=6.18	9.92 SD=6.36	6.77 SD=4.21	15.17 SD=7.36	F(4,378) =3.16 P=0.014
SWB* (7)	23.39 SD=3.07	20.59 SD=4.99	19.08 SD=6.29	22.25 SD=3.50	21.25 SD=6.84	F(4,365) =11.90 P<0.001
EWB* (6)	19.71 SD=3.64	17.46 SD=4.79	16.28 SD=5.66	17.52 SD=4.49	20.29 SD=3.22	F(4,356) =9.32 P<0.001
FACTG (27)	69.54 SD=12.27	62.33 SD=16.29	56.34 SD=17.29	64.72 SD=12.96	69.00 SD=14.14	F(4,350) =10.05 P=0.005

*PWB=physical wellbeing; FWB=functional wellbeing; SWB=social wellbeing; EWB=emotional wellbeing

7.6 DISCUSSION

The present chapter evaluated whether differences in cancer treatment modality are associated with important quality of life issues in breast and gynaecologic cancers. The results indicate that there are several quality of life issues that are significantly associated with treatment modality, most commonly in the physical and emotional domains. Further analysis showed that overall quality of life was also significantly associated with treatment modality with the lowest FACT-G scores recorded in patients on palliative care.

Differences in treatment side effects in patients were significant among treatment modalities. Similar differences were seen for nausea, pain, feeling ill, and time that patients were forced to spend in bed. In common with the findings of this study on the physical quality of life issues, previous studies have shown that different treatment modalities affect long-term survivors of cervical cancer to varying degrees.²¹³ The trend observed in a review of such studies showed that radiotherapy is more associated with reduced quality of life than

surgery or chemotherapy.²¹³ In the current study, patients treated using radiotherapy alone commonly reported nausea compared to those on the remaining treatment modalities. For treatment side effects and being forced to spend time in bed, radiotherapy ranked high among the treatment modalities, while for pain and feeling ill the patients on radiotherapy ranked low.

Outside the physical domain, the other domain that showed important associations between quality of life issues and treatment modality was the emotional well being domain. First, most issues in the emotional domain were reported as important issues for each modality of treatment i.e. at least half of patients on each treatment considered these issues as important. Second, although patients in each modality considered emotional issues as important, significantly higher percentages of patients on specific treatment modalities selected the worst categories for certain quality of life issues. For example, multiple treatment modalities (surgery, chemotherapy and radiotherapy in combination) appeared to cause greater anxiety and worry in patients compared to single treatment modalities. The same is also true of treatment modalities classified as 'other treatment' that similarly comprised various combinations of treatment modalities.

Psychosocial adjustment in gynaecological cancer patients is different for patients receiving different treatments,²¹⁴ and treatment with radiotherapy or multi-modality treatment has been reported to result in lower quality of life compared to either single treatment modality or other treatments.^{215, 216} The present findings are in agreement with reports in previous studies.^{62, 64, 210} However, methodological reviews of a number of studies reporting such associations have noted important weaknesses in the designs of these studies.²¹³ Good quality studies designed with the primary objective of evaluating the

impact of treatment modality on quality of life generally, and specifically on quality of life issues, are required to provide comparative data for the findings reported from our analysis.

The analysis also showed significant issues in the social well being domain and especially related to sexual well being. This finding confirms reports that changes in sexual function and fertility preservation occurs following cancer treatment in females with cervical and gynaecologic cancers. These changes in sexual functioning were uniform across the various treatment modalities evaluated in the present study. This finding contrasts to studies that report greater loss in sexual function for patients on specific types of treatment, implying that loss in sexual function could be more related with the disease process involving the genital tract and the accompanying psychosocial changes rather than treatment of the disease.

Finally, in interpreting the findings reported above, it is important to note that the choice of treatment modality is based on disease extent, patient's age and general condition. Early stages of cervical cancer for example are treated with surgery, radiotherapy or their combination and concurrent chemotherapy could be used to achieve cure.²¹⁷ Thus the findings presented here are aimed at helping in the prioritisation of issues that need to be addressed during therapy rather than identifying therapies that are associated with the least quality of life issues among patients.

QUALITY OF LIFE ISSUES: A QUALITATIVE ANALYSIS

8.1 Introduction

This chapter addresses the objective on describing the perception of the term quality of life among Kenyan women with gynaecologic and breast cancer, and explores in detail the experience of women living with cancer as expressed through their own narratives. A key consideration for the analysis presented in this chapter is to determine the role of the FACT-G tool in identifying quality of life issues in the Kenyan context and this is achieved by determining whether the 27 items used in the FACT-G tool which were considered as quality of life issues in chapters 5, 6 and 7 were actually identified in patient narratives of experience of living with cancer. As outlined in the methodology in Chapter 3, the patient narratives were obtained prior to administering the FACT-G tool to ensure patient narratives were not influenced by issues contained in the FACT-G tool.

8.2 Findings

The results of the qualitative analysis presented here are organised around issues of interest within the two objectives that the study set to answer qualitatively:

- To document the perception of the term 'quality of life' of the women with breast and gynaecologic cancer in Kenya.
- To determine, between an oral interview and FACT, which method is appropriate for QOL assessment in Kenya setting.

8.3 Perceptions of the term 'quality of life'

From the participants' responses it was apparent that patients had difficulties defining the term 'quality of life' with a significant number of patients beginning their responses by stating that quality of life is a very broad construct that is difficult to define in definite terms. Instead of defining quality of life patients commonly proceeded to provide a description of quality of life based on the perceived impact of cancer diagnosis on their state of health.

"Quality of life is a very broad term that cannot be equated to only one meaning. All the same I can say that quality life is one that is enjoyable without worries and pressure brought about by illness." (Respondent 25, Mombasa)

"Quality of life is a really difficult term to explain. However I can liken it to whereby one is healthy and can get on with daily business of living unabated by illness and sickness." (Respondent 27, Mombasa)

The narratives of most female patients with breast cancer and gynaecologic cancers were dominated by description of three overlapping components of quality of life: preserving pre-diagnosis capacities, personal meaning based on individual expectations and/ or hope and finally, the physical effects of disease (Figure 8.1).

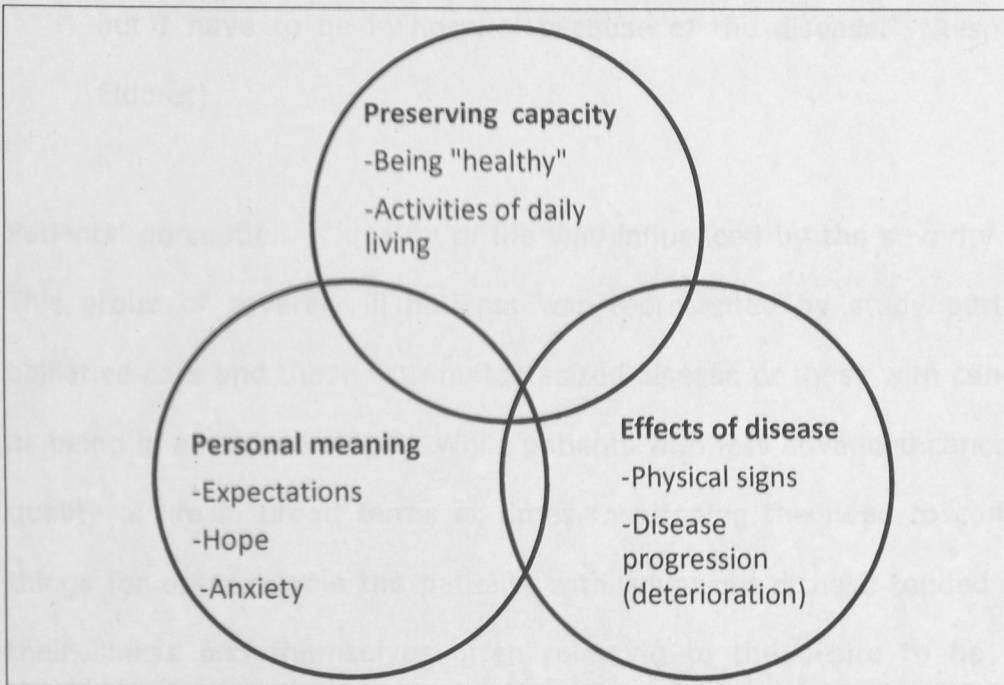


Figure 8.1: Breast and gynaecologic cancer patients' perception of the term quality of life

8.4 Preserving pre-diagnosis capacities

The ability to perform activities of daily living for oneself and to retain performance at the level prior to cancer diagnosis appeared to be important considerations for patients when they were asked to define quality of life. Other important aspects that featured in most definitions were related to being healthy or free from physical illness, ability to enjoy life, and to continue functioning "normally".

"Good quality of life is having good health and being able to do my daily work independently. I feel weak and have to use a wheelchair to move around... Life has no meaning when I am staying in hospital for long without going home. I cannot enjoy anything here. I even can't walk around because I feel sick. I am not able to stay with my family members

but I have to be in hospital because of the disease.” (Respondent 23, Eldoret)

Patients’ perception of quality of life was influenced by the severity of disease. This group of severely ill patients was represented by study participants on palliative care and those with metastasized disease or those with cancers staged as being in advanced stages. While patients with less advanced cancers spoke of quality of life in broad terms at times mentioning the need to continue doing things for other people the patients with advanced disease tended to focus on their illness and themselves often referring to the desire to be free of the physical effects of illness which they were currently experiencing.

“According to me quality of life means staying without any disease and enjoying life. The disease has affected my entire body until my legs too. The legs are paining and my body is also paining...” (Respondent 17, Nakuru. Breast cancer with metastases)

8.5 Physical effects of disease

A key feature of most definitions of quality of life was that patients outlined the impact of the disease by listing the physical signs associated with their illness. The detailed descriptions of physical signs implicitly illustrated the importance of disease progression resulting in manifestation of more clinical signs on patients’ perception of quality of life.

While describing the effects of disease most patients did not distinguish between the physical signs of the disease and the signs that resulted from the side effects

of treatment. However, a few patients were able to tell apart the side effects of treatment from the physical signs of cancer.

"The term quality of life means being able to do things one is used to do for the self and others. It also means being healthy. This illness has affected the state of my body in very many ways because I have constipation often. ... I am experiencing body aches and pains ... I also experience appetite changes quite often due to the effects of the illness and medication. I have been experiencing weight loss in the last 2-3 weeks." (Respondent 158, Nairobi. Cervix cancer)

8.6 Personal meaning/ Expectation and hope

Regardless of the type of cancer and in addition to the components of quality of life described above (functional capacity and clinical features of disease) it was noted that patients had an individualised dimension in their perception of quality of life.

"The care of my family is not much affected because I do not have children. I had one child but unfortunately he passed away a few years ago. My financial status is poor because the treatment of cancer is expensive and we are peasant farmers. I have financial strains."
(Respondent 114, Nairobi)

Importantly, patients who reported that the disease had not yet directly impacted on their quality of life gave a perception of quality of life that was shaped by fears and anxiety related to their future health state. In most cases patients feared that their condition would deteriorate, and this impacted on their present emotional state.

"Having a quality of life is being healthy and enjoying life in this world. This disease has not affected much in my life but it is just that I am worried and I feel that it might kill me. I have not changed body wise yet. I still care for myself very well. Right now I can go and work. I work as a tailor. I really don't feel happy and good in life after getting this disease."

(Respondent 16, Nakuru. Breast cancer)

Separately, there were patients who displayed hope concerning their condition and had positive expectation regarding the outcome of their illness. The patients with this perspective of quality of life reported different sources of hope that inspired expectation of positive outcome including previous experiences, knowledge, interactions with cancer patients, and spirituality.

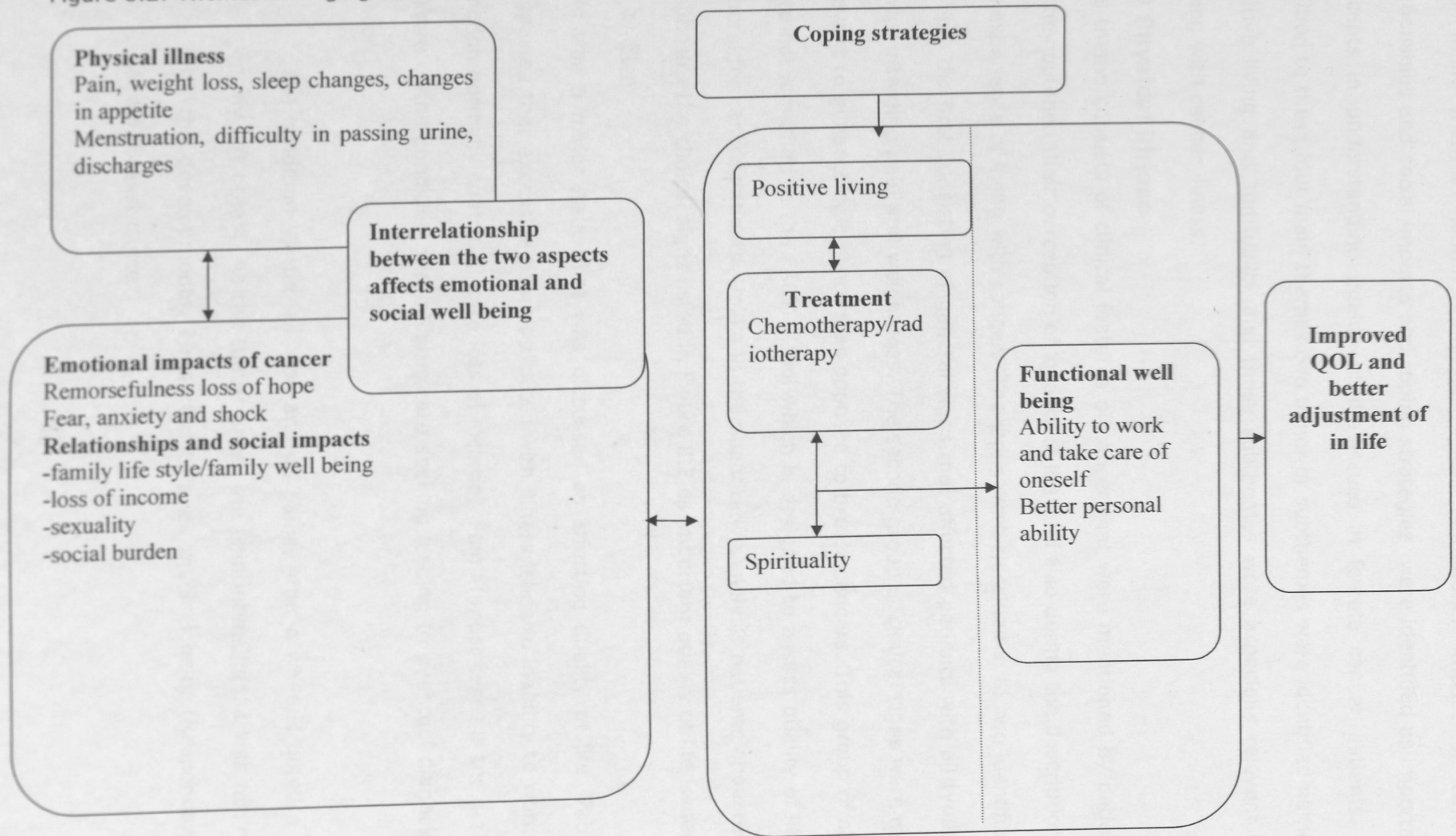
8.7 Quality of life issues

The qualitative analysis of quality of life issues took two approaches. First an inductive analysis of quality of life was done to identify important themes. The second and final section of the qualitative analysis used content analysis of patient narratives to determine how often patients mentioned the items or issues contained in the FACT-G tool so as to determine whether there were specific quality of life issues in female Kenyan cancer patients that were not identified by the FACT-G tool.

8.8 Themes identified

The model presented in figure 8.2 is proposed to explain how patients with breast and gynaecologic cancers perceive quality of life and each theme is discussed in the following section.

Figure 8.2: Themes emerging from inductive analysis of quality of life in female Kenyan cancer patients



Four main themes namely, physical illness, emotional impact of cancer, relationships and social impacts and coping strategies were identified as important concepts in understanding quality of life issues in female cancer patients. In addition to these four main themes two minor or subthemes were identified namely positive living and spirituality and these subthemes were especially relevant for coping with cancer illness.

8.9 Physical illness

This theme consists of clinical features of cancer that were mentioned by patients as they outlined their perception of 'quality of life' and also during the description of the experience of living with cancer. The signs were classified in to two identifiable groups, the first consisting of general signs that affected patients with all types of cancer including pain and weight loss. The second group of clinical signs were more relevant to gynaecologic cancers as opposed to breast cancers. This group of signs were not identified in the FACT-G tool which is designed to assess quality of life in general for cancer patients. Unlike in the quantitative analysis patients appeared to emphasise the clinical signs listed in Figure 8.2 as important quality of life issues.

a) Pain

Pain was a major issue that was discussed as affecting quality of life. Patients suggested that excessive pain associated with illness leads to inability to work and function normally contributing to loss of income. Pain in most cases is the defining feature of the condition and initiates care seeking leading to eventual diagnosis of cancer.

"The condition started with on and off pains. After a while, I noted a lump on my left breast. As the tumor grew, the pain intensified. I was not happy with the developments. I resorted to seek medical help. (Respondent 18, Nairobi. Breast cancer)

"This disease started just like a small one. I was scratching and scratching. It started like something sharp has gone inside then it went on swelling and swelling until it became so painful that if you bent like this you feel a lot of pain in the chest." (Respondent 1, Kisumu. Breast cancer)

Pain was noted to lead to further quality of life issues with patients explaining that it characterizes all aspects of the disease leading to unhappiness, loss of sleep. Pain was also described as occurring in specific locations depending on the type of cancer. Managing pain is among the critical aspects of care requiring resources both financially and emotionally and effective pain management in turn determines the patient coping with cancer.

b). Lack of appetite

One other aspect of physical well being that is affected by cancer is loss of appetite described as a result of chemotherapy or radiotherapy as the treatment increases as was described by a breast cancer patient:

"Physically, during the earlier times I had such difficulty getting up because I was so weak. I had no appetite and lost the taste for food. I would eat just because I had to but it was just as well as swallowing. My hair fell, and the color of my nails is darkened and my tongue is chipped such that I have difficulty eating" (Respondent 29, Nairobi)

Apart from being considered a treatment side effect, lack of appetite was also described as a symptom of the cancer by patients who reported that they experienced loss of appetite prior to initiation of cancer therapy. In addition this physical complaint was associated with other gastrointestinal symptoms most commonly nausea and vomiting.

c). Difficulty in passing urine

Pain and difficulty in passing urine was described by women who have cervical cancer as an initial effect. An important aspect of this sign was that though it is a physical issue it tended to affect social life style leading to emotional problems and a thus had greater overall impact on patient well being.

"When I go to the toilet I take so long until my children are concerned... I cannot seem to control urine and sometimes it just comes out on its own. You know, when it comes out like that I have to change so often and sometimes when in so much pain somebody has to assist me in changing."

d). discharges

The fourth feature of the effect of the illness on the physical well being is discharges which were described by patients with cancer of the cervix or ovary. Two key issues emanate from the description on discharges; It appears to signal that something is wrong thus makes patient seek care or generates emotional problems leading to some form of social stigma.

e). problems with bowels movement

Other patients did describe constipation and bloating as some of the effects of cancer. Although not clear on whether this was common in all types of cancer, patient's bowel problems were commonly associated with symptoms of certain cancers –ovarian, pelvic. Patients feel constipated most of the time when they eat making them unable to work or take care of themselves, resulting in low productivity at the work place.

f).Changes in Menstruation

Changes in menstruation were often described as part of the effect of cervical or breast cancer. Patients described a number of changes including complete stop of

menses after hysterectomy or chemotherapy. While in other cases, patients described intermittent menses heavy flow and changes in menses. What is not clear from the data is at what stage do these menses stop. However there were descriptions of intermittent menses and heavy flow as an initial symptom that prompts action while other physical changes such as dry mouth, difficulty in passing urine, pain and loss of hair were associated with changes in menstruation

g). Weight loss

In addition to the changes in menses patients also mentioned weight loss as a feature that is associated with treatment undertaken and in some cases the effect of the illness itself. Weight loss was also described with other physical changes such as dry mouth, loss of breadth, fatigue:

These changes in many instances were viewed to require effort to recover generating extra demand for good nutrition. In other cases weight loss was described to be linked to poor appetite and financial strains that leads to poor nutrition as well as stress.

8.10 Emotional impact of cancer

The other broad domain of cancer's impact on QOL is the emotional aspects which contribute to poor QOL. Emotional support was often described by patients to be a key area that is affected most. Social support from family and friends generate positive feelings that provide emotional support necessary to cope with the illness. In cases where family members are aware and had accepted the illness if appeared that patients had fewer challenges compared to those whose families were not aware as one patient pointed out:

"I get support from my husband and friends financially and materially. They have accepted my illness and support me in all ways." (Respondent 114, Nairobi)

a). Remorsefulness, powerless and loss of hope

Emotional support is key to better quality of life and is facilitated by both family and social networks as it has already been alluded to. However in almost all the patients there was an expression of remorsefulness and desperation. The feelings of remorse and powerless appear to be linked to the challenge of dealing with the illness and its effects. The magnitude was dependant on the stage of illness with those in the late stages of the disease seemingly expressing loss of hope feel powerless to do anything about it. Secondly, as patients cannot explain the cause and due to the bitterness associated with the effect patients appear to be helpless and expressed life full of anxiety. Lack of explanations leads to seek divine intervention as one patient pointed out:

"I don't understand what exactly brings about cancer. I trust God will do his will. I feel bloated even after eating very little food. I have lost my appetite and lost weight too" (Respondent 13, Nairobi)

Anxiety fear and remorse is also linked to the fact since they know it is a terminal illness, they seem to dwell on the effects of the illness to their families once they die. Failure to adjust to the emotional stress leads to depression affecting the emotional well being and overall QOL. This was also linked to the situations when they have fear of resurgence of the illness as one patient described it:

"At the moment I am very anxious and depressed. The doctors fear that my cancer has spread and resurged. I really feel that my fate hangs on the balance. My family members have been very empathetic. They have also

been the main source of support for me. My husband has also been very supportive. Since this disease resurfaced sexual relationship with him have been put on hold" (Respondent 31, Mombasa)

b). Fear and shock

A closer look of the effect of the emotional dimension is the relationship between fear anxiety and shock. This section highlights the role of fear and how it affects the emotional well being. Overall, fear is expressed in different ways either as fear of the future of family or fear of the condition itself and whether it will recur. Fear about the future of the family especially for patients that have small children appear to dominate the patient's lives. The fear of loss of income and livelihood to the patients and their family brings the emotive responses as clearly depicted by a patient from Kisumu:

"The reasons for worry sometimes are because I have a child in primary standard four for whom I had to sell my sawing machine to raise school fees. I feel useful and my body has not changed much".(Respondent 14, Kisumu)

The second aspect in which fear is expressed is fear of resurgence of the illness for those who have undergone some form of treatment. Since the disease challenges every aspect of the patient's life, the loss of hope is reflected in the patient's many social dimensions.

8.11 Relationships and social impacts of cancer

a). Effect on family life style and destabilizes the social fabric

The illness generates a perception that patients are a social burden to their immediate families, friends and relatives. Some noted that as they seek care in

referral facilities that are far from their homes, they spend time in either homes of families or friends of which case burdening them. The nature of the specialised care sought for cancer following referral results in patients spending time with relatives and friends which was seen as burden to the wider community. Separately the inability to work is also perceived as an additional burden on other family member who are forced to work for sick members.

"Now that I am not working, I depend on support from friends and close friends. I was informed about the nature of my disease when I was admitted in this ward last week (Nakuru Rift Valley General Hospital).

The effect of illness on family life style was also clear when patients described how the illness itself has strained relationships between husbands and wives, and also patients and other family members.

b). Effect on family income

The role of cancer in precipitating a financial burden to the families of patients who have cancer was clearly an issue that affects both the social and emotional dimension of their lives. One patient described this:

"Economically the bills are normally paid for by my daughter. My husband has no steady salary and this makes us look up to the daughter and sister who cater for practically everything. I feel we have overburdened them instead of them concentrating on different personal issues" (Respondent 09, Nairobi, Cervical cancer)

Inability to work also leads to loss of income. Due to the effects on physical structure and the pains associated with the illness, cancer patients are unable to work and thus their family or their own source of income is curtailed. Cancer patients also mentioned that loss of income is linked to the payments for services

such as medicines and diagnostics which continue to deplete the existing resources. The illness leads to families relying on well wishers and other member of the wider family and friends generating a perception of burdening the other members which exacerbates the emotional well being. Furthermore due to poverty levels already existing, the illness pushes families and individuals further into poorer levels due to costs of medicines and diagnostics. Financial problems contributes to worries and anxiety too which leads to poor emotional well being it also increases the dependence ratio. The social effects of cancer begins with diagnosis and the process of seeking care then depletes existing resources and as the disease progresses it strains the sources of income leading to impoverished families- ie leads to catastrophic expenditure making them poorer

The illness also has played a big role in impoverishing household as some patients almost lost their jobs as the process of treatment took a lot of time necessitating the employer to almost retire them. This has made them loose income and has threatened family bond in that the family source of income is curtailed compounding effect on current family fabric threatening it. This illness affects social support of the family in that the pain deters women from effectively caring for their families.

c). Effect on sexuality

The other question worth exploring is the effect of cancer on sexuality and the implications of such an event on the social and emotional well being. Pain and bad odour associated with cancer affects sexual activities denying partners their marital needs:

"My husband was shocked at first but we talked about the condition but later he accepted it. He has been very understanding. Imagine we have not

made love since March, I think it is also because smell puts him off. I have never felt that sexy since then but I hope it will end after my operation”

However there appears to be some level of understanding on the part of partners amongst those who have accepted the condition. The fear of loss of sexual activities generates another social problem of fear of infections and thus threatens the social fabric in the family.

Sexual problems strains relationships and although not well expressed may have implications on emotional well being of patients.

8.12 Coping strategies

To address the above problems, patients described a number of coping strategies ranging from simple actions of dressing to complex social structures that exist in the communities.

a). Dressing

One simple strategy is changing some aspects of life style. For those patients that have breast cancer for example was reported to using clothes that cover chest well and do not irritate them. This appears like a practice that is used to illustrate how the disease has made patients make personal choices that are positive: *“Sometimes back, I used to dress any kind of attire but you know since I had the operation, I normally put on clothes that cover my chest. It gets to a point where some things cannot be done because of a particular condition but I thank God for everything”*

8.13 Positive living

To overcome the challenges of the illness, patients expressed the need to live positively as one strategy that keeps them going. This reduces the effects of anxiety and depression especially when one knows the state of illness and deals with it. Acceptance of the condition precipitates better positive living as was described by ovarian cancer patients:

"The good thing is I accepted my fate and decided to go on with the treatment. It was discovered at the time of the biopsy that I had just conceived and I was not even aware yet I was just taking the drugs for cancer. I was told that it was possible that I contracted the cancer at the time I was using contraception. I suspected this is because, I was asked a lot of questions about the contraception I used before and if I had ever used pills for the same. After carrying my pregnancy to term and giving birth, my husband urged me to go back for treatment"

The discussion of positive living was largely affected by the way they perceived the illness and level of acceptance of the conditions by oneself as well as family. To cope with the disease most patients have to accept the way things are.

For those who use the strong social family ties this instils in themselves a sense of hope. Positive living is thus an outcome of many factors such as acceptance, family support, spiritual support and ability to cope with the disease.

8.14 Spirituality

Positive living is also intertwined with religious aspects with patients who hold deep spiritual beliefs showing better adjustment and positive attitude toward their illness. Positive living is thus a function of a number of factors: spirituality and

religion. Being a Christian has helped families come to terms with the illness leading to absolute trust in God. This realization is likely to be linked to the fact that they cannot explain the causes of illness or their inability to do anything in the event of identifying they have cancer a terminal illness. This faith appears to increase with the patient's desire to have more reliance to God and eventually helps them cope with the illness. For those who were previously religiously are likely to have better chances of coping with the illness. Families with religious affiliation appear to have a higher probability to deal with the illness and gives them hope spiritual activities either increase or decrease when patients for example cannot move or walk.

"What I treasure most, is that apart from accepting the condition, you need support and also the mind...Being a Christian, I went through the word of God searching to know why it had to happen to me. The answer I got was some things happen for God's name to be glorified. I had to come up strongly and leave everything to God to take control.

Secondly apart from the spiritual support offered by religion, it is noteworthy that religious organisations at times assist with financial and material aspects of cancer care. The religious principles that patients adopt in turn makes them even support others and seek ways of keeping themselves busy as was described by a participant:

"In Africa, that amount of money is not easy to get and many people die because of lack of money. You also vomit a lot. Just thinking about it gives me pain. I normally vomit blood. With the second chemo (Docetaxel) there is no vomiting. I go to Emmanuel's church near Nairobi University. I feel peace here in Kenya because of my spiritual life. I am teaching people about

cancer, how you can take care of yourself and also on HIV in church, village and around wedding places especially amongst the Borana people”

8.15 Content analysis of quality of life issues

The ranking of quality of life issues contained within FACT-G questionnaire based on content analysis of oral narratives obtained from female cancer patients is shown in Table 8.1.

The leading quality of life issues were either physical or functional well being issues and included: lack of fulfilment in work, inability to work, lack of energy, pain, trouble meeting family needs, feeling ill, inability to enjoy life and things done for fun. These issues corresponded to the patients’ perceptions of quality of life and the themes that emerged from the inductive analysis.

The following issues were ranked as unimportant based on content analysis of patient narratives: losing hope in fight against cancer, lack of emotional support from families, family communication about illness and worrying about dying.

Table 8.1: Ranking of quality of life issues from content analysis of QOL narratives of female cancer patients

Quality of life issue	Domain
My work (include work at home) is fulfilling	Functional
I am able to work	Functional
I have a lack of energy	Physical
I have pain	Physical
I have trouble meeting the needs of my family	Physical
I feel ill	Physical
I am able to enjoy life	Functional
I am enjoying the things I usually do for fun	Functional
I feel sad	Emotional
I am sleeping well	Functional
I am content with the quality of my life right now	Functional
I am bothered by side effects of treatment	Physical
I am satisfied with my sex life	Social
I am forced to spend time in bed	Physical
I worry that my condition will get worse	Emotional
I am satisfied with how I am coping with my illness	Emotional
I have nausea	Physical
I feel nervous	Emotional
I feel close to my partner	Social
I feel close to my friends	Social
I get support from my friends	Social
I worry about dying	Emotional
I am satisfied with family communication about my illness	Social
My family has accepted my illness	Social
I get emotional support from my family	Social
I have accepted my illness	Functional
I am losing hope in the fight against my illness	Emotional

8.16 DISCUSSION

The qualitative analysis presented in this chapter can be summarized by two broad findings. Firstly, perception of term 'quality of life' in cancer patients is multifaceted with significant overlap and interactions between the different facets. In general, 'quality of life' is defined based on the impact of cancer. Secondly, four main themes (physical illness, emotional impact of cancer, relationships and social impacts and coping strategies) and two emerging themes (spirituality and positive living) are identifiable in narratives of patient experiences living with breast and gynecologic cancer.

The finding on perception of quality of life points to the complexity of defining a concept that spans different aspects of an individual's life and also encapsulates a patient's daily and ongoing interactions with his immediate environment. As such patient perceptions of quality of life can evolve over time,²¹⁸ be shaped by both internal and external factors key among these being the severity of illness and social support available to an individual.²¹⁹ These issues that shape an individual patient's perception of quality of life constitute the 'personal meaning' facet of quality of life defined in our analysis. Other qualitative explorations of quality of life in cancer patients have similarly recognized the prominent role of contextualized factors in shaping patient perceptions.²²⁰ For cancer patients, the personal meaning of an illness is also influenced to a large extent by patient expectations or hopes following the diagnosis of cancer, especially for side effect of therapy.^{221, 222}

Whilst in the quantitative analysis presented in chapter 5, the physical domain was the third domain in the ranking of quality of issues physical illness emerged as an important theme in the qualitative analysis. Use of qualitative and quantitative methods is a major strength of this study as demonstrated in this particular instance. While recognizing previous effort to translate the FACT-G tool into foreign languages including Swahili, which is predominantly used in our settings it is

plausible that the apparent incongruence between the quantitative findings in the FACT-G tool and the qualitative findings could point to the importance of context specific issues which could impact on the validity and reliability of the responses in Kenyan females.²²³

In common with other qualitative studies the functional, emotional and social issues emerged as important factors in the experiences of female patients with cancer.²²⁴⁻²²⁸ The common social and relationship issues that emerge following diagnosis with gynecologic or breast cancers affect marital relationships and specifically impact on sexual functioning, therefore agreeing with the quantitative analysis presented in the preceding chapters of this thesis and also in previous quality of life studies.²²⁸

The finding that spirituality was an important quality of life issue has been reported previously with documentation of evidence that the importance of religiosity and spirituality on quality of life depends on contextual factors including ethnicity and race.²²⁹⁻²³¹ These factors reflect societal or technological advancements in medical care which are known to have a direct impact on outcome of illness possibly explaining the importance of the spirituality theme in the Kenyan society. It is important to state that the expanded version of the FACT-G tool contains a spiritual domain but data for this domain was not used in this analysis. Therefore rather than representing a limitation of the FACT-G tool the emergence of this subtheme implies a greater utility of the extended version of the tool compared to the general version of FACT tool in settings like Kenya.

CONCLUSION AND RECOMMENDATIONS

9.1 Summary

The study reported in this thesis aimed at conducting a comprehensive assessment of the quality of life issues of female patients with breast cancer and gynaecologic cancers in Kenya. The findings presented here demonstrated the following:

- The leading quality of life issues among patients with breast and gynaecologic cancers in Kenya are: worrying that condition will get worse, lack of satisfaction with sexual life, losing hope, worry about dying, lack of fulfilment in work and feeling nervous. The issues in the emotional domain were most affected by cancer.
- The oral interview identified themes which matched the domains of the FACT-G tool namely physical illness, emotional impact of cancer, relationships and social impacts of cancer and coping strategies. In addition the oral interviews demonstrated the prominent role of positive living and spirituality themes in defining quality of life of Kenyan patients.
- Patients perceived the term quality of life as having three interrelated components: preserving pre-diagnosis capacities, personal meaning, and effects of cancer.
- Patient demographic factors and socio-economic factors were reported to influence specific quality of life issues.
- Patient scores of overall quality of life measured using the FACT-G score patients were lower scores on the functional well being and emotional well being domains.
- Overall quality of life (FACT-G) was influenced by type of cancer and treatment modality.

- In comparison to FACT-G, which reported emotional issues were the leading quality of life issues content analysis of patient narratives identified functional and physical issues including pain as important issues.

9.2 Study strengths and limitations

A key strength of this study lies in the fact that it used a pragmatic approach to the assessment of the real life experience of cancer patients utilising routine cancer treatment services as opposed to studies which are conducted within trials or under other idealised conditions. This is an important consideration given the high cost of cancer management in Kenya and the prevailing absence of health insurance cover for majority of Kenyans. Within the Kenyan context, public facilities as captured in this study provide most of the cancer care. Second and from a methodological perspective, the internal validity of the study was improved by using FACT-G, a previously developed and validated tool for assessing quality of life. Additionally the study employed methodological triangulation by using different data collection instruments.

The study sample was drawn from across the country but there was overrepresentation of Christians and residents from Central and Eastern regions of the country, compared to national demographics. This overrepresentation of specific groups could impact on the external validity of the study. In addition, the demographic characteristics were also fairly representative of that of females in the Kenyan population. The main limitation of this study was the failure to accurately capture histological staging of the different cancer type among participants. To a and other low income settings. Availability of such data would have made it possible to clarify the effect of disease stage on quality of life more conclusively.

The sample for the study was drawn from patients who came to the hospitals and hospices. As such, it is only those patients admitted or attending outpatient clinics or Hospices, who participated in the study. This limits the patient characteristics to hospital regulations and rules about admissions and outpatient units' attendance, as there are hospital policies relating to whom, why, when to attend particularly government-run health services. Also noted is dependence on the referring medical personnel involved in the initial evaluation of the patient, the consulting or specialist centres that have the capacity and facilities to manage patients with gynaecological and breast cancers.

It may be seen also that the FACT and interview guide have not been validated, not only in the Kenyan society, but also purely in an African setting. This raised difficulties during analysis as standard terms and phrases had to be used against an unfamiliar background. However, openness of the interviews and the possibility of reaching saturation points in the themes and reducing observer's biases ameliorated this difficulty.

In spite of these considered limitations; provisions were made to ensure the study's most important questions were answered satisfactorily.

9.3 Significance of results

9.3.1 Methodological:

The findings presented in this thesis represent a significant step towards advancing existing approaches used to assess quality of life of patients with cancer and in particular breast and other gynaecologic cancers in Africa. There are several validated tools for assessing QOL, most notably the EQ-5D, SF-36 and FACT-G which have all originated in the developed countries. Recent efforts to develop tools for assessment of QOL in Africa have focused in Southern Africa countries. The FACT-G tool used in this study has been translated into three African languages spoken in Southern Africa.²³² The EQ-5D has also been validated in Zimbabwe

another Southern Africa country. In East Africa, notable quality of life work was undertaken with the translation of SF-36 health survey instrument into Swahili in Dar es Salaam, Tanzania.²²³

This study is unique for the following reasons:

- i. Based on a systematic literature search this is the first study to apply FACT-G approach in evaluating QOL issues among Kenyan or East African females with breast and other gynaecologic cancers.
- ii. As reported above several African studies have examined QOL among terminally ill cancer patients and cancer patients undergoing treatment. However, this study is among the first to examine whether the issues contained within the tools for measuring QOL originating in developed countries encompass the African perception of QOL.
- iii. This study demonstrates the need for better conceptual foundations in developing QOL instruments by demonstrating the possible exclusion of pertinent QOL issues (among African women) from the FACT-G tool.

9.3.2 Understanding perception of QOL:

This study has made significant contributions in defining the perception of QOL among Kenyan female patients with cancer. The main findings in this study indicate that the social domain of the FACT-G tool did not match the perception of QOL among Kenyan females with breast and gynaecologic cancer. Compared to the other domain the social domain as currently constituted in the tool elicited the widest variability in the range of responses from patients. In addition only one item, which is dissatisfaction with sexual life, was considered an important issue. This finding implies that the tool may be lacking in pertinent areas of concern for African women with gynaecologic cancers.

As noted earlier the FACT-G tool has previously been translated into three African languages. During this prior work by Mullin and colleagues and in agreement with the findings reported in this thesis cultural difference in social values and functioning were noted to have caused problems with translation of the Social/Family wellbeing subscale.²³²

9.4 Implication for patient care

This study has successfully highlighted several areas of patient care that should receive due consideration while providing care to female patients with breast or gynaecologic cancers. The main issues include emotional concerns, family well being manifesting as lack of satisfaction with sexual life and functional well being related to satisfaction from work.

Out of the factors examined for associations with QOL issues in this study including demographic factors, socioeconomic factors, treatment modality and type of cancer, treatment modality is the factor that showed the greatest influence on QOL issues. Patients on palliative care and those on combined modalities reported more concern about their QOL. The mode of treatment therefore should be a primary consideration in addressing QOL issues among patients with breast or gynaecologic cancers.

Apart from patient related issues the study also underscored important gaps in the nursing and clinical care of cancer patients in Kenya.

9.5 Implication for nursing practice

In common with health systems in other resource-constrained setting the Kenya health sector faces severe human resource shortages prompting use of substitute health workers in expanding access to services. The capacity of the nursing workforce in Kenya is already overstretched. As such there are no easy solutions to

the additional patient care demands placed on nurses by the recommendations made in this study. However, reorientation of current nursing practice can result in increased efficiency in delivering patients care and to a degree help with realising study recommendations. These changes can be made both at the professional and individual nurse levels.

As a profession nursing practice should strongly embrace a multidisciplinary approach to provision of patient care. In facilities where multidisciplinary teams exist which are rare in Africa, nurses should develop strong functional relationships with health worker cadres charged with providing psychosocial support to patients to ensure cancer patients benefit from such care. The nurses should also strive to acquire such skills themselves. In the past except for nurses in sub specialities dealing directly with mental health and psychiatric nursing nurses had tended to view emotional and psychosocial support of patients as the domain of specially trained cadres of health workers. As a result most patients miss out on psychosocial care as evidenced by the observation in this study that issues in the emotional domain were the leading cause of concern among cancer patients. Since for most patients the nurse is the first point of contact within the health system nurses should be better equipped to handle emotional concerns among patients. This can be achieved by reviewing nursing curriculums and emphasising psychosocial aspects of care during nursing training.

Apart from re-evaluating nursing training at professional level nurses can play a role at the individual level to effect changes in practice. Nurses should ensure that their practice promotes holistic care of patients rather than adopting a focus on the disease conditions patients present with.

9.6 Conclusion

QOL issues related to the emotional well being of patients rank high compared to issues in the functional, physical, and social domains. The modality of treatment used in patient management had the greatest influence on QOL issues while demographic factors had limited influence on these issues. The emotional issues identified in this study are amenable to nursing intervention and nurses should be prepared during their training to provide patient-centred and holistic care.

To address concerns related to QOL issues among female cancer patients emphasis should also be placed on multidisciplinary approach to patient care ensuring involvement of health worker cadres that provide psychosocial support in cancer patient care. QOL assessment in African patients should consider cultural differences in patient settings and the influence of these differences on social functioning and patient perception of QOL issues. Further studies are required to better define social issues influencing QOL of female Kenyan patients with cancer and evaluate effective interventions to promote QOL.

9.7 Recommendations

The findings presented here are interesting because the emotional domain which is amenable to nursing intervention presents the most important challenges to attainment of optimal quality of life among Kenyan patients. This finding deserves consideration among both the stake holder involved in formulating nursing care policies and nursing education as well as the nurses providing frontline care to terminally ill patients. In resource constrained setting like ours, provision of holistic patient care should be emphasized at all stages beginning from training, through to patient care guidelines and patient care policy recommendations made both at the broader health system level and lower units. Counsellors are rarely available and it

should be the duty of each health worker to provide psychosocial care to patients concurrently with other therapeutic management.

Among the demographic factors, formal education appeared to have a strong influence on patient perception of QOL issues pointing to the potential benefit of awareness creation on cancer among the public and more specifically among patients undergoing treatment or on palliative care. The study recommends that viable alternatives for sustained awareness creation on cancer be explored. These interventions and the content delivered should be targeted because public campaigns as currently implemented might not achieve the desired level of awareness among patients. Further, such interventions should target populations with socioeconomic indicators related with limited formal education including low income or socioeconomic status, and occupations associated with low levels of formal education.

The study finding that certain domains consistently rank high while others are consistently scored as unimportant reinforces the argument that quality of life issues are context specific. While family well being issues are important within the setting in which the FACT-G tool was developed this is not the case in Kenya and possibly other African countries. Based on this finding the study recommends that in the interim period before development of specific tools for assessing QOL in African settings methodological triangulation provides a viable option for applying existing tools while providing information on the shortcoming of these tools in the African setting through collecting additional data on QOL issues outside the domains in FACT-G tool with a view of developing tools that will overcome these limitations.

Following the identification of the main quality of life issues in Kenyan females with breast and gynaecologic cancer and the documentation of the differences in perception of QOL in this group of patients this study has highlighted several areas

with significant scope for future research aimed at improving QOL of cancer patients. The following areas are relevant particularly for female patients with breast and gynaecologic cancers:

- i. Examine the social values and functioning among the different African cultures with the aim of defining the issues that impact on patient perception of QOL in the social domain within African settings.
- ii. Evaluate effective interventions or approaches for providing psychosocial support and addressing emotional concerns of cancer patients within the constraints of the Kenyan health system.
- iii. Design interventions to help patients with cancer adjust to the changes in functional well being especially related to their ability to work and provide for their families during the phases of active treatment or during advanced stages of illness.
- iv. Identify and develop standard approaches to assess quality of life issues.

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APPENDICES

APPENDIX I- Influence of patient demographic and socioeconomic factors of quality of life issues

APPENDIX Ia- Physical well being issues

1) I have a lack of energy

	I have a lack of energy			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Age category				
18-24 years	0(0%)	1(11%)	8(89%)	0(0%)
25-34 years	7(18%)	18(45%)	15(38%)	0(0%)
35-44 years	11(11%)	54(53%)	32(31%)	5(5%)
45-54 years	18(16%)	56(49%)	34(30%)	7(6%)
55-64 years	6(8%)	36(48%)	27(36%)	6(8%)
65-74 years	3(8%)	18(50%)	12(33%)	3(8%)
75 years and above	2(14%)	4(29%)	8(57%)	0(0%)
Not stated	0(0%)	2(67%)	0(0%)	1(33%)
Marital status				
Married	29(11%)	131(50%)	86(33%)	15(6%)
Widowed	12(21%)	25(43%)	20(34%)	1(2%)
Single	4(9%)	18(38%)	23(49%)	2(4%)
Divorced	2(8%)	12(50%)	7(29%)	3(13%)
Not stated	0(0%)	3(75%)	0(0%)	1(25%)
Tribe				
Kikuyu	18(10%)	82(47%)	62(35%)	13(7%)
Kamba	2(5%)	25(57%)	14(32%)	3(7%)
Luo	8(21%)	13(34%)	16(42%)	1(3%)
Luhya	5(15%)	18(53%)	11(32%)	0(0%)
Coastal tribes	4(11%)	20(54%)	12(32%)	1(3%)
Kisii	3(14%)	9(43%)	7(33%)	2(10%)
Kalenjin	3(23%)	6(46%)	4(31%)	0(0%)
Meru	0(0%)	7(64%)	3(27%)	1(9%)
Embu	0(0%)	4(67%)	2(33%)	0(0%)
Others	3(23%)	5(38%)	5(38%)	0(0%)
Religion				
Protestant	29(10%)	136(49%)	97(35%)	16(6%)
Catholic	16(18%)	40(44%)	30(33%)	4(4%)
Muslim	2(9%)	11(50%)	8(36%)	1(5%)
Other	0(0%)	2(50%)	1(25%)	1(25%)

Socioeconomic factors

	I have a lack of energy			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Level of formal education				
No formal education	18(17%)	55(50%)	30(28%)	6(6%)
Primary education	19(11%)	93(52%)	56(31%)	11(6%)
Secondary education	6(7%)	32(40%)	39(48%)	4(5%)
Tertiary education	4(22%)	5(28%)	9(50%)	0(0%)
Not stated	0(0%)	4(57%)	2(29%)	1(14%)
Occupation				
Small scale farmer	20(15%)	77(57%)	33(25%)	4(3%)
Housewife	14(11%)	53(41%)	51(39%)	12(9%)
Small scale business	7(16%)	21(48%)	15(34%)	1(2%)
Professional	5(15%)	10(29%)	17(50%)	2(6%)
Skilled employment	1(11%)	3(33%)	4(44%)	1(11%)
Other	0(0%)	5(38%)	7(54%)	1(8%)
Not stated	0(0%)	20(67%)	9(30%)	1(3%)
Monthly income				
Less than KES 2500	26(10%)	129(51%)	80(32%)	16(6%)
KES 2501-7500	5(9%)	25(46%)	21(39%)	3(6%)
KES 7500	2(8%)	12(48%)	10(40%)	1(4%)
KES 12501	1(6%)	6(38%)	9(56%)	0(0%)
KES 17501	0(0%)	5(56%)	4(44%)	0(0%)
Above KES 22500	2(40%)	1(20%)	1(20%)	1(20%)
Undisclosed	11(32%)	11(32%)	11(32%)	1(3%)
Permanent residence				
Central	18(11%)	79(46%)	61(36%)	13(8%)
Eastern	3(5%)	36(58%)	19(31%)	4(6%)
Nyanza	10(17%)	21(36%)	24(41%)	3(5%)
Coast	4(11%)	21(55%)	12(32%)	1(3%)
Western	6(17%)	20(56%)	10(28%)	0(0%)
Rift valley	4(22%)	7(39%)	7(39%)	0(0%)
Other regions	2(18%)	5(45%)	3(27%)	1(9%)

2) I have nausea

Demographic factors

	I have nausea			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Age category				
18-24 years	0(0%)	4(44%)	5(56%)	0(0%)
25-34 years	2(5%)	21(53%)	17(43%)	0(0%)
35-44 years	11(11%)	40(39%)	46(45%)	5(5%)
45-54 years	13(11%)	42(37%)	52(45%)	8(7%)
55-64 years	2(3%)	30(40%)	37(49%)	6(8%)
65-74 years	5(14%)	13(36%)	15(42%)	3(8%)
75 years and above	2(14%)	6(43%)	6(43%)	0(0%)
Not stated	0(0%)	0(0%)	2(67%)	1(33%)
Marital status				
Married	21(8%)	112(43%)	112(43%)	16(6%)
Widowed	9(16%)	16(28%)	32(55%)	1(2%)
Single	2(4%)	17(36%)	26(55%)	2(4%)
Divorced	3(13%)	9(38%)	9(38%)	3(13%)
Not stated	0(0%)	2(50%)	1(25%)	1(25%)
Tribe				
Kikuyu	17(10%)	75(43%)	70(40%)	13(7%)
Kamba	3(7%)	14(32%)	23(52%)	4(9%)
Luo	4(11%)	17(45%)	16(42%)	1(3%)
Luhya	4(12%)	13(38%)	17(50%)	0(0%)
Coastal tribes	0(0%)	15(41%)	21(57%)	1(3%)
Kisii	3(14%)	4(19%)	12(57%)	2(10%)
Kalenjin	3(23%)	3(23%)	7(54%)	0(0%)
Meru	0(0%)	4(36%)	6(55%)	1(9%)
Embu	0(0%)	3(50%)	3(50%)	0(0%)
Others	0(0%)	8(62%)	5(38%)	0(0%)
Religion				
Protestant	22(8%)	106(38%)	133(48%)	17(6%)
Catholic	12(13%)	37(41%)	37(41%)	4(4%)
Muslim	1(5%)	12(55%)	8(36%)	1(5%)
Other	0(0%)	1(25%)	2(50%)	1(25%)

Socioeconomic factors

	I have nausea			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Level of formal education				
No formal education	2	39(36%)	50(46%)	7(6%)
Primary education	11(6%)	84(47%)	73(41%)	11(6%)
Secondary education	9(11%)	26(32%)	42(52%)	4(5%)
Tertiary education	2(11%)	4(22%)	12(67%)	0(0%)
Not stated	0(0%)	3(43%)	3(43%)	1(14%)
Occupation				
Small scale farmer	18(13%)	48(36%)	63(47%)	5(4%)
Housewife	6(5%)	56(43%)	56(43%)	12(9%)
Small scale business	5(11%)	19(43%)	19(43%)	1(2%)
Professional	2(6%)	10(29%)	20(59%)	2(6%)
Skilled employment	2(22%)	2(22%)	4(44%)	1(11%)
Other	1(8%)	4(31%)	7(54%)	1(8%)
Not stated	1(3%)	17(57%)	11(37%)	1(3%)
Monthly income				
Less than KES 2500	18(7%)	113(45%)	104(41%)	16(6%)
KES 2501-7500	8(15%)	18(33%)	25(46%)	3(6%)
KES 7500	1(4%)	8(32%)	15(60%)	1(4%)
KES 12501	1(6%)	4(25%)	10(63%)	1(6%)
KES 17501	0(0%)	3(33%)	6(67%)	0(0%)
Above KES 22500	1(20%)	2(40%)	1(20%)	1(20%)
Undisclosed	6(18%)	8(24%)	19(56%)	1(3%)
Permanent residence				
Central	17(10%)	74(43%)	67(39%)	13(8%)
Eastern	3(5%)	21(34%)	33(53%)	5(8%)
Nyanza	7(12%)	20(34%)	28(48%)	3(5%)
Coast	0(0%)	15(39%)	22(58%)	1(3%)
Western	4(11%)	14(39%)	18(50%)	0(0%)
Rift valley	3(17%)	5(28%)	10(56%)	0(0%)
Other regions	1(9%)	7(64%)	2(18%)	1(9%)

3) I have trouble meeting the needs of my family
Demographic factors

	I have trouble meeting the needs of my family			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Age category				
18-24 years	0(0%)	2(22%)	5(56%)	2(22%)
25-34 years	12(30%)	20(50%)	8(20%)	0(0%)
35-44 years	27(26%)	50(49%)	20(20%)	5(5%)
45-54 years	36(31%)	51(44%)	20(17%)	8(7%)
55-64 years	17(23%)	41(55%)	11(15%)	6(8%)
65-74 years	9(25%)	17(47%)	6(17%)	4(11%)
75 years and above	4(29%)	7(50%)	3(21%)	0(0%)
Not stated	0(0%)	1(33%)	1(33%)	1(33%)
Marital status				
Married	62(24%)	142(54%)	40(15%)	17(7%)
Widowed	26(45%)	15(26%)	16(28%)	1(2%)
Single	12(26%)	19(40%)	13(28%)	3(6%)
Divorced	4(17%)	12(50%)	4(17%)	4(17%)
Not stated	1(25%)	1(25%)	1(25%)	1(25%)
Tribe				
Kikuyu	38(22%)	93(53%)	27(15%)	17(10%)
Kamba	10(23%)	23(52%)	8(18%)	3(7%)
Luo	16(42%)	15(39%)	6(16%)	1(3%)
Luhya	11(32%)	13(38%)	10(29%)	0(0%)
Coastal tribes	13(35%)	15(41%)	8(22%)	1(3%)
Kisii	7(33%)	8(38%)	4(19%)	2(10%)
Kalenjin	4(31%)	5(38%)	4(31%)	0(0%)
Meru	0(0%)	7(64%)	3(27%)	1(9%)
Embu	1(17%)	4(67%)	1(17%)	0(0%)
Others	4(31%)	6(46%)	3(23%)	0(0%)
Religion				
Protestant	71(26%)	135(49%)	52(19%)	20(7%)
Catholic	29(32%)	39(43%)	18(20%)	4(4%)
Muslim	4(18%)	14(64%)	3(14%)	1(5%)
Other	1(25%)	1(25%)	1(25%)	1(25%)

Socioeconomic factors

	I have trouble meeting the needs of my family			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Level of formal education				
No formal education	40(37%)	43(39%)	20(18%)	6(6%)
Primary education	40(22%)	100(56%)	25(14%)	14(8%)
Secondary education	18(22%)	34(42%)	24(30%)	5(6%)
Tertiary education	5(28%)	8(44%)	5(28%)	0(0%)
Not stated	2(29%)	4(57%)	0(0%)	1(14%)
Occupation				
Small scale farmer	41(31%)	63(47%)	24(18%)	6(4%)
Housewife	35(27%)	64(49%)	19(15%)	12(9%)
Small scale business	15(34%)	21(48%)	7(16%)	1(2%)
Professional	8(24%)	14(41%)	10(29%)	2(6%)
Skilled employment	3(33%)	3(33%)	2(22%)	1(11%)
Other	2(15%)	4(31%)	6(46%)	1(8%)
Not stated	1(3%)	20(67%)	6(20%)	3(10%)
Monthly income				
Less than KES 2500	66(26%)	129(51%)	39(16%)	17(7%)
KES 2501-7500	12(22%)	26(48%)	13(24%)	3(6%)
KES 7500	3(12%)	13(52%)	7(28%)	2(8%)
KES 12501	4(25%)	12(75%)	0(0%)	0(0%)
KES 17501	1(11%)	3(33%)	5(56%)	0(0%)
Above KES 22500	2(40%)	2(40%)	0(0%)	1(20%)
Undisclosed	17(50%)	4(12%)	10(29%)	3(9%)
Permanent residence				
Central	37(22%)	90(53%)	27(16%)	17(10%)
Eastern	11(18%)	35(56%)	12(19%)	4(6%)
Nyanza	21(36%)	24(41%)	10(17%)	3(5%)
Coast	13(34%)	16(42%)	8(21%)	1(3%)
Western	14(39%)	13(36%)	9(25%)	0(0%)
Rift valley	6(33%)	7(39%)	5(28%)	0(0%)
Other regions	3(27%)	4(36%)	3(27%)	1(9%)

4) I have pain

Demographic factors

	I have pain			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Age category				
18-24 years	1(11%)	5(56%)	3(33%)	0(0%)
25-34 years	6(15%)	19(48%)	15(38%)	0(0%)
35-44 years	22(22%)	42(41%)	33(32%)	5(5%)
45-54 years	16(14%)	60(52%)	32(28%)	7(6%)
55-64 years	14(19%)	40(53%)	15(20%)	6(8%)
65-74 years	8(22%)	19(53%)	6(17%)	3(8%)
75 years and above	2(14%)	9(64%)	3(21%)	0(0%)
Not stated	1(33%)	0(0%)	1(33%)	1(33%)
Marital status				
Married	42(16%)	128(49%)	76(29%)	15(6%)
Widowed	17(29%)	25(43%)	15(26%)	1(2%)
Single	6(13%)	24(51%)	15(32%)	2(4%)
Divorced	4(17%)	15(63%)	2(8%)	3(13%)
Not stated	1(25%)	2(50%)	0(0%)	1(25%)
Tribe				
Kikuyu	21(12%)	93(53%)	48(27%)	
Kamba	6(14%)	19(43%)	16(36%)	
Luo	15(39%)	17(45%)	5(13%)	
Luhya	7(21%)	17(50%)	10(29%)	
Coastal tribes	12(32%)	19(51%)	5(14%)	
Kisii	4(19%)	10(48%)	5(24%)	
Kalenjin	1(8%)	4(31%)	8(62%)	
Meru	2(18%)	4(36%)	4(36%)	
Embu	0(0%)	2(33%)	4(67%)	
Others	1(8%)	9(69%)	3(23%)	
Religion				
Protestant	39(14%)	140(50%)	83(30%)	16(6%)
Catholic	25(28%)	42(47%)	19(21%)	4(4%)
Muslim	5(23%)	11(50%)	5(23%)	1(5%)
Other	1(25%)	1(25%)	1(25%)	1(25%)

Socioeconomic factors

	I have pain			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Level of formal education				
No formal education	29(27%)	52(48%)	22(20%)	6(6%)
Primary education	28(16%)	96(54%)	44(25%)	11(6%)
Secondary education	12(15%)	32(40%)	33(41%)	4(5%)
Tertiary education	1(6%)	9(50%)	8(44%)	0(0%)
Not stated	0(0%)	5(71%)	1(14%)	1(14%)
Occupation				
Small scale farmer	34(25%)	60(45%)	36(27%)	4(3%)
Housewife	14(11%)	74(57%)	30(23%)	12(9%)
Small scale business	10(23%)	23(52%)	10(23%)	1(2%)
Professional	3(9%)	13(38%)	16(47%)	2(6%)
Skilled employment	2(22%)	2(22%)	4(44%)	1(11%)
Other	3(23%)	5(38%)	4(31%)	1(8%)
Not stated	4(13%)	17(57%)	8(27%)	1(3%)
Monthly income				
Less than KES 2500	36(14%)	138(55%)	61(24%)	16(6%)
KES 2501-7500	14(26%)	20(37%)	17(31%)	3(6%)
KES 7500	4(16%)	11(44%)	9(36%)	1(4%)
KES 12501	3(19%)	7(44%)	6(38%)	0(0%)
KES 17501	1(11%)	3(33%)	5(56%)	0(0%)
Above KES 22500	0(0%)	4(80%)	0(0%)	1(20%)
Undisclosed	12(35%)	11(32%)	10(29%)	1(3%)
Permanent residence				
Central	20(12%)	91(53%)	47(27%)	13(8%)
Eastern	8(13%)	26(42%)	24(39%)	4(6%)
Nyanza	18(31%)	26(45%)	11(19%)	3(5%)
Coast	12(32%)	20(53%)	5(13%)	1(3%)
Western	8(22%)	19(53%)	9(25%)	0(0%)
Rift valley	2(11%)	7(39%)	9(50%)	0(0%)
Other regions	2(18%)	5(45%)	3(27%)	1(9%)

5) I am bothered by side effects of treatment
Demographic factors

	I am bothered by side effects of treatment			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Age category				
18-24 years	4(44%)	1(11%)	4(44%)	0(0%)
25-34 years	4(10%)	16(40%)	20(50%)	0(0%)
35-44 years	16(16%)	28(27%)	53(52%)	5(5%)
45-54 years	14(12%)	44(38%)	50(43%)	7(6%)
55-64 years	5(7%)	27(36%)	37(49%)	6(8%)
65-74 years	1(3%)	14(39%)	18(50%)	3(8%)
75 years and above	0(0%)	7(50%)	7(50%)	0(0%)
Not stated	0(0%)	1(33%)	1(33%)	1(33%)
Marital status				
Married	29(11%)	94(36%)	123(47%)	15(6%)
Widowed	7(12%)	17(29%)	33(57%)	1(2%)
Single	6(13%)	20(43%)	19(40%)	2(4%)
Divorced	1(4%)	6(25%)	14(58%)	3(13%)
Not stated	1(25%)	1(25%)	1(25%)	1(25%)
Tribe				
Kikuyu	22(13%)	73(42%)	67(38%)	13(7%)
Kamba	6(14%)	14(32%)	21(48%)	3(7%)
Luo	2(5%)	8(21%)	27(71%)	1(3%)
Luhya	3(9%)	10(29%)	21(62%)	0(0%)
Coastal tribes	4(11%)	8(22%)	24(65%)	1(3%)
Kisii	1(5%)	6(29%)	12(57%)	2(10%)
Kalenjin	1(8%)	5(38%)	7(54%)	0(0%)
Meru	1(9%)	4(36%)	5(45%)	1(9%)
Embu	1(17%)	3(50%)	2(33%)	0(0%)
Others	2(15%)	7(54%)	4(31%)	0(0%)
Religion				
Protestant	31(11%)	97(35%)	134(48%)	16(6%)
Catholic	8(9%)	33(37%)	45(50%)	4(4%)
Muslim	5(23%)	7(32%)	9(41%)	1(5%)
Other	0(0%)	1(25%)	2(50%)	1(25%)

Socioeconomic factors

	I am bothered by side effects of treatment			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Level of formal education				
No formal education	14(13%)	34(31%)	55(50%)	6(6%)
Primary education	8(4%)	64(36%)	96(54%)	11(6%)
Secondary education	15(19%)	30(37%)	32(40%)	4(5%)
Tertiary education	7(39%)	7(39%)	4(22%)	0(0%)
Not stated	0(0%)	3(43%)	3(43%)	1(14%)
Occupation				
Small scale farmer	17(13%)	38(28%)	75(56%)	4(3%)
Housewife	5(4%)	50(38%)	63(48%)	12(9%)
Small scale business	6(14%)	20(45%)	17(39%)	1(2%)
Professional	12(35%)	8(24%)	12(35%)	2(6%)
Skilled employment	0(0%)	2(22%)	6(67%)	1(11%)
Other	1(8%)	6(46%)	5(38%)	1(8%)
Not stated	3(10%)	14(47%)	12(40%)	1(3%)
Monthly income				
Less than KES 2500	17(7%)	94(37%)	124(49%)	16(6%)
KES 2501-7500	9(17%)	21(39%)	21(39%)	3(6%)
KES 7500	5(20%)	9(36%)	10(40%)	1(4%)
KES 12501	2(13%)	6(38%)	8(50%)	0(0%)
KES 17501	5(56%)	0(0%)	4(44%)	0(0%)
Above KES 22500	1(20%)	3(60%)	0(0%)	1(20%)
Undisclosed	5(15%)	5(15%)	23(68%)	1(3%)
Permanent residence				
Central	22(13%)	72(42%)	64(37%)	13(8%)
Eastern	8(13%)	21(34%)	29(47%)	4(6%)
Nyanza	3(5%)	14(24%)	38(66%)	3(5%)
Coast	4(11%)	8(21%)	25(66%)	1(3%)
Western	2(6%)	11(31%)	23(64%)	0(0%)
Rift valley	1(6%)	7(39%)	10(56%)	0(0%)
Other regions	4(36%)	5(45%)	1(9%)	1(9%)

6) I feel ill

	I feel ill			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Age category				
18-24 years	0(0%)	5(56%)	4(44%)	0(0%)
25-34 years	5(13%)	19(48%)	16(40%)	0(0%)
35-44 years	17(17%)	51(50%)	29(28%)	5(5%)
45-54 years	30(26%)	55(48%)	23(20%)	7(6%)
55-64 years	11(15%)	42(56%)	16(21%)	6(8%)
65-74 years	5(14%)	22(61%)	5(14%)	4(11%)
75 years and above	2(14%)	9(64%)	3(21%)	0(0%)
Not stated	1(33%)	1(33%)	0(0%)	1(33%)
Marital status				
Married	40(15%)	137(52%)	69(26%)	15(6%)
Widowed	17(29%)	28(48%)	12(21%)	1(2%)
Single	7(15%)	25(53%)	13(28%)	2(4%)
Divorced	5(21%)	13(54%)	2(8%)	4(17%)
Not stated	2(50%)	1(25%)	0(0%)	1(25%)
Tribe				
Kikuyu	20(11%)	97(55%)	44(25%)	14(8%)
Kamba	7(16%)	23(52%)	11(25%)	3(7%)
Luo	15(39%)	16(42%)	6(16%)	1(3%)
Luhya	9(26%)	15(44%)	10(29%)	0(0%)
Coastal tribes	8(22%)	24(65%)	4(11%)	1(3%)
Kisii	5(24%)	8(38%)	6(29%)	2(10%)
Kalenjin	1(8%)	5(38%)	7(54%)	0(0%)
Meru	2(18%)	4(36%)	4(36%)	1(9%)
Embu	0(0%)	5(83%)	1(17%)	0(0%)
Others	3(23%)	7(54%)	3(23%)	0(0%)
Religion				
Protestant	43(15%)	150(54%)	68(24%)	17(6%)
Catholic	23(26%)	39(43%)	24(27%)	4(4%)
Muslim	4(18%)	13(59%)	4(18%)	1(5%)
Other	1(25%)	2(50%)	0(0%)	1(25%)

Socioeconomic factors

	I feel ill			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Level of formal education				
No formal education	26(24%)	60(55%)	17(16%)	6(6%)
Primary education	26(15%)	99(55%)	42(23%)	12(7%)
Secondary education	15(19%)	34(42%)	28(35%)	4(5%)
Tertiary education	3(17%)	7(39%)	8(44%)	0(0%)
Not stated	1(14%)	4(57%)	1(14%)	1(14%)
Occupation				
Small scale farmer	34(25%)	58(43%)	37(28%)	5(4%)
Housewife	16(12%)	83(64%)	19(15%)	12(9%)
Small scale business	9(20%)	22(50%)	12(27%)	1(2%)
Professional	6(18%)	12(35%)	14(41%)	2(6%)
Skilled employment	0(0%)	4(44%)	4(44%)	1(11%)
Other	1(8%)	6(46%)	5(38%)	1(8%)
Not stated	5(17%)	19(63%)	5(17%)	1(3%)
Monthly income				
Less than KES 2500	36(14%)	150(60%)	48(19%)	17(7%)
KES 2501-7500	14(26%)	18(33%)	19(35%)	3(6%)
KES 7500	5(20%)	11(44%)	8(32%)	1(4%)
KES 12501	2(13%)	8(50%)	6(38%)	0(0%)
KES 17501	1(11%)	3(33%)	5(56%)	0(0%)
Above KES 22500	1(20%)	3(60%)	0(0%)	1(20%)
Undisclosed	12(35%)	11(32%)	10(29%)	1(3%)
Permanent residence				
Central	19(11%)	97(57%)	41(24%)	14(8%)
Eastern	10(16%)	32(52%)	16(26%)	4(6%)
Nyanza	20(34%)	23(40%)	12(21%)	3(5%)
Coast	8(21%)	24(63%)	5(13%)	1(3%)
Western	10(28%)	17(47%)	9(25%)	0(0%)
Rift valley	1(6%)	7(39%)	10(56%)	0(0%)
Other regions	3(27%)	4(36%)	3(27%)	1(9%)

7) I am forced to spend time in bed

Demographic factors

	I am forced to spend time in bed			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Age category				
18-24 years	1(11%)	3(33%)	5(56%)	0(0%)
25-34 years	10(25%)	13(33%)	17(43%)	0(0%)
35-44 years	19(19%)	34(33%)	44(43%)	5(5%)
45-54 years	24(21%)	27(23%)	57(50%)	7(6%)
55-64 years	8(11%)	36(48%)	25(33%)	6(8%)
65-74 years	4(11%)	20(56%)	9(25%)	3(8%)
75 years and above	2(14%)	6(43%)	6(43%)	0(0%)
Not stated	1(33%)	1(33%)	0(0%)	1(33%)
Marital status				
Married	39(15%)	94(36%)	113(43%)	15(6%)
Widowed	16(28%)	21(36%)	20(34%)	1(2%)
Single	7(15%)	14(30%)	24(51%)	2(4%)
Divorced	6(25%)	9(38%)	6(25%)	3(13%)
Not stated	1(25%)	2(50%)	0(0%)	1(25%)
Tribe				
Kikuyu	19(11%)	57(33%)	86(49%)	13(7%)
Kamba	7(16%)	18(41%)	16(36%)	3(7%)
Luo	6(16%)	21(55%)	10(26%)	1(3%)
Luhya	9(26%)	8(24%)	17(50%)	0(0%)
Coastal tribes	10(27%)	19(51%)	7(19%)	1(3%)
Kisii	8(38%)	1(5%)	10(48%)	2(10%)
Kalenjin	4(31%)	3(23%)	6(46%)	0(0%)
Meru	1(9%)	4(36%)	5(45%)	1(9%)
Embu	0(0%)	5(83%)	1(17%)	0(0%)
Others	4(31%)	4(31%)	5(38%)	0(0%)
Religion				
Protestant	43(15%)	102(37%)	117(42%)	16(6%)
Catholic	19(21%)	29(32%)	38(42%)	4(4%)
Muslim	6(27%)	9(41%)	6(27%)	1(5%)
Other	1(25%)	0(0%)	2(50%)	1(25%)

Socioeconomic factors
FACTORS AND INFLUENCE SOCIAL WELL

	I am forced to spend time in bed			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Level of formal education				
No formal education	22(20%)	53(49%)	28(26%)	6(6%)
Primary education	25(14%)	67(37%)	76(42%)	11(6%)
Secondary education	16(20%)	15(19%)	46(57%)	4(5%)
Tertiary education	5(28%)	4(22%)	9(50%)	0(0%)
Not stated	1(14%)	1(14%)	4(57%)	1(14%)
Occupation				
Small scale farmer	27(20%)	46(34%)	57(43%)	4(3%)
Housewife	22(17%)	49(38%)	47(36%)	12(9%)
Small scale business	10(23%)	18(41%)	15(34%)	1(2%)
Professional	6(18%)	7(21%)	19(56%)	2(6%)
Skilled employment	0(0%)	2(22%)	6(67%)	1(11%)
Other	1(8%)	4(31%)	7(54%)	1(8%)
Not stated	3(10%)	14(47%)	12(40%)	1(3%)
Monthly income				
Less than KES 2500	37(15%)	102(41%)	96(38%)	16(6%)
KES 2501-7500	10(19%)	20(37%)	21(39%)	3(6%)
KES 7500	4(16%)	5(20%)	15(60%)	1(4%)
KES 12501	5(31%)	3(19%)	8(50%)	0(0%)
KES 17501	1(11%)	1(11%)	7(78%)	0(0%)
Above KES 22500	2(40%)	1(20%)	1(20%)	1(20%)
Undisclosed	10(29%)	8(24%)	15(44%)	1(3%)
Permanent residence				
Central	17(10%)	56(33%)	85(50%)	13(8%)
Eastern	8(13%)	27(44%)	23(37%)	4(6%)
Nyanza	14(24%)	21(36%)	20(34%)	3(5%)
Coast	10(26%)	20(53%)	7(18%)	1(3%)
Western	10(28%)	10(28%)	16(44%)	0(0%)
Rift valley	6(33%)	4(22%)	8(44%)	0(0%)
Other regions	4(36%)	2(18%)	4(36%)	1(9%)

APPENDIX Ib- PATIENT FACTORS AND INFLUENCE SOCIAL WELL BEING ISSUES

I am close to my friends

	I am close to my friends			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Age category				
18-24 years	2(22%)	0(0%)	7(78%)	0(0%)
25-34 years	0(0%)	5(13%)	35(88%)	0(0%)
35-44 years	3(3%)	14(14%)	79(77%)	6(6%)
45-54 years	1(1%)	15(13%)	92(80%)	7(6%)
55-64 years	0(0%)	2(3%)	67(89%)	6(8%)
65-74 years	0(0%)	3(8%)	30(83%)	3(8%)
75 years and above	1(7%)	2(14%)	11(79%)	0(0%)
Not stated	0(0%)	1(33%)	2(67%)	0(0%)
Marital status				
Married	4(2%)	28(11%)	213(82%)	16(6%)
Widowed	1(2%)	8(14%)	48(83%)	1(2%)
Single	2(4%)	3(6%)	40(85%)	2(4%)
Divorced	0(0%)	2(8%)	19(79%)	3(13%)
Not stated	0(0%)	1(25%)	3(75%)	0(0%)
Tribe				
Kikuyu	3(2%)	7(4%)	152(87%)	13(7%)
Kamba	0(0%)	2(5%)	39(89%)	3(7%)
Luo	1(3%)	6(16%)	29(76%)	2(5%)
Luhya	2(6%)	9(26%)	23(68%)	0(0%)
Coastal tribes	1(3%)	6(16%)	29(78%)	1(3%)
Kisii	0(0%)	7(33%)	12(57%)	2(10%)
Kalenjin	0(0%)	2(15%)	10(77%)	1(8%)
Meru	0(0%)	1(9%)	10(91%)	0(0%)
Embu	0(0%)	0(0%)	6(100%)	0(0%)
Others	0(0%)	2(15%)	11(85%)	0(0%)
Religion				
Protestant	6(2%)	28(10%)	228(82%)	16(6%)
Catholic	1(1%)	11(12%)	73(81%)	5(6%)
Muslim	0(0%)	3(14%)	18(82%)	1(5%)
Other	0(0%)	0(0%)	4(100%)	0(0%)

Socioeconomic factors

	I am close to my friends			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Level of formal education				
No formal education	1(1%)	10(9%)	91(83%)	7(6%)
Primary education	3(2%)	23(13%)	141(79%)	12(7%)
Secondary education	3(4%)	6(7%)	69(85%)	3(4%)
Tertiary education	0(0%)	3(17%)	15(83%)	0(0%)
Not stated	0(0%)	0(0%)	7(100%)	0(0%)
Occupation				
Small scale farmer	2(1%)	15(11%)	113(84%)	4(3%)
Housewife	0(0%)	14(11%)	103(79%)	13(10%)
Small scale business	1(2%)	5(11%)	37(84%)	1(2%)
Professional	0(0%)	2(6%)	31(91%)	1(3%)
Skilled employment	0(0%)	2(22%)	6(67%)	1(11%)
Other	1(8%)	1(8%)	10(77%)	1(8%)
Not stated	3(10%)	3(10%)	23(77%)	1(3%)
Monthly income				
Less than KES 2500	4(2%)	23(9%)	207(82%)	17(7%)
KES 2501-7500	0(0%)	7(13%)	44(81%)	3(6%)
KES 7500	1(4%)	3(12%)	21(84%)	0(0%)
KES 12501	0(0%)	1(6%)	15(94%)	0(0%)
KES 17501	0(0%)	0(0%)	9(100%)	0(0%)
Above KES 22500	0(0%)	2(40%)	2(40%)	1(20%)
Undisclosed	2(6%)	6(18%)	25(74%)	1(3%)
Permanent residence				
Central	3(2%)	7(4%)	148(87%)	13(8%)
Eastern	0(0%)	3(5%)	56(90%)	3(5%)
Nyanza	1(2%)	11(19%)	42(72%)	4(7%)
Coast	1(3%)	6(16%)	30(79%)	1(3%)
Western	2(6%)	11(31%)	23(64%)	0(0%)
Rift valley	0(0%)	4(22%)	13(72%)	1(6%)
Other regions	0(0%)	0(0%)	11(100%)	0(0%)

I get emotional support from my family
Demographic factors

	I get emotional support from my family			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Age category				
18-24 years	0(0%)	0(0%)	9(100%)	0(0%)
25-34 years	1(3%)	4(10%)	35(88%)	0(0%)
35-44 years	1(1%)	6(6%)	89(87%)	6(6%)
45-54 years	3(3%)	6(5%)	99(86%)	7(6%)
55-64 years	2(3%)	4(5%)	63(84%)	6(8%)
65-74 years	0(0%)	2(6%)	31(86%)	3(8%)
75 years and above	0(0%)	1(7%)	13(93%)	0(0%)
Not stated	0(0%)	1(33%)	2(67%)	0(0%)
Marital status				
Married	5(2%)	13(5%)	227(87%)	16(6%)
Widowed	1(2%)	4(7%)	52(90%)	1(2%)
Single	0(0%)	4(9%)	41(87%)	2(4%)
Divorced	1(4%)	1(4%)	19(79%)	3(13%)
Not stated	0(0%)	2(50%)	2(50%)	0(0%)
Tribe				
Kikuyu	2(1%)	7(4%)	153(87%)	13(7%)
Kamba	0(0%)	0(0%)	41(93%)	3(7%)
Luo	3(8%)	2(5%)	31(82%)	2(5%)
Luhya	0(0%)	5(15%)	29(85%)	0(0%)
Coastal tribes	0(0%)	4(11%)	32(86%)	1(3%)
Kisii	2(10%)	3(14%)	14(67%)	2(10%)
Kalenjin	0(0%)	2(15%)	10(77%)	1(8%)
Meru	0(0%)	0(0%)	11(100%)	0(0%)
Embu	0(0%)	0(0%)	6(100%)	0(0%)
Others	0(0%)	1(8%)	12(92%)	0(0%)
Religion				
Protestant	6(2%)	14(5%)	242(87%)	16(6%)
Catholic	1(1%)	6(7%)	78(87%)	5(6%)
Muslim	0(0%)	3(14%)	18(82%)	1(5%)
Other	0(0%)	1(25%)	3(75%)	0(0%)

Socioeconomic factors

	I get emotional support from my family			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Level of formal education				
No formal education	1(1%)	6(6%)	95(87%)	7(6%)
Primary education	4(2%)	14(8%)	149(83%)	12(7%)
Secondary education	2(2%)	4(5%)	72(89%)	3(4%)
Tertiary education	0(0%)	0(0%)	18(100%)	0(0%)
Not stated	0(0%)	0(0%)	7(100%)	0(0%)
Occupation				
Small scale farmer	5(4%)	10(7%)	115(86%)	4(3%)
Housewife	0(0%)	5(4%)	112(86%)	13(10%)
Small scale business	2(5%)	4(9%)	37(84%)	1(2%)
Professional	0(0%)	0(0%)	33(97%)	1(3%)
Skilled employment	0(0%)	2(22%)	6(67%)	1(11%)
Other	0(0%)	1(8%)	11(85%)	1(8%)
Not stated	0(0%)	2(7%)	27(90%)	1(3%)
Monthly income				
Less than KES 2500	4(2%)	18(7%)	212(84%)	17(7%)
KES 2501-7500	1(2%)	3(6%)	47(87%)	3(6%)
KES 7500	0(0%)	1(4%)	24(96%)	0(0%)
KES 12501	0(0%)	0(0%)	16(100%)	0(0%)
KES 17501	0(0%)	0(0%)	9(100%)	0(0%)
Above KES 22500	0(0%)	0(0%)	4(80%)	1(20%)
Undisclosed	2(6%)	2(6%)	29(85%)	1(3%)
Permanent residence				
Central	2(1%)	7(4%)	149(87%)	13(8%)
Eastern	0(0%)	0(0%)	59(95%)	3(5%)
Nyanza	4(7%)	5(9%)	45(78%)	4(7%)
Coast	0(0%)	4(11%)	33(87%)	1(3%)
Western	1(3%)	5(14%)	30(83%)	0(0%)
Rift valley	0(0%)	3(17%)	14(78%)	1(6%)
Other regions	0(0%)	0(0%)	11(100%)	0(0%)

I get emotional support from my friends
Demographic factors

	I get emotional support from my friends			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Age category				
18-24 years	1(11%)	1(11%)	6(67%)	1(11%)
25-34 years	4(10%)	7(18%)	29(73%)	0(0%)
35-44 years	12(12%)	15(15%)	69(68%)	6(6%)
45-54 years	8(7%)	15(13%)	85(74%)	7(6%)
55-64 years	3(4%)	5(7%)	61(81%)	6(8%)
65-74 years	1(3%)	5(14%)	27(75%)	3(8%)
75 years and above	1(7%)	2(14%)	11(79%)	0(0%)
Not stated	0(0%)	2(67%)	1(33%)	0(0%)
Marital status				
Married	13(5%)	34(13%)	197(75%)	17(7%)
Widowed	7(12%)	8(14%)	42(72%)	1(2%)
Single	8(17%)	2(4%)	35(74%)	2(4%)
Divorced	2(8%)	6(25%)	13(54%)	3(13%)
Not stated	0(0%)	2(50%)	2(50%)	0(0%)
Tribe				
Kikuyu	6(3%)	19(11%)	136(78%)	14(8%)
Kamba	2(5%)	4(9%)	35(80%)	3(7%)
Luo	10(26%)	4(11%)	22(58%)	2(5%)
Luhya	1(3%)	10(29%)	23(68%)	0(0%)
Coastal tribes	4(11%)	6(16%)	26(70%)	1(3%)
Kisii	3(14%)	5(24%)	11(52%)	2(10%)
Kalenjin	2(15%)	1(8%)	9(69%)	1(8%)
Meru	0(0%)	0(0%)	11(100%)	0(0%)
Embu	0(0%)	0(0%)	6(100%)	0(0%)
Others	2(15%)	2(15%)	9(69%)	0(0%)
Religion				
Protestant	19(7%)	36(13%)	206(74%)	17(6%)
Catholic	9(10%)	12(13%)	64(71%)	5(6%)
Muslim	2(9%)	3(14%)	16(73%)	1(5%)
Other	0(0%)	1(25%)	3(75%)	0(0%)

Socioeconomic factors

	I get emotional support from my friends			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Level of formal education				
No formal education	8(7%)	17(16%)	77(71%)	7(6%)
Primary education	14(8%)	23(13%)	129(72%)	13(7%)
Secondary education	7(9%)	7(9%)	64(79%)	3(4%)
Tertiary education	1(6%)	4(22%)	13(72%)	0(0%)
Not stated	0(0%)	1(14%)	6(86%)	0(0%)
Occupation				
Small scale farmer	12(9%)	21(16%)	97(72%)	4(3%)
Housewife	4(3%)	16(12%)	97(75%)	13(10%)
Small scale business	4(9%)	4(9%)	35(80%)	1(2%)
Professional	2(6%)	5(15%)	26(76%)	1(3%)
Skilled employment	0(0%)	1(11%)	7(78%)	1(11%)
Other	5(38%)	0(0%)	7(54%)	1(8%)
Not stated	3(10%)	5(17%)	20(67%)	2(7%)
Monthly income				
Less than KES 2500	16(6%)	29(12%)	189(75%)	17(7%)
KES 2501-7500	1(2%)	7(13%)	43(80%)	3(6%)
KES 7500	5(20%)	4(16%)	16(64%)	0(0%)
KES 12501	0(0%)	3(19%)	13(81%)	0(0%)
KES 17501	1(11%)	0(0%)	8(89%)	0(0%)
Above KES 22500	0(0%)	2(40%)	2(40%)	1(20%)
Undisclosed	7(21%)	7(21%)	18(53%)	2(6%)
Permanent residence				
Central	5(3%)	16(9%)	136(80%)	14(8%)
Eastern	3(5%)	4(6%)	52(84%)	3(5%)
Nyanza	11(19%)	7(12%)	36(62%)	4(7%)
Coast	4(11%)	7(18%)	26(68%)	1(3%)
Western	3(8%)	12(33%)	21(58%)	0(0%)
Rift valley	3(17%)	4(22%)	10(56%)	1(6%)
Other regions	1(9%)	2(18%)	8(73%)	0(0%)

My family has accepted my illness
Demographic factors

	My family has accepted my illness			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Age category				
18-24 years	0(0%)	2(22%)	7(78%)	0(0%)
25-34 years	2(5%)	7(18%)	30(75%)	1(3%)
35-44 years	4(4%)	17(17%)	74(73%)	7(7%)
45-54 years	4(3%)	13(11%)	90(78%)	8(7%)
55-64 years	2(3%)	8(11%)	59(79%)	6(8%)
65-74 years	2(6%)	3(8%)	28(78%)	3(8%)
75 years and above	0(0%)	1(7%)	13(93%)	0(0%)
Not stated	0(0%)	1(33%)	2(67%)	0(0%)
Marital status				
Married	7(3%)	37(14%)	199(76%)	18(7%)
Widowed	3(5%)	3(5%)	50(86%)	2(3%)
Single	3(6%)	5(11%)	37(79%)	2(4%)
Divorced	1(4%)	5(21%)	15(63%)	3(13%)
Not stated	0(0%)	2(50%)	2(50%)	0(0%)
Tribe				
Kikuyu	3(2%)	17(10%)	142(81%)	13(7%)
Kamba	1(2%)	3(7%)	36(82%)	4(9%)
Luo	2(5%)	6(16%)	27(71%)	3(8%)
Luhya	1(3%)	6(18%)	27(79%)	0(0%)
Coastal tribes	5(14%)	8(22%)	23(62%)	1(3%)
Kisii	1(5%)	4(19%)	13(62%)	3(14%)
Kalenjin	0(0%)	3(23%)	9(69%)	1(8%)
Meru	0(0%)	1(9%)	10(91%)	0(0%)
Embu	0(0%)	0(0%)	6(100%)	0(0%)
Others	1(8%)	3(23%)	9(69%)	0(0%)
Religion				
Protestant	6(2%)	36(13%)	217(78%)	19(7%)
Catholic	5(6%)	11(12%)	69(77%)	5(6%)
Muslim	2(9%)	5(23%)	14(64%)	1(5%)
Other	1(25%)	0(0%)	3(75%)	0(0%)

Socioeconomic factors

	My family has accepted my illness			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Level of formal education				
No formal education	5(5%)	14(13%)	81(74%)	9(8%)
Primary education	3(2%)	24(13%)	139(78%)	13(7%)
Secondary education	5(6%)	8(10%)	65(80%)	3(4%)
Tertiary education	1(6%)	6(33%)	11(61%)	0(0%)
Not stated	0(0%)	0(0%)	7(100%)	0(0%)
Occupation				
Small scale farmer	4(3%)	20(15%)	103(77%)	7(5%)
Housewife	4(3%)	13(10%)	100(77%)	13(10%)
Small scale business	2(5%)	4(9%)	37(84%)	1(2%)
Professional	2(6%)	8(24%)	23(68%)	1(3%)
Skilled employment	0(0%)	1(11%)	7(78%)	1(11%)
Other	0(0%)	2(15%)	10(77%)	1(8%)
Not stated	2(7%)	4(13%)	23(77%)	1(3%)
Monthly income				
Less than KES 2500	9(4%)	28(11%)	196(78%)	18(7%)
KES 2501-7500	2(4%)	10(19%)	39(72%)	3(6%)
KES 7500	3(12%)	5(20%)	17(68%)	0(0%)
KES 12501	0(0%)	2(13%)	14(88%)	0(0%)
KES 17501	0(0%)	1(11%)	8(89%)	0(0%)
Above KES 22500	0(0%)	2(40%)	2(40%)	1(20%)
Undisclosed	0(0%)	4(12%)	27(79%)	3(9%)
Permanent residence				
Central	3(2%)	14(8%)	141(82%)	13(8%)
Eastern	2(3%)	4(6%)	52(84%)	4(6%)
Nyanza	1(2%)	11(19%)	40(69%)	6(10%)
Coast	5(13%)	9(24%)	23(61%)	1(3%)
Western	3(8%)	5(14%)	28(78%)	0(0%)
Rift valley	0(0%)	6(33%)	11(61%)	1(6%)
Other regions	0(0%)	3(27%)	8(73%)	0(0%)

I am satisfied with family communication about my illness

Demographic factors

	I am satisfied with family communication about my illness			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Age category				
18-24 years	0(0%)	1(11%)	8(89%)	0(0%)
25-34 years	1(3%)	6(15%)	32(80%)	1(3%)
35-44 years	2(2%)	15(15%)	78(76%)	7(7%)
45-54 years	6(5%)	14(12%)	86(75%)	9(8%)
55-64 years	2(3%)	3(4%)	62(83%)	8(11%)
65-74 years	0(0%)	4(11%)	29(81%)	3(8%)
75 years and above	0(0%)	3(21%)	11(79%)	0(0%)
Not stated	0(0%)	0(0%)	3(100%)	0(0%)
Marital status				
Married	6(2%)	28(11%)	207(79%)	20(8%)
Widowed	2(3%)	8(14%)	45(78%)	3(5%)
Single	2(4%)	5(11%)	38(81%)	2(4%)
Divorced	1(4%)	4(17%)	16(67%)	3(13%)
Not stated	0(0%)	1(25%)	3(75%)	0(0%)
Tribe				
Kikuyu	3(2%)	10(6%)	149(85%)	13(7%)
Kamba	1(2%)	1(2%)	37(84%)	5(11%)
Luo	2(5%)	5(13%)	26(68%)	5(13%)
Luhya	3(9%)	8(24%)	23(68%)	0(0%)
Coastal tribes	0(0%)	12(32%)	24(65%)	1(3%)
Kisii	0(0%)	4(19%)	14(67%)	3(14%)
Kalenjin	1(8%)	3(23%)	8(62%)	1(8%)
Meru	0(0%)	1(9%)	10(91%)	0(0%)
Embu	0(0%)	0(0%)	6(100%)	0(0%)
Others	1(8%)	2(15%)	10(77%)	0(0%)
Religion				
Protestant	6(2%)	30(11%)	220(79%)	22(8%)
Catholic	5(6%)	10(11%)	70(78%)	5(6%)
Muslim	0(0%)	6(27%)	15(68%)	1(5%)
Other	0(0%)	0(0%)	4(100%)	0(0%)

Socioeconomic factors

	I am satisfied with family communication about my illness			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Level of formal education				
No formal education	1(1%)	15(14%)	81(74%)	12(11%)
Primary education	4(2%)	22(12%)	140(78%)	13(7%)
Secondary education	5(6%)	7(9%)	66(81%)	3(4%)
Tertiary education	1(6%)	2(11%)	15(83%)	0(0%)
Not stated	0(0%)	0(0%)	7(100%)	0(0%)
Occupation				
Small scale farmer	3(2%)	15(11%)	108(81%)	8(6%)
Housewife	2(2%)	13(10%)	100(77%)	15(12%)
Small scale business	4(9%)	3(7%)	36(82%)	1(2%)
Professional	2(6%)	3(9%)	28(82%)	1(3%)
Skilled employment	0(0%)	2(22%)	6(67%)	1(11%)
Other	0(0%)	4(31%)	8(62%)	1(8%)
Not stated	0(0%)	6(20%)	23(77%)	1(3%)
Monthly income				
Less than KES 2500	6(2%)	34(14%)	193(77%)	18(7%)
KES 2501-7500	1(2%)	5(9%)	45(83%)	3(6%)
KES 7500	2(8%)	1(4%)	22(88%)	0(0%)
KES 12501	0(0%)	1(6%)	14(88%)	1(6%)
KES 17501	0(0%)	0(0%)	9(100%)	0(0%)
Above KES 22500	0(0%)	1(20%)	3(60%)	1(20%)
Undisclosed	2(6%)	4(12%)	23(68%)	5(15%)
Permanent residence				
Central	3(2%)	10(6%)	145(85%)	13(8%)
Eastern	2(3%)	2(3%)	53(85%)	5(8%)
Nyanza	1(2%)	10(17%)	39(67%)	8(14%)
Coast	0(0%)	12(32%)	25(66%)	1(3%)
Western	4(11%)	7(19%)	25(69%)	0(0%)
Rift valley	1(6%)	5(28%)	11(61%)	1(6%)
Other regions	0(0%)	0(0%)	11(100%)	0(0%)

I feel close to my partner
Demographic factors

	I feel close to my friends			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Age category				
18-24 years	0(0%)	0(0%)	8(89%)	1(11%)
25-34 years	3(8%)	2(5%)	33(83%)	2(5%)
35-44 years	11(11%)	5(5%)	75(74%)	11(11%)
45-54 years	8(7%)	5(4%)	93(81%)	9(8%)
55-64 years	5(7%)	3(4%)	58(77%)	9(12%)
65-74 years	2(6%)	1(3%)	28(78%)	5(14%)
75 years and above	1(7%)	2(14%)	11(79%)	0(0%)
Not stated	0(0%)	0(0%)	3(100%)	0(0%)
Marital status				
Married	8(3%)	12(5%)	222(85%)	19(7%)
Widowed	11(19%)	1(2%)	38(66%)	8(14%)
Single	8(17%)	3(6%)	29(62%)	7(15%)
Divorced	2(8%)	2(8%)	17(71%)	3(13%)
Not stated	1(25%)	0(0%)	3(75%)	0(0%)
Tribe				
Kikuyu	9(5%)	6(3%)	143(82%)	17(10%)
Kamba	1(2%)	1(2%)	35(80%)	7(16%)
Luo	6(16%)	3(8%)	25(66%)	4(11%)
Luhya	6(18%)	2(6%)	26(76%)	0(0%)
Coastal tribes	1(3%)	2(5%)	30(81%)	4(11%)
Kisii	2(10%)	1(5%)	15(71%)	3(14%)
Kalenjin	0(0%)	1(8%)	10(77%)	2(15%)
Meru	1(9%)	0(0%)	10(91%)	0(0%)
Embu	3(50%)	0(0%)	3(50%)	0(0%)
Others	1(8%)	2(15%)	10(77%)	0(0%)
Religion				
Protestant	21(8%)	8(3%)	223(80%)	26(9%)
Catholic	8(9%)	7(8%)	66(73%)	9(10%)
Muslim	1(5%)	3(14%)	16(73%)	2(9%)
Other	0(0%)	0(0%)	4(100%)	0(0%)

Socioeconomic factors

	I feel close to my friends			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Level of formal education				
No formal education	4(4%)	4(4%)	87(80%)	14(13%)
Primary education	14(8%)	10(6%)	140(78%)	15(8%)
Secondary education	10(12%)	4(5%)	59(73%)	8(10%)
Tertiary education	2(11%)	0(0%)	16(89%)	0(0%)
Not stated	0(0%)	0(0%)	7(100%)	0(0%)
Occupation				
Small scale farmer	5(4%)	7(5%)	114(85%)	8(6%)
Housewife	5(4%)	7(5%)	100(77%)	18(14%)
Small scale business	6(14%)	1(2%)	34(77%)	3(7%)
Professional	4(12%)	0(0%)	28(82%)	2(6%)
Skilled employment	5(56%)	1(11%)	1(11%)	2(22%)
Other	3(23%)	1(8%)	7(54%)	2(15%)
Not stated	2(7%)	1(3%)	25(83%)	2(7%)
Monthly income				
Less than KES 2500	19(8%)	12(5%)	195(78%)	25(10%)
KES 2501-7500	2(4%)	4(7%)	44(81%)	4(7%)
KES 7500	3(12%)	0(0%)	20(80%)	2(8%)
KES 12501	0(0%)	0(0%)	16(100%)	0(0%)
KES 17501	2(22%)	0(0%)	7(78%)	0(0%)
Above KES 22500	0(0%)	0(0%)	4(80%)	1(20%)
Undisclosed	4(12%)	2(6%)	23(68%)	5(15%)
Permanent residence				
Central	9(5%)	6(4%)	139(81%)	17(10%)
Eastern	5(8%)	1(2%)	49(79%)	7(11%)
Nyanza	6(10%)	4(7%)	41(71%)	7(12%)
Coast	1(3%)	2(5%)	31(82%)	4(11%)
Western	8(22%)	2(6%)	26(72%)	0(0%)
Rift valley	1(6%)	3(17%)	12(67%)	2(11%)
Other regions	0(0%)	0(0%)	11(100%)	0(0%)

I am satisfied with my sex life
Demographic factors

	I am satisfied with my sex life			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Age category				
18-24 years	6(67%)	0(0%)	2(22%)	1(11%)
25-34 years	26(65%)	2(5%)	5(13%)	7(18%)
35-44 years	64(63%)	13(13%)	8(8%)	17(17%)
45-54 years	65(57%)	7(6%)	15(13%)	28(24%)
55-64 years	45(60%)	4(5%)	2(3%)	24(32%)
65-74 years	21(58%)	1(3%)	2(6%)	12(33%)
75 years and above	9(64%)	1(7%)	1(7%)	3(21%)
Not stated	2(67%)	0(0%)	0(0%)	1(33%)
Marital status				
Married	159(61%)	23(9%)	30(11%)	49(19%)
Widowed	32(55%)	3(5%)	2(3%)	21(36%)
Single	32(68%)	0(0%)	3(6%)	12(26%)
Divorced	13(54%)	2(8%)	0(0%)	9(38%)
Not stated	2(50%)	0(0%)	0(0%)	2(50%)
Tribe				
Kikuyu	107(61%)	10(6%)	13(7%)	45(26%)
Kamba	27(61%)	4(9%)	3(7%)	10(23%)
Luo	25(66%)	2(5%)	3(8%)	8(21%)
Luhya	22(65%)	4(12%)	3(9%)	5(15%)
Coastal tribes	26(70%)	2(5%)	1(3%)	8(22%)
Kisii	12(57%)	2(10%)	2(10%)	5(24%)
Kalenjin	2(15%)	1(8%)	4(31%)	6(46%)
Meru	7(64%)	1(9%)	1(9%)	2(18%)
Embu	5(83%)	0(0%)	1(17%)	0(0%)
Others	4(31%)	2(15%)	4(31%)	3(23%)
Religion				
Protestant	173(62%)	21(8%)	25(9%)	59(21%)
Catholic	45(50%)	6(7%)	8(9%)	31(34%)
Muslim	17(77%)	1(5%)	2(9%)	2(9%)
Other	3(75%)	0(0%)	0(0%)	1(25%)

Socioeconomic factors

	I am satisfied with my sex life			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Level of formal education				
No formal education	63(58%)	5(5%)	7(6%)	34(31%)
Primary education	117(65%)	11(6%)	14(8%)	37(21%)
Secondary education	44(54%)	8(10%)	11(14%)	18(22%)
Tertiary education	9(50%)	3(17%)	3(17%)	3(17%)
Not stated	5(71%)	1(14%)	0(0%)	1(14%)
Occupation				
Small scale farmer	68(51%)	9(7%)	20(15%)	37(28%)
Housewife	94(72%)	6(5%)	3(2%)	27(21%)
Small scale business	28(64%)	7(16%)	2(5%)	7(16%)
Professional	14(41%)	3(9%)	6(18%)	11(32%)
Skilled employment	7(78%)	1(11%)	0(0%)	1(11%)
Other	5(38%)	1(8%)	2(15%)	5(38%)
Not stated	22(73%)	1(3%)	2(7%)	5(17%)
Monthly income				
Less than KES 2500	182(73%)	11(4%)	8(3%)	50(20%)
KES 2501-7500	18(33%)	6(11%)	13(24%)	17(31%)
KES 7500	11(44%)	3(12%)	3(12%)	8(32%)
KES 12501	8(50%)	2(13%)	3(19%)	3(19%)
KES 17501	3(33%)	1(11%)	2(22%)	3(33%)
Above KES 22500	2(40%)	1(20%)	0(0%)	2(40%)
Undisclosed	14(41%)	4(12%)	6(18%)	10(29%)
Permanent residence				
Central	107(63%)	9(5%)	13(8%)	42(25%)
Eastern	39(63%)	5(8%)	5(8%)	13(21%)
Nyanza	34(59%)	5(9%)	6(10%)	13(22%)
Coast	26(68%)	3(8%)	1(3%)	8(21%)
Western	25(69%)	4(11%)	2(6%)	5(14%)
Rift valley	2(11%)	2(11%)	4(22%)	10(56%)
Other regions	5(45%)	0(0%)	4(36%)	2(18%)

APPENDIX Ic- PATIENT FACTORS AND INFLUENCE EMOTIONAL WELL BEING ISSUES

I feel sad

Demographic factors

	I feel sad			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Age category				
18-24 years	1(11%)	1(11%)	7(78%)	0(0%)
25-34 years	1(3%)	13(33%)	25(63%)	1(3%)
35-44 years	12(12%)	28(27%)	54(53%)	8(8%)
45-54 years	12(10%)	25(22%)	69(60%)	9(8%)
55-64 years	5(7%)	16(21%)	46(61%)	8(11%)
65-74 years	2(6%)	11(31%)	19(53%)	4(11%)
75 years and above	0(0%)	3(21%)	9(64%)	2(14%)
Not stated	0(0%)	1(33%)	2(67%)	0(0%)
Marital status				
Married	16(6%)	65(25%)	156(60%)	24(9%)
Widowed	11(19%)	13(22%)	30(52%)	4(7%)
Single	5(11%)	8(17%)	32(68%)	2(4%)
Divorced	1(4%)	10(42%)	11(46%)	2(8%)
Not stated	0(0%)	2(50%)	2(50%)	0(0%)
Tribe				
Kikuyu	6(3%)	31(18%)	120(69%)	18(10%)
Kamba	2(5%)	13(30%)	24(55%)	5(11%)
Luo	8(21%)	8(21%)	21(55%)	1(3%)
Luhya	7(21%)	8(24%)	18(53%)	1(3%)
Coastal tribes	4(11%)	23(62%)	9(24%)	1(3%)
Kisii	2(10%)	6(29%)	9(43%)	4(19%)
Kalenjin	2(15%)	3(23%)	7(54%)	1(8%)
Meru	0(0%)	2(18%)	8(73%)	1(9%)
Embu	0(0%)	0(0%)	6(100%)	0(0%)
Others	1(8%)	4(31%)	8(62%)	0(0%)
Religion				
Protestant	19(7%)	63(23%)	171(62%)	25(9%)
Catholic	9(10%)	26(29%)	50(56%)	5(6%)
Muslim	4(18%)	8(36%)	8(36%)	2(9%)
Other	1(25%)	1(25%)	2(50%)	0(0%)

Socioeconomic factors

	I feel sad			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Level of formal education				
No formal education	10(9%)	31(28%)	57(52%)	11(10%)
Primary education	16(9%)	46(26%)	103(58%)	14(8%)
Secondary education	4(5%)	17(21%)	54(67%)	6(7%)
Tertiary education	3(17%)	3(17%)	12(67%)	0(0%)
Not stated	0(0%)	1(14%)	5(71%)	1(14%)
Occupation				
Small scale farmer	14(10%)	34(25%)	73(54%)	13(10%)
Housewife	11(8%)	27(21%)	79(61%)	13(10%)
Small scale business	0(0%)	12(27%)	29(66%)	3(7%)
Professional	3(9%)	7(21%)	23(68%)	1(3%)
Skilled employment	1(11%)	2(22%)	5(56%)	1(11%)
Other	2(15%)	5(38%)	5(38%)	1(8%)
Not stated	2(7%)	11(37%)	17(57%)	0(0%)
Monthly income				
Less than KES 2500	19(8%)	67(27%)	143(57%)	22(9%)
KES 2501-7500	2(4%)	15(28%)	30(56%)	7(13%)
KES 7500	2(8%)	6(24%)	17(68%)	0(0%)
KES 12501	1(6%)	3(19%)	11(69%)	1(6%)
KES 17501	0(0%)	1(11%)	8(89%)	0(0%)
Above KES 22500	2(40%)	1(20%)	1(20%)	1(20%)
Undisclosed	7(21%)	5(15%)	21(62%)	1(3%)
Permanent residence				
Central	5(3%)	29(17%)	119(70%)	18(11%)
Eastern	2(3%)	16(26%)	38(61%)	6(10%)
Nyanza	8(14%)	15(26%)	30(52%)	5(9%)
Coast	4(11%)	24(63%)	9(24%)	1(3%)
Western	9(25%)	8(22%)	18(50%)	1(3%)
Rift valley	3(17%)	4(22%)	10(56%)	1(6%)
Other regions	2(18%)	2(18%)	7(64%)	0(0%)

I am satisfied with how I am coping with my illness
Demographic factors

	I am satisfied with how I am coping with my illness			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Age category				
18-24 years	1(11%)	3(33%)	4(44%)	1(11%)
25-34 years	3(8%)	25(63%)	11(28%)	1(3%)
35-44 years	12(12%)	42(41%)	40(39%)	8(8%)
45-54 years	11(10%)	57(50%)	38(33%)	9(8%)
55-64 years	6(8%)	46(61%)	14(19%)	9(12%)
65-74 years	2(6%)	21(58%)	8(22%)	5(14%)
75 years and above	0(0%)	9(64%)	3(21%)	2(14%)
Not stated	0(0%)	1(33%)	2(67%)	0(0%)
Marital status				
Married	21(8%)	140(54%)	76(29%)	24(9%)
Widowed	8(14%)	25(43%)	19(33%)	6(10%)
Single	4(9%)	25(53%)	15(32%)	3(6%)
Divorced	2(8%)	14(58%)	6(25%)	2(8%)
Not stated	0(0%)	0(0%)	4(100%)	0(0%)
Tribe				
Kikuyu	11(6%)	95(54%)	50(29%)	19(11%)
Kamba	3(7%)	24(55%)	12(27%)	5(11%)
Luo	4(11%)	21(55%)	10(26%)	3(8%)
Luhya	4(12%)	19(56%)	10(29%)	1(3%)
Coastal tribes	11(30%)	15(41%)	10(27%)	1(3%)
Kisii	0(0%)	8(38%)	9(43%)	4(19%)
Kalenjin	0(0%)	6(46%)	6(46%)	1(8%)
Meru	0(0%)	6(55%)	4(36%)	1(9%)
Embu	0(0%)	4(67%)	2(33%)	0(0%)
Others	1(8%)	6(46%)	6(46%)	0(0%)
Religion				
Protestant	19(7%)	147(53%)	86(31%)	26(9%)
Catholic	9(10%)	46(51%)	28(31%)	7(8%)
Muslim	5(23%)	10(45%)	5(23%)	2(9%)
Other	2(50%)	1(25%)	1(25%)	0(0%)

Socioeconomic factors

	I am satisfied with how I am coping with my illness			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Level of formal education				
No formal education	14(13%)	55(50%)	27(25%)	13(12%)
Primary education	17(9%)	105(59%)	43(24%)	14(8%)
Secondary education	4(5%)	32(40%)	38(47%)	7(9%)
Tertiary education	0(0%)	8(44%)	10(56%)	0(0%)
Not stated	0(0%)	4(57%)	2(29%)	1(14%)
Occupation				
Small scale farmer	14(10%)	60(45%)	47(35%)	13(10%)
Housewife	10(8%)	91(70%)	14(11%)	15(12%)
Small scale business	3(7%)	18(41%)	20(45%)	3(7%)
Professional	1(3%)	13(38%)	19(56%)	1(3%)
Skilled employment	0(0%)	2(22%)	6(67%)	1(11%)
Other	1(8%)	3(23%)	7(54%)	2(15%)
Not stated	6(20%)	17(57%)	7(23%)	0(0%)
Monthly income				
Less than KES 2500	23(9%)	154(61%)	51(20%)	23(9%)
KES 2501-7500	4(7%)	18(33%)	25(46%)	7(13%)
KES 7500	3(12%)	12(48%)	10(40%)	0(0%)
KES 12501	1(6%)	5(31%)	9(56%)	1(6%)
KES 17501	0(0%)	3(33%)	6(67%)	0(0%)
Above KES 22500	0(0%)	3(60%)	1(20%)	1(20%)
Undisclosed	4(12%)	9(26%)	18(53%)	3(9%)
Permanent residence				
Central	10(6%)	93(54%)	49(29%)	19(11%)
Eastern	3(5%)	35(56%)	18(29%)	6(10%)
Nyanza	3(5%)	28(48%)	20(34%)	7(12%)
Coast	11(29%)	16(42%)	10(26%)	1(3%)
Western	5(14%)	20(56%)	10(28%)	1(3%)
Rift valley	1(6%)	8(44%)	8(44%)	1(6%)
Other regions	2(18%)	4(36%)	5(45%)	0(0%)

I am losing hope in the fight against my illness
Demographic factors

	I am losing hope in the fight against my illness			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Age category				
18-24 years	1(11%)	2(22%)	6(67%)	0(0%)
25-34 years	0(0%)	6(15%)	33(83%)	1(3%)
35-44 years	2(2%)	12(12%)	80(78%)	8(8%)
45-54 years	4(3%)	17(15%)	85(74%)	9(8%)
55-64 years	4(5%)	4(5%)	59(79%)	8(11%)
65-74 years	0(0%)	5(14%)	26(72%)	5(14%)
75 years and above	1(7%)	1(7%)	10(71%)	2(14%)
Not stated	0(0%)	0(0%)	3(100%)	0(0%)
Marital status				
Married	6(2%)	32(12%)	199(76%)	24(9%)
Widowed	5(9%)	9(16%)	40(69%)	4(7%)
Single	1(2%)	4(9%)	40(85%)	2(4%)
Divorced	0(0%)	1(4%)	20(83%)	3(13%)
Not stated	0(0%)	1(25%)	3(75%)	0(0%)
Tribe				
Kikuyu	7(4%)	16(9%)	133(76%)	19(11%)
Kamba	1(2%)	4(9%)	34(77%)	5(11%)
Luo	1(3%)	4(11%)	32(84%)	1(3%)
Luhya	0(0%)	6(18%)	27(79%)	1(3%)
Coastal tribes	1(3%)	14(38%)	21(57%)	1(3%)
Kisii	1(5%)	0(0%)	16(76%)	4(19%)
Kalenjin	0(0%)	1(8%)	11(85%)	1(8%)
Meru	0(0%)	0(0%)	10(91%)	1(9%)
Embu	0(0%)	0(0%)	6(100%)	0(0%)
Others	1(8%)	1(8%)	11(85%)	0(0%)
Religion				
Protestant	8(3%)	31(11%)	214(77%)	25(9%)
Catholic	2(2%)	10(11%)	72(80%)	6(7%)
Muslim	1(5%)	6(27%)	13(59%)	2(9%)
Other	1(25%)	0(0%)	3(75%)	0(0%)

Socioeconomic factors

	I am losing hope in the fight against my illness			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Level of formal education				
No formal education	4(4%)	19(17%)	74(68%)	12(11%)
Primary education	5(3%)	21(12%)	139(78%)	14(8%)
Secondary education	2(2%)	5(6%)	68(84%)	6(7%)
Tertiary education	1(6%)	2(11%)	15(83%)	0(0%)
Not stated	0(0%)	0(0%)	6(86%)	1(14%)
Occupation				
Small scale farmer	6(4%)	17(13%)	98(73%)	13(10%)
Housewife	3(2%)	17(13%)	97(75%)	13(10%)
Small scale business	0(0%)	5(11%)	35(80%)	4(9%)
Professional	0(0%)	2(6%)	31(91%)	1(3%)
Skilled employment	0(0%)	1(11%)	7(78%)	1(11%)
Other	1(8%)	1(8%)	10(77%)	1(8%)
Not stated	2(7%)	4(13%)	24(80%)	0(0%)
Monthly income				
Less than KES 2500	4(2%)	31(12%)	194(77%)	22(9%)
KES 2501-7500	1(2%)	9(17%)	36(67%)	8(15%)
KES 7500	2(8%)	1(4%)	22(88%)	0(0%)
KES 12501	1(6%)	1(6%)	13(81%)	1(6%)
KES 17501	0(0%)	0(0%)	9(100%)	0(0%)
Above KES 22500	0(0%)	1(20%)	3(60%)	1(20%)
Undisclosed	4(12%)	4(12%)	25(74%)	1(3%)
Permanent residence				
Central	7(4%)	15(9%)	130(76%)	19(11%)
Eastern	1(2%)	4(6%)	51(82%)	6(10%)
Nyanza	2(3%)	3(5%)	48(83%)	5(9%)
Coast	1(3%)	14(37%)	22(58%)	1(3%)
Western	0(0%)	7(19%)	28(78%)	1(3%)
Rift valley	0(0%)	3(17%)	14(78%)	1(6%)
Other regions	1(9%)	1(9%)	9(82%)	0(0%)

I feel nervous
Demographic factors

	I feel nervous			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Age category				
18-24 years	3(33%)	1(11%)	5(56%)	0(0%)
25-34 years	0(0%)	11(28%)	28(70%)	1(3%)
35-44 years	8(8%)	18(18%)	68(67%)	8(8%)
45-54 years	9(8%)	13(11%)	84(73%)	9(8%)
55-64 years	4(5%)	9(12%)	54(72%)	8(11%)
65-74 years	0(0%)	5(14%)	27(75%)	4(11%)
75 years and above	0(0%)	1(7%)	11(79%)	2(14%)
Not stated	0(0%)	0(0%)	3(100%)	0(0%)
Marital status				
Married	13(5%)	34(13%)	190(73%)	24(9%)
Widowed	5(9%)	15(26%)	34(59%)	4(7%)
Single	5(11%)	3(6%)	37(79%)	2(4%)
Divorced	1(4%)	5(21%)	16(67%)	2(8%)
Not stated	0(0%)	1(25%)	3(75%)	0(0%)
Tribe				
Kikuyu	5(3%)	16(9%)	136(78%)	18(10%)
Kamba	2(5%)	4(9%)	33(75%)	5(11%)
Luo	7(18%)	2(5%)	28(74%)	1(3%)
Luhya	2(6%)	8(24%)	23(68%)	1(3%)
Coastal tribes	3(8%)	19(51%)	14(38%)	1(3%)
Kisii	0(0%)	4(19%)	13(62%)	4(19%)
Kalenjin	2(15%)	3(23%)	7(54%)	1(8%)
Meru	0(0%)	1(9%)	9(82%)	1(9%)
Embu	0(0%)	0(0%)	6(100%)	0(0%)
Others	2(15%)	1(8%)	10(77%)	0(0%)
Religion				
Protestant	13(5%)	38(14%)	202(73%)	25(9%)
Catholic	6(7%)	13(14%)	66(73%)	5(6%)
Muslim	4(18%)	7(32%)	9(41%)	2(9%)
Other	1(25%)	0(0%)	3(75%)	0(0%)

Socioeconomic factors

	I feel nervous			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Level of formal education				
No formal education	7(6%)	21(19%)	70(64%)	11(10%)
Primary education	10(6%)	23(13%)	132(74%)	14(8%)
Secondary education	5(6%)	10(12%)	60(74%)	6(7%)
Tertiary education	2(11%)	4(22%)	12(67%)	0(0%)
Not stated	0(0%)	0(0%)	6(86%)	1(14%)
Occupation				
Small scale farmer	10(7%)	19(14%)	92(69%)	13(10%)
Housewife	7(5%)	14(11%)	96(74%)	13(10%)
Small scale business	0(0%)	9(20%)	32(73%)	3(7%)
Professional	4(12%)	4(12%)	25(74%)	1(3%)
Skilled employment	0(0%)	1(11%)	7(78%)	1(11%)
Other	1(8%)	3(23%)	8(62%)	1(8%)
Not stated	2(7%)	8(27%)	20(67%)	0(0%)
Monthly income				
Less than KES 2500	9(4%)	40(16%)	180(72%)	22(9%)
KES 2501-7500	3(6%)	7(13%)	37(69%)	7(13%)
KES 7500	2(8%)	3(12%)	20(80%)	0(0%)
KES 12501	1(6%)	4(25%)	10(63%)	1(6%)
KES 17501	0(0%)	1(11%)	8(89%)	0(0%)
Above KES 22500	1(20%)	1(20%)	2(40%)	1(20%)
Undisclosed	8(24%)	2(6%)	23(68%)	1(3%)
Permanent residence				
Central	5(3%)	15(9%)	133(78%)	18(11%)
Eastern	2(3%)	5(8%)	49(79%)	6(10%)
Nyanza	8(14%)	5(9%)	40(69%)	5(9%)
Coast	3(8%)	19(50%)	15(39%)	1(3%)
Western	2(6%)	9(25%)	24(67%)	1(3%)
Rift valley	2(11%)	5(28%)	10(56%)	1(6%)
Other regions	2(18%)	0(0%)	9(82%)	0(0%)

I worry about dying
Demographic factors

	I worry about dying			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Age category				
18-24 years	2(22%)	0(0%)	7(78%)	0(0%)
25-34 years	2(5%)	6(15%)	31(78%)	1(3%)
35-44 years	6(6%)	6(6%)	81(79%)	9(9%)
45-54 years	6(5%)	16(14%)	84(73%)	9(8%)
55-64 years	4(5%)	8(11%)	54(72%)	9(12%)
65-74 years	0(0%)	4(11%)	28(78%)	4(11%)
75 years and above	0(0%)	1(7%)	11(79%)	2(14%)
Not stated	0(0%)	0(0%)	3(100%)	0(0%)
Marital status				
Married	13(5%)	24(9%)	199(76%)	25(10%)
Widowed	3(5%)	9(16%)	41(71%)	5(9%)
Single	3(6%)	3(6%)	39(83%)	2(4%)
Divorced	1(4%)	4(17%)	17(71%)	2(8%)
Not stated	0(0%)	1(25%)	3(75%)	0(0%)
Tribe				
Kikuyu	5(3%)	10(6%)	142(81%)	18(10%)
Kamba	2(5%)	3(7%)	34(77%)	5(11%)
Luo	3(8%)	2(5%)	30(79%)	3(8%)
Luhya	3(9%)	8(24%)	22(65%)	1(3%)
Coastal tribes	4(11%)	13(35%)	19(51%)	1(3%)
Kisii	1(5%)	1(5%)	15(71%)	4(19%)
Kalenjin	0(0%)	2(15%)	10(77%)	1(8%)
Meru	0(0%)	1(9%)	9(82%)	1(9%)
Embu	0(0%)	0(0%)	6(100%)	0(0%)
Others	1(8%)	1(8%)	11(85%)	0(0%)
Religion				
Protestant	12(4%)	23(8%)	217(78%)	26(9%)
Catholic	4(4%)	13(14%)	67(74%)	6(7%)
Muslim	3(14%)	5(23%)	12(55%)	2(9%)
Other	1(25%)	0(0%)	3(75%)	0(0%)

Socioeconomic factors

	I worry about dying			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Level of formal education				
No formal education	4(4%)	15(14%)	77(71%)	13(12%)
Primary education	7(4%)	22(12%)	136(76%)	14(8%)
Secondary education	5(6%)	4(5%)	66(81%)	6(7%)
Tertiary education	4(22%)	0(0%)	14(78%)	0(0%)
Not stated	0(0%)	0(0%)	6(86%)	1(14%)
Occupation				
Small scale farmer	6(4%)	18(13%)	96(72%)	14(10%)
Housewife	6(5%)	10(8%)	100(77%)	14(11%)
Small scale business	0(0%)	7(16%)	34(77%)	3(7%)
Professional	5(15%)	0(0%)	28(82%)	1(3%)
Skilled employment	0(0%)	0(0%)	8(89%)	1(11%)
Other	2(15%)	1(8%)	9(69%)	1(8%)
Not stated	1(3%)	5(17%)	24(80%)	0(0%)
Monthly income				
Less than KES 2500	9(4%)	30(12%)	190(76%)	22(9%)
KES 2501-7500	1(2%)	5(9%)	40(74%)	8(15%)
KES 7500	3(12%)	2(8%)	20(80%)	0(0%)
KES 12501	2(13%)	1(6%)	12(75%)	1(6%)
KES 17501	0(0%)	0(0%)	9(100%)	0(0%)
Above KES 22500	2(40%)	0(0%)	2(40%)	1(20%)
Undisclosed	3(9%)	3(9%)	26(76%)	2(6%)
Permanent residence				
Central	5(3%)	10(6%)	138(81%)	18(11%)
Eastern	2(3%)	4(6%)	50(81%)	6(10%)
Nyanza	5(9%)	1(2%)	45(78%)	7(12%)
Coast	4(11%)	13(34%)	20(53%)	1(3%)
Western	3(8%)	10(28%)	22(61%)	1(3%)
Rift valley	0(0%)	3(17%)	14(78%)	1(6%)
Other regions	1(9%)	0(0%)	10(91%)	0(0%)

I worry that my condition will get worse
Demographic factors

	I worry that my condition will get worse			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Age category				
18-24 years	2(22%)	0(0%)	7(78%)	0(0%)
25-34 years	0(0%)	2(5%)	37(93%)	1(3%)
35-44 years	4(4%)	2(2%)	88(86%)	8(8%)
45-54 years	2(2%)	3(3%)	101(88%)	9(8%)
55-64 years	1(1%)	2(3%)	63(84%)	9(12%)
65-74 years	1(3%)	2(6%)	29(81%)	4(11%)
75 years and above	0(0%)	1(7%)	11(79%)	2(14%)
Not stated	0(0%)	0(0%)	3(100%)	0(0%)
Marital status				
Married	6(2%)	8(3%)	223(85%)	24(9%)
Widowed	3(5%)	1(2%)	49(84%)	5(9%)
Single	1(2%)	2(4%)	42(89%)	2(4%)
Divorced	0(0%)	1(4%)	21(88%)	2(8%)
Not stated	0(0%)	0(0%)	4(100%)	0(0%)
Tribe				
Kikuyu	3(2%)	6(3%)	148(85%)	18(10%)
Kamba	0(0%)	0(0%)	39(89%)	5(11%)
Luo	2(5%)	2(5%)	32(84%)	2(5%)
Luhya	4(12%)	0(0%)	29(85%)	1(3%)
Coastal tribes	0(0%)	1(3%)	35(95%)	1(3%)
Kisii	1(5%)	1(5%)	15(71%)	4(19%)
Kalenjin	0(0%)	1(8%)	11(85%)	1(8%)
Meru	0(0%)	0(0%)	10(91%)	1(9%)
Embu	0(0%)	0(0%)	6(100%)	0(0%)
Others	0(0%)	1(8%)	12(92%)	0(0%)
Religion				
Protestant	8(3%)	7(3%)	237(85%)	26(9%)
Catholic	2(2%)	5(6%)	78(87%)	5(6%)
Muslim	0(0%)	0(0%)	20(91%)	2(9%)
Other	0(0%)	0(0%)	4(100%)	0(0%)

Socioeconomic factors

	I worry that my condition will get worse			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Level of formal education				
No formal education	1(1%)	3(3%)	93(85%)	12(11%)
Primary education	6(3%)	6(3%)	153(85%)	14(8%)
Secondary education	1(1%)	3(4%)	71(88%)	6(7%)
Tertiary education	2(11%)	0(0%)	16(89%)	0(0%)
Not stated	0(0%)	0(0%)	6(86%)	1(14%)
Occupation				
Small scale farmer	4(3%)	3(2%)	114(85%)	13(10%)
Housewife	2(2%)	4(3%)	110(85%)	14(11%)
Small scale business	0(0%)	5(11%)	36(82%)	3(7%)
Professional	1(3%)	0(0%)	32(94%)	1(3%)
Skilled employment	1(11%)	0(0%)	7(78%)	1(11%)
Other	0(0%)	0(0%)	12(92%)	1(8%)
Not stated	2(7%)	0(0%)	28(93%)	0(0%)
Monthly income				
Less than KES 2500	5(2%)	9(4%)	215(86%)	22(9%)
KES 2501-7500	1(2%)	2(4%)	44(81%)	7(13%)
KES 7500	1(4%)	1(4%)	23(92%)	0(0%)
KES 12501	1(6%)	0(0%)	14(88%)	1(6%)
KES 17501	0(0%)	0(0%)	9(100%)	0(0%)
Above KES 22500	1(20%)	0(0%)	3(60%)	1(20%)
Undisclosed	1(3%)	0(0%)	31(91%)	2(6%)
Permanent residence				
Central	3(2%)	6(4%)	144(84%)	18(11%)
Eastern	0(0%)	0(0%)	56(90%)	6(10%)
Nyanza	3(5%)	2(3%)	47(81%)	6(10%)
Coast	0(0%)	1(3%)	36(95%)	1(3%)
Western	4(11%)	1(3%)	30(83%)	1(3%)
Rift valley	0(0%)	2(11%)	15(83%)	1(6%)
Other regions	0(0%)	0(0%)	11(100%)	0(0%)

APPENDIX Id- PATIENT FACTORS AND INFLUENCE FUNCTIONAL WELL BEING ISSUES

I am able to work
Demographic factors

	I am able to work			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Age category				
18-24 years	0(0%)	6(67%)	3(33%)	0(0%)
25-34 years	10(25%)	24(60%)	5(13%)	1(3%)
35-44 years	23(23%)	53(52%)	21(21%)	5(5%)
45-54 years	45(39%)	52(45%)	17(15%)	1(1%)
55-64 years	28(37%)	39(52%)	7(9%)	1(1%)
65-74 years	13(36%)	18(50%)	4(11%)	1(3%)
75 years and above	6(43%)	6(43%)	2(14%)	0(0%)
Not stated	3(100%)	0(0%)	0(0%)	0(0%)
Marital status				
Married	83(32%)	135(52%)	38(15%)	5(2%)
Widowed	22(38%)	24(41%)	10(17%)	2(3%)
Single	14(30%)	24(51%)	8(17%)	1(2%)
Divorced	7(29%)	13(54%)	3(13%)	1(4%)
Not stated	2(50%)	2(50%)	0(0%)	0(0%)
Tribe				
Kikuyu	55(31%)	92(53%)	25(14%)	3(2%)
Kamba	15(34%)	21(48%)	6(14%)	2(5%)
Luo	9(24%)	21(55%)	7(18%)	1(3%)
Luhya	10(29%)	18(53%)	6(18%)	0(0%)
Coastal tribes	19(51%)	14(38%)	3(8%)	1(3%)
Kisii	8(38%)	11(52%)	1(5%)	1(5%)
Kalenjin	4(31%)	6(46%)	3(23%)	0(0%)
Meru	0(0%)	7(64%)	3(27%)	1(9%)
Embu	3(50%)	3(50%)	0(0%)	0(0%)
Others	3(23%)	5(38%)	5(38%)	0(0%)
Religion				
Protestant	82(29%)	144(52%)	46(17%)	6(2%)
Catholic	34(38%)	44(49%)	11(12%)	1(1%)
Muslim	9(41%)	9(41%)	2(9%)	2(9%)
Other	3(75%)	1(25%)	0(0%)	0(0%)

Socioeconomic factors

	I am able to work			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Level of formal education				
No formal education	48(44%)	46(42%)	12(11%)	3(3%)
Primary education	54(30%)	97(54%)	26(15%)	2(1%)
Secondary education	18(22%)	45(56%)	15(19%)	3(4%)
Tertiary education	5(28%)	7(39%)	6(33%)	0(0%)
Not stated	3(43%)	3(43%)	0(0%)	1(14%)
Occupation				
Small scale farmer	52(39%)	59(44%)	18(13%)	5(4%)
Housewife	46(35%)	72(55%)	11(8%)	1(1%)
Small scale business	12(27%)	23(52%)	7(16%)	2(5%)
Professional	8(24%)	15(44%)	11(32%)	0(0%)
Skilled employment	2(22%)	4(44%)	3(33%)	0(0%)
Other	3(23%)	5(38%)	4(31%)	1(8%)
Not stated	5(17%)	20(67%)	5(17%)	0(0%)
Monthly income				
Less than KES 2500	91(36%)	133(53%)	24(10%)	3(1%)
KES 2501-7500	14(26%)	26(48%)	9(17%)	5(9%)
KES 7500	6(24%)	14(56%)	5(20%)	0(0%)
KES 12501	5(31%)	9(56%)	2(13%)	0(0%)
KES 17501	1(11%)	3(33%)	5(56%)	0(0%)
Above KES 22500	2(40%)	2(40%)	1(20%)	0(0%)
Undisclosed	9(26%)	11(32%)	13(38%)	1(3%)
Permanent residence				
Central	55(32%)	88(51%)	25(15%)	3(2%)
Eastern	18(29%)	31(50%)	10(16%)	3(5%)
Nyanza	15(26%)	32(55%)	9(16%)	2(3%)
Coast	19(50%)	15(39%)	3(8%)	1(3%)
Western	13(36%)	18(50%)	5(14%)	0(0%)
Rift valley	4(22%)	10(56%)	4(22%)	0(0%)
Other regions	4(36%)	4(36%)	3(27%)	0(0%)

My work is fulfilling
Demographic factors

	My work is fulfilling			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Age category				
18-24 years	2(22%)	5(56%)	1(11%)	1(11%)
25-34 years	10(25%)	25(63%)	4(10%)	1(3%)
35-44 years	32(31%)	44(43%)	21(21%)	5(5%)
45-54 years	47(41%)	50(43%)	17(15%)	1(1%)
55-64 years	30(40%)	33(44%)	9(12%)	3(4%)
65-74 years	11(31%)	22(61%)	2(6%)	1(3%)
75 years and above	8(57%)	4(29%)	2(14%)	0(0%)
Not stated	3(100%)	0(0%)	0(0%)	0(0%)
Marital status				
Married	97(37%)	123(47%)	34(13%)	7(3%)
Widowed	23(40%)	25(43%)	7(12%)	3(5%)
Single	15(32%)	22(47%)	9(19%)	1(2%)
Divorced	6(25%)	12(50%)	5(21%)	1(4%)
Not stated	2(50%)	1(25%)	1(25%)	0(0%)
Tribe				
Kikuyu	57(33%)	86(49%)	28(16%)	4(2%)
Kamba	16(36%)	23(52%)	3(7%)	2(5%)
Luo	15(39%)	14(37%)	6(16%)	3(8%)
Luhya	12(35%)	18(53%)	4(12%)	0(0%)
Coastal tribes	23(62%)	9(24%)	4(11%)	1(3%)
Kisii	8(38%)	10(48%)	2(10%)	1(5%)
Kalenjin	4(31%)	8(62%)	1(8%)	0(0%)
Meru	3(27%)	5(45%)	2(18%)	1(9%)
Embu	2(33%)	4(67%)	0(0%)	0(0%)
Others	1(8%)	6(46%)	6(46%)	0(0%)
Religion				
Protestant	93(33%)	131(47%)	45(16%)	9(3%)
Catholic	38(42%)	41(46%)	10(11%)	1(1%)
Muslim	10(45%)	9(41%)	1(5%)	2(9%)
Other	2(50%)	2(50%)	0(0%)	0(0%)

Socioeconomic factors

	My work is fulfilling			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Level of formal education				
No formal education	53(49%)	43(39%)	8(7%)	5(5%)
Primary education	61(34%)	92(51%)	23(13%)	3(2%)
Secondary education	22(27%)	36(44%)	20(25%)	3(4%)
Tertiary education	5(28%)	8(44%)	5(28%)	0(0%)
Not stated	2(29%)	4(57%)	0(0%)	1(14%)
Occupation				
Small scale farmer	54(40%)	56(42%)	19(14%)	5(4%)
Housewife	49(38%)	72(55%)	6(5%)	3(2%)
Small scale business	16(36%)	19(43%)	7(16%)	2(5%)
Professional	7(21%)	12(35%)	15(44%)	0(0%)
Skilled employment	2(22%)	4(44%)	3(33%)	0(0%)
Other	5(38%)	4(31%)	3(23%)	1(8%)
Not stated	10(33%)	16(53%)	3(10%)	1(3%)
Monthly income				
Less than KES 2500	96(38%)	133(53%)	19(8%)	3(1%)
KES 2501-7500	22(41%)	18(33%)	9(17%)	5(9%)
KES 7500	6(24%)	13(52%)	6(24%)	0(0%)
KES 12501	4(25%)	7(44%)	5(31%)	0(0%)
KES 17501	1(11%)	3(33%)	5(56%)	0(0%)
Above KES 22500	2(40%)	2(40%)	1(20%)	0(0%)
Undisclosed	12(35%)	7(21%)	11(32%)	4(12%)
Permanent residence				
Central	56(33%)	83(49%)	28(16%)	4(2%)
Eastern	21(34%)	33(53%)	5(8%)	3(5%)
Nyanza	21(36%)	23(40%)	10(17%)	4(7%)
Coast	23(61%)	10(26%)	4(11%)	1(3%)
Western	14(39%)	19(53%)	3(8%)	0(0%)
Rift valley	5(28%)	11(61%)	2(11%)	0(0%)
Other regions	3(27%)	4(36%)	4(36%)	0(0%)

I am able to enjoy life
Demographic factors

	I am able to enjoy life			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Age category				
18-24 years	1(11%)	5(56%)	3(33%)	0(0%)
25-34 years	8(20%)	22(55%)	9(23%)	1(3%)
35-44 years	22(22%)	47(46%)	28(27%)	5(5%)
45-54 years	23(20%)	61(53%)	30(26%)	1(1%)
55-64 years	16(21%)	46(61%)	11(15%)	2(3%)
65-74 years	7(19%)	24(67%)	3(8%)	2(6%)
75 years and above	3(21%)	8(57%)	3(21%)	0(0%)
Not stated	0(0%)	2(67%)	1(33%)	0(0%)
Marital status				
Married	50(19%)	147(56%)	58(22%)	6(2%)
Widowed	18(31%)	27(47%)	10(17%)	3(5%)
Single	7(15%)	27(57%)	12(26%)	1(2%)
Divorced	5(21%)	12(50%)	6(25%)	1(4%)
Not stated	0(0%)	2(50%)	2(50%)	0(0%)
Tribe				
Kikuyu	27(15%)	101(58%)	43(25%)	4(2%)
Kamba	10(23%)	29(66%)	3(7%)	2(5%)
Luo	5(13%)	18(47%)	13(34%)	2(5%)
Luhya	8(24%)	17(50%)	9(26%)	0(0%)
Coastal tribes	21(57%)	13(35%)	2(5%)	1(3%)
Kisii	6(29%)	8(38%)	6(29%)	1(5%)
Kalenjin	1(8%)	9(69%)	3(23%)	0(0%)
Meru	0(0%)	9(82%)	1(9%)	1(9%)
Embu	0(0%)	3(50%)	3(50%)	0(0%)
Others	1(8%)	7(54%)	5(38%)	0(0%)
Religion				
Protestant	52(19%)	151(54%)	68(24%)	7(3%)
Catholic	17(19%)	53(59%)	18(20%)	2(2%)
Muslim	10(45%)	8(36%)	2(9%)	2(9%)
Other	1(25%)	3(75%)	0(0%)	0(0%)

Socioeconomic factors

	I am able to enjoy life			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Level of formal education				
No formal education	28(26%)	59(54%)	17(16%)	5(5%)
Primary education	38(21%)	100(56%)	39(22%)	2(1%)
Secondary education	11(14%)	42(52%)	25(31%)	3(4%)
Tertiary education	3(17%)	8(44%)	7(39%)	0(0%)
Not stated	0(0%)	6(86%)	0(0%)	1(14%)
Occupation				
Small scale farmer	27(20%)	66(49%)	36(27%)	5(4%)
Housewife	33(25%)	83(64%)	11(8%)	3(2%)
Small scale business	4(9%)	25(57%)	13(30%)	2(5%)
Professional	5(15%)	15(44%)	14(41%)	0(0%)
Skilled employment	2(22%)	4(44%)	3(33%)	0(0%)
Other	3(23%)	4(31%)	5(38%)	1(8%)
Not stated	6(20%)	18(60%)	6(20%)	0(0%)
Monthly income				
Less than KES 2500	54(22%)	159(63%)	34(14%)	4(2%)
KES 2501-7500	7(13%)	25(46%)	17(31%)	5(9%)
KES 7500	7(28%)	11(44%)	7(28%)	0(0%)
KES 12501	3(19%)	7(44%)	6(38%)	0(0%)
KES 17501	0(0%)	5(56%)	4(44%)	0(0%)
Above KES 22500	1(20%)	2(40%)	2(40%)	0(0%)
Undisclosed	8(24%)	6(18%)	18(53%)	2(6%)
Permanent residence				
Central	27(16%)	98(57%)	42(25%)	4(2%)
Eastern	10(16%)	41(66%)	8(13%)	3(5%)
Nyanza	9(16%)	27(47%)	19(33%)	3(5%)
Coast	21(55%)	14(37%)	2(5%)	1(3%)
Western	10(28%)	17(47%)	9(25%)	0(0%)
Rift valley	2(11%)	11(61%)	5(28%)	0(0%)
Other regions	1(9%)	7(64%)	3(27%)	0(0%)

I have accepted my illness
Demographic factors

	I have accepted my illness			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Age category	0(0%)	1(11%)	8(89%)	0(0%)
18-24 years	2(5%)	11(28%)	26(65%)	1(3%)
25-34 years	4(4%)	15(15%)	78(76%)	5(5%)
35-44 years	12(10%)	14(12%)	88(77%)	1(1%)
45-54 years	7(9%)	9(12%)	56(75%)	3(4%)
55-64 years	4(11%)	5(14%)	25(69%)	2(6%)
65-74 years	0(0%)	1(7%)	13(93%)	0(0%)
75 years and above	0(0%)	0(0%)	3(100%)	0(0%)
Not stated				
Marital status	24(9%)	35(13%)	196(75%)	6(2%)
Married	3(5%)	10(17%)	42(72%)	3(5%)
Widowed	1(2%)	6(13%)	39(83%)	1(2%)
Single	1(4%)	5(21%)	16(67%)	2(8%)
Divorced	0(0%)	0(0%)	4(100%)	0(0%)
Not stated				
Tribe	17(10%)	9(5%)	145(83%)	4(2%)
Kikuyu	3(7%)	4(9%)	35(80%)	2(5%)
Kamba	3(8%)	7(18%)	25(66%)	3(8%)
Luo	2(6%)	6(18%)	26(76%)	0(0%)
Luhya	0(0%)	22(59%)	14(38%)	1(3%)
Coastal tribes	2(10%)	4(19%)	14(67%)	1(5%)
Kisii	1(8%)	1(8%)	11(85%)	0(0%)
Kalenjin	0(0%)	1(9%)	9(82%)	1(9%)
Meru	0(0%)	0(0%)	6(100%)	0(0%)
Embu	0(0%)	2(15%)	11(85%)	0(0%)
Others				
Religion	21(8%)	35(13%)	214(77%)	8(3%)
Protestant	7(8%)	11(12%)	70(78%)	2(2%)
Catholic	1(5%)	9(41%)	10(45%)	2(9%)
Muslim	0(0%)	1(25%)	3(75%)	0(0%)
Other	0(0%)	1(11%)	8(89%)	0(0%)

Socioeconomic factors

	I have accepted my illness			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Level of formal education				
No formal education	11(10%)	17(16%)	75(69%)	6(6%)
Primary education	15(8%)	26(15%)	136(76%)	2(1%)
Secondary education	3(4%)	9(11%)	66(81%)	3(4%)
Tertiary education	0(0%)	4(22%)	14(78%)	0(0%)
Not stated	0(0%)	0(0%)	6(86%)	1(14%)
Occupation				
Small scale farmer	7(5%)	16(12%)	106(79%)	5(4%)
Housewife	18(14%)	20(15%)	89(68%)	3(2%)
Small scale business	0(0%)	6(14%)	35(80%)	3(7%)
Professional	1(3%)	5(15%)	28(82%)	0(0%)
Skilled employment	1(11%)	1(11%)	7(78%)	0(0%)
Other	0(0%)	1(8%)	11(85%)	1(8%)
Not stated	2(7%)	7(23%)	21(70%)	0(0%)
Monthly income				
Less than KES 2500	21(8%)	41(16%)	186(74%)	3(1%)
KES 2501-7500	2(4%)	7(13%)	39(72%)	6(11%)
KES 7500	1(4%)	5(20%)	19(76%)	0(0%)
KES 12501	0(0%)	2(13%)	14(88%)	0(0%)
KES 17501	0(0%)	0(0%)	9(100%)	0(0%)
Above KES 22500	1(20%)	1(20%)	3(60%)	0(0%)
Undisclosed	4(12%)	0(0%)	27(79%)	3(9%)
Permanent residence				
Central	16(9%)	9(5%)	142(83%)	4(2%)
Eastern	3(5%)	6(10%)	50(81%)	3(5%)
Nyanza	5(9%)	10(17%)	39(67%)	4(7%)
Coast	0(0%)	22(58%)	15(39%)	1(3%)
Western	2(6%)	7(19%)	27(75%)	0(0%)
Rift valley	2(11%)	2(11%)	14(78%)	0(0%)
Other regions	1(9%)	0(0%)	10(91%)	0(0%)

I am sleeping well
Demographic factors

	I am sleeping well			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Age category				
18-24 years	2(22%)	3(33%)	4(44%)	0(0%)
25-34 years	5(13%)	26(65%)	8(20%)	1(3%)
35-44 years	20(20%)	44(43%)	34(33%)	4(4%)
45-54 years	20(17%)	63(55%)	30(26%)	2(2%)
55-64 years	13(17%)	46(61%)	14(19%)	2(3%)
65-74 years	7(19%)	20(56%)	8(22%)	1(3%)
75 years and above	3(21%)	7(50%)	4(29%)	0(0%)
Not stated	0(0%)	2(67%)	1(33%)	0(0%)
Marital status				
Married	43(16%)	142(54%)	69(26%)	7(3%)
Widowed	15(26%)	28(48%)	14(24%)	1(2%)
Single	6(13%)	27(57%)	13(28%)	1(2%)
Divorced	5(21%)	12(50%)	6(25%)	1(4%)
Not stated	1(25%)	2(50%)	1(25%)	0(0%)
Tribe				
Kikuyu	27(15%)	98(56%)	47(27%)	3(2%)
Kamba	10(23%)	25(57%)	8(18%)	1(2%)
Luo	6(16%)	18(47%)	11(29%)	3(8%)
Luhya	6(18%)	18(53%)	10(29%)	0(0%)
Coastal tribes	12(32%)	19(51%)	5(14%)	1(3%)
Kisii	5(24%)	10(48%)	5(24%)	1(5%)
Kalenjin	2(15%)	5(38%)	6(46%)	0(0%)
Meru	0(0%)	6(55%)	4(36%)	1(9%)
Embu	0(0%)	5(83%)	1(17%)	0(0%)
Others	1(8%)	7(54%)	5(38%)	0(0%)
Religion				
Protestant	45(16%)	149(54%)	77(28%)	7(3%)
Catholic	16(18%)	52(58%)	21(23%)	1(1%)
Muslim	8(36%)	8(36%)	4(18%)	2(9%)
Other	1(25%)	2(50%)	1(25%)	0(0%)

Socioeconomic factors

	I am sleeping well			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Level of formal education				
No formal education	23(21%)	57(52%)	26(24%)	3(3%)
Primary education	37(21%)	102(57%)	37(21%)	3(2%)
Secondary education	9(11%)	38(47%)	31(38%)	3(4%)
Tertiary education	1(6%)	10(56%)	7(39%)	0(0%)
Not stated	0(0%)	4(57%)	2(29%)	1(14%)
Occupation				
Small scale farmer	25(19%)	66(49%)	38(28%)	5(4%)
Housewife	32(25%)	79(61%)	17(13%)	2(2%)
Small scale business	3(7%)	25(57%)	14(32%)	2(5%)
Professional	2(6%)	16(47%)	16(47%)	0(0%)
Skilled employment	1(11%)	3(33%)	5(56%)	0(0%)
Other	2(15%)	6(46%)	4(31%)	1(8%)
Not stated	5(17%)	16(53%)	9(30%)	0(0%)
Monthly income				
Less than KES 2500	49(20%)	156(62%)	44(18%)	2(1%)
KES 2501-7500	8(15%)	23(43%)	18(33%)	5(9%)
KES 7500	4(16%)	13(52%)	8(32%)	0(0%)
KES 12501	0(0%)	6(38%)	10(63%)	0(0%)
KES 17501	0(0%)	2(22%)	7(78%)	0(0%)
Above KES 22500	1(20%)	3(60%)	1(20%)	0(0%)
Undisclosed	8(24%)	8(24%)	15(44%)	3(9%)
Permanent residence				
Central	27(16%)	97(57%)	44(26%)	3(2%)
Eastern	10(16%)	37(60%)	13(21%)	2(3%)
Nyanza	10(17%)	26(45%)	18(31%)	4(7%)
Coast	12(32%)	19(50%)	6(16%)	1(3%)
Western	7(19%)	20(56%)	9(25%)	0(0%)
Rift valley	3(17%)	6(33%)	9(50%)	0(0%)
Other regions	1(9%)	6(55%)	4(36%)	0(0%)

I am enjoying the things I usually do for fun
Demographic factors

	I am enjoying the things I usually do for fun			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Age category				
18-24 years	2(22%)	3(33%)	3(33%)	1(11%)
25-34 years	8(20%)	24(60%)	7(18%)	1(3%)
35-44 years	30(29%)	53(52%)	14(14%)	5(5%)
45-54 years	35(30%)	54(47%)	24(21%)	2(2%)
55-64 years	23(31%)	38(51%)	11(15%)	3(4%)
65-74 years	10(28%)	22(61%)	3(8%)	1(3%)
75 years and above	4(29%)	7(50%)	3(21%)	0(0%)
Not stated	0(0%)	2(67%)	1(33%)	0(0%)
Marital status				
Married	78(30%)	131(50%)	44(17%)	8(3%)
Widowed	18(31%)	28(48%)	9(16%)	3(5%)
Single	10(21%)	27(57%)	9(19%)	1(2%)
Divorced	6(25%)	14(58%)	3(13%)	1(4%)
Not stated	0(0%)	3(75%)	1(25%)	0(0%)
Tribe				
Kikuyu	39(22%)	94(54%)	38(22%)	4(2%)
Kamba	10(23%)	26(59%)	6(14%)	2(5%)
Luo	17(45%)	16(42%)	1(3%)	4(11%)
Luhya	9(26%)	20(59%)	5(15%)	0(0%)
Coastal tribes	26(70%)	9(24%)	1(3%)	1(3%)
Kisii	5(24%)	12(57%)	3(14%)	1(5%)
Kalenjin	2(15%)	8(62%)	3(23%)	0(0%)
Meru	0(0%)	6(55%)	4(36%)	1(9%)
Embu	0(0%)	6(100%)	0(0%)	0(0%)
Others	3(23%)	6(46%)	4(31%)	0(0%)
Religion				
Protestant	69(25%)	155(56%)	44(16%)	10(4%)
Catholic	31(34%)	38(42%)	20(22%)	1(1%)
Muslim	11(50%)	8(36%)	1(5%)	2(9%)
Other	1(25%)	2(50%)	1(25%)	0(0%)

Socioeconomic factors

	I am enjoying the things I usually do for fun			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Level of formal education				
No formal education	41(38%)	51(47%)	12(11%)	5(5%)
Primary education	49(27%)	98(55%)	28(16%)	4(2%)
Secondary education	18(22%)	40(49%)	20(25%)	3(4%)
Tertiary education	4(22%)	10(56%)	4(22%)	0(0%)
Not stated	0(0%)	4(57%)	2(29%)	1(14%)
Occupation				
Small scale farmer	36(27%)	64(48%)	28(21%)	6(4%)
Housewife	43(33%)	79(61%)	5(4%)	3(2%)
Small scale business	14(32%)	14(32%)	14(32%)	2(5%)
Professional	7(21%)	18(53%)	9(26%)	0(0%)
Skilled employment	2(22%)	4(44%)	3(33%)	0(0%)
Other	4(31%)	6(46%)	2(15%)	1(8%)
Not stated	6(20%)	18(60%)	5(17%)	1(3%)
Monthly income				
Less than KES 2500	78(31%)	143(57%)	27(11%)	3(1%)
KES 2501-7500	10(19%)	25(46%)	14(26%)	5(9%)
KES 7500	6(24%)	11(44%)	8(32%)	0(0%)
KES 12501	4(25%)	7(44%)	5(31%)	0(0%)
KES 17501	0(0%)	5(56%)	4(44%)	0(0%)
Above KES 22500	2(40%)	2(40%)	1(20%)	0(0%)
Undisclosed	12(35%)	10(29%)	7(21%)	5(15%)
Permanent residence				
Central	39(23%)	91(53%)	37(22%)	4(2%)
Eastern	10(16%)	39(63%)	10(16%)	3(5%)
Nyanza	20(34%)	27(47%)	6(10%)	5(9%)
Coast	26(68%)	10(26%)	1(3%)	1(3%)
Western	11(31%)	21(58%)	4(11%)	0(0%)
Rift valley	3(17%)	10(56%)	5(28%)	0(0%)
Other regions	3(27%)	5(45%)	3(27%)	0(0%)

I am content with the quality of my life right now
Demographic factors

	I am content with the quality of my life right now			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Age category				
18-24 years	1(11%)	4(44%)	4(44%)	0(0%)
25-34 years	9(23%)	23(58%)	7(18%)	1(3%)
35-44 years	25(25%)	53(52%)	19(19%)	5(5%)
45-54 years	32(28%)	55(48%)	27(23%)	1(1%)
55-64 years	20(27%)	39(52%)	13(17%)	3(4%)
65-74 years	10(28%)	17(47%)	8(22%)	1(3%)
75 years and above	3(21%)	8(57%)	3(21%)	0(0%)
Not stated	0(0%)	2(67%)	1(33%)	0(0%)
Marital status				
Married	67(26%)	141(54%)	47(18%)	6(2%)
Widowed	20(34%)	21(36%)	14(24%)	3(5%)
Single	6(13%)	27(57%)	13(28%)	1(2%)
Divorced	7(29%)	10(42%)	6(25%)	1(4%)
Not stated	0(0%)	2(50%)	2(50%)	0(0%)
Tribe				
Kikuyu	36(21%)	96(55%)	40(23%)	3(2%)
Kamba	8(18%)	26(59%)	8(18%)	2(5%)
Luo	14(37%)	15(39%)	6(16%)	3(8%)
Luhya	11(32%)	19(56%)	4(12%)	0(0%)
Coastal tribes	19(51%)	12(32%)	5(14%)	1(3%)
Kisii	6(29%)	10(48%)	4(19%)	1(5%)
Kalenjin	3(23%)	4(31%)	6(46%)	0(0%)
Meru	0(0%)	8(73%)	2(18%)	1(9%)
Embu	0(0%)	4(67%)	2(33%)	0(0%)
Others	2(15%)	7(54%)	4(31%)	0(0%)
Religion				
Protestant	63(23%)	150(54%)	57(21%)	8(3%)
Catholic	26(29%)	40(44%)	23(26%)	1(1%)
Muslim	10(45%)	9(41%)	1(5%)	2(9%)
Other	1(25%)	2(50%)	1(25%)	0(0%)

Socioeconomic factors

	I am content with the quality of my life right now			
	Not at all	A little bit/ Somewhat	Quite a bit/ very much	Not stated
Level of formal education				
No formal education	35(32%)	51(47%)	18(17%)	5(5%)
Primary education	46(26%)	100(56%)	31(17%)	2(1%)
Secondary education	15(19%)	37(46%)	26(32%)	3(4%)
Tertiary education	4(22%)	9(50%)	5(28%)	0(0%)
Not stated	0(0%)	4(57%)	2(29%)	1(14%)
Occupation				
Small scale farmer	32(24%)	63(47%)	34(25%)	5(4%)
Housewife	41(32%)	76(58%)	10(8%)	3(2%)
Small scale business	11(25%)	17(39%)	14(32%)	2(5%)
Professional	5(15%)	17(50%)	12(35%)	0(0%)
Skilled employment	2(22%)	5(56%)	2(22%)	0(0%)
Other	2(15%)	4(31%)	6(46%)	1(8%)
Not stated	7(23%)	19(63%)	4(13%)	0(0%)
Monthly income				
Less than KES 2500	66(26%)	146(58%)	36(14%)	3(1%)
KES 2501-7500	11(20%)	22(41%)	16(30%)	5(9%)
KES 7500	8(32%)	9(36%)	8(32%)	0(0%)
KES 12501	2(13%)	9(56%)	5(31%)	0(0%)
KES 17501	0(0%)	5(56%)	4(44%)	0(0%)
Above KES 22500	2(40%)	1(20%)	2(40%)	0(0%)
Undisclosed	11(32%)	9(26%)	11(32%)	3(9%)
Permanent residence				
Central	35(20%)	93(54%)	40(23%)	3(2%)
Eastern	8(13%)	39(63%)	12(19%)	3(5%)
Nyanza	17(29%)	25(43%)	12(21%)	4(7%)
Coast	19(50%)	13(34%)	5(13%)	1(3%)
Western	14(39%)	18(50%)	4(11%)	0(0%)
Rift valley	4(22%)	7(39%)	7(39%)	0(0%)
Other regions	3(27%)	6(55%)	2(18%)	0(0%)

APPENDIX II: INTERVIEW GUIDE**INTERVIEW SCHEDULE FOR MEASUREMENT OF QUALITY OF LIFE OF WOMEN WITH GYNAECOLOGICAL OR BREAST CANCER**

Interviewer's name I would like to ask you a few questions regarding yourself and the condition you are suffering from if you will allow me. Any information you give me will be treated confidentially.

a). DEMOGRAPHIC DATA

1. Your Age years (specify exact age)
2. Ethnic group (Tribe)
3. Home District
4. Marital Status
 Single Married Divorced Widowed
 Others (specify) _____
5. Number of children
 None - 2 3 - 4 5 - 6 Above 6
6. Age of the eldest child years
7. Age of the youngest child s
8. Education level
 None Primary Secondary Tertiary
9. Occupation: _____
10. Type of work _____

Form serial No. _____

11. Total income per month

<input type="checkbox"/> Less than 2,500	<input type="checkbox"/> 2,500 - 7,500	
<input type="checkbox"/> 7,500 - 12,500	<input type="checkbox"/> 12,500 - 17,500	<input type="checkbox"/> 17,500
<input type="checkbox"/> - 22,500	<input type="checkbox"/> Above 22,500	<input type="checkbox"/>

12. Sources of income

<input type="checkbox"/> None from self	<input type="checkbox"/> Self alone
<input type="checkbox"/> Spouse/partner	<input type="checkbox"/> Collective from all

13. Religion

<input type="checkbox"/> Catholic	<input type="checkbox"/> Protestant
<input type="checkbox"/> Muslim	<input type="checkbox"/> Other _____

14. With whom are you currently living?

<input type="checkbox"/> Alone	<input type="checkbox"/> Spouse/partner
<input type="checkbox"/> Son/son in-law	<input type="checkbox"/> Daughter/daughter in-law
<input type="checkbox"/> Friend	<input type="checkbox"/> Others (specify) _____

Disease and treatment related data (from patient's records)

Diagnosis _____

Stage of disease (FIGO) _____

Treatment:

Surgery _____ Dates _____

Surgery and radiotherapy _____ Dates _____

Radiotherapy _____ Dates _____

Chemotherapy _____ Dates _____

Palliative care _____ Dates _____

Other (specify) _____ Dates _____

I am kindly requesting you to explain to me **your personal experiences and feelings, in the last 2 weeks**, with regard to the following:

1. Your meaning/understanding of the term "quality of life".
 - Sense of well-being / enjoyment of life
 - Being able to do things one is used to doing for the self and others
 - Not having undue worries
 - Being healthy / enjoying life.

2. How this illness has affected the state of your body:
 - Fatigue; appetite changes; aches or pain; sleep changes; constipation; menstrual changes; weight loss; tolerance to food;
 - Body complexion or hair changes; muscle bulk / body shape changes.

3. How this illness has affected:
 - i) your own self care
 - ii) motivation to work
 - iii) time away from work
 - iv) productivity of work
 - v) quality of work.

4. Your body's state of wellbeing.

5. Your views on:
 - i) how well you cope with the disease
 - ii) how good your quality of life is
 - iii) how much happiness you feel
 - iv) how much you feel you are in control of things in your life
 - v) how satisfying your life is
 - vi) how much you can concentrate or remember things
 - vii) how useful you feel
 - viii) how much the disease has caused changes in your appearance
 - ix) how much the disease has caused changes in the way you see yourself (self concept).

I am kindly requesting you to explain to me **your personal experiences and feelings, in the last 2 weeks**, with regard to the following:

1. Your meaning/understanding of the term "quality of life".
 - Sense of well-being / enjoyment of life
 - Being able to do things one is used to doing for the self and others
 - Not having undue worries
 - Being healthy / enjoying life.
2. How this illness has affected the state of your body:
 - Fatigue; appetite changes; aches or pain; sleep changes; constipation; menstrual changes; weight loss; tolerance to food;
 - Body complexion or hair changes; muscle bulk / body shape changes.
3. How this illness has affected:
 - i) your own self care
 - ii) motivation to work
 - iii) time away from work
 - iv) productivity of work
 - v) quality of work.
4. Your body's state of wellbeing.
5. Your views on:
 - i) how well you cope with the disease
 - ii) how good your quality of life is
 - iii) how much happiness you feel
 - iv) how much you feel you are in control of things in your life
 - v) how satisfying your life is
 - vi) how much you can concentrate or remember things
 - vii) how useful you feel
 - viii) how much the disease has caused changes in your appearance
 - ix) how much the disease has caused changes in the way you see yourself (self concept).

6. Your reaction to:
- i) being told the diagnosis of this illness
 - ii) surgery / operations for this disease
 - iii) chemotherapy treatment being completed
 - iv) the initial radiotherapy treatment
 - v) stopping chemotherapy / cytotoxic drugs.
7. Your status on:
- i) how anxious you feel
 - ii) how depressed you feel
 - iii) how fearful you are of:
 - a) future diagnostic tests
 - b) a cancer in general
 - c) recurrence of your cancer
 - d) spreading of your cancer.
8. The influence of this disease on:
- i) members of your family
 - ii) the support you get from others to enable you meet your needs
 - iii) your personal relationships like, with your husband/partner
 - iv) your sexuality.
9. How this illness has affected the care of your family.
10. How this illness has affected your financial status.
11. How this illness has affected your ability to:
- i) maintain your house clean
 - ii) perform household chores
 - iii) prepare meals
 - iv) have leisure time activities.
12. What you or others think is the cause of this disease and how it should be managed.
13. How important / relevant to you are:
- i) participation in religious activities (such as praying)
 - ii) reading / listening to the word of God and thinking about it.

14. Your views and reflections on how much:

- a) Your spiritual life has changed as a result of this disease
- b) The illness has made positive changes in your life
- c) You feel there is a purpose for being alive
- d) Hope you feel.

15. Your overall quality of life.

16. How your culture or tradition has influenced your state of disease

17. The role of culture and tradition with regard to this disease or others like it.

18. Perhaps you can tell me what else you feel you wish to let me know which we may have left out during this talk _____

APPENDIX III: FUNCTIONAL ASSESSMENT OF CANCER THERAPY

(FACT)

Below is a list of statements that other people with your illness have said are important. By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.

PHYSICAL WELL-BEING

		Not at all	A little bit	Some-what	Quite a bit	Very much
GP1	I have a lack of energy	0	1	2	3	4
GP2	I have nausea	0	1	2	3	4
GP3	Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
GP4	I have pain	0	1	2	3	4
GP5	I am bothered by side effects of treatment	0	1	2	3	4
GP6	I feel ill	0	1	2	3	4
GP7	I am forced to spend time in bed.....	0	1	2	3	4

SOCIAL/FAMILY WELL-BEING

		Not at all	A little bit	Some-what	Quite a bit	Very much
GS1	I feel close to my friends	0	1	2	3	4
GS2	I get emotional support from my family	0	1	2	3	4
GS3	I get support from my friends	0	1	2	3	4
GS4	My family has accepted my illness	0	1	2	3	4
GS5	I am satisfied with family communication about my illness	0	1	2	3	4
GS6	I feel close to my partner (or the person who is my main support)	0	1	2	3	4
Q1	<i>Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please check this box <input type="checkbox"/> and go to the next section.</i>					
GS7	I am satisfied with my sex life	0	1	2	3	4

By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.

EMOTIONAL WELL-BEING

Not at all A little bit Some-what Quite a bit Very much

GE1	I feel sad	0	1	2	3	4
GE2	I am satisfied with how I am coping with my illness	0	1	2	3	4
GE3	I am losing hope in the fight against my illness	0	1	2	3	4
GE4	I feel nervous	0	1	2	3	4
GE5	I worry about dying	0	1	2	3	4
GE6	I worry that my condition will get worse	0	1	2	3	4

FUNCTIONAL WELL-BEING

Not at all A little bit Some-what Quite a bit Very much

GF1	I am able to work (include work at home)	0	1	2	3	4
GF2	My work (include work at home) is fulfilling	0	1	2	3	4
GF3	I am able to enjoy life	0	1	2	3	4
GF4	I have accepted my illness	0	1	2	3	4
GF5	I am sleeping well	0	1	2	3	4
GF6	I am enjoying the things I usually do for fun	0	1	2	3	4
GF7	I am content with the quality of my life right now	0	1	2	3	4

Serial No..... Hospital No..... Date of
interview.....

FACT-B ADDITIONAL

By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.

Serial No..... Hospital No..... Date of
interview.....

ADDITIONAL CONCERNS

		Not at all	A little bit	Some- what	Quite a bit	Very much
B1	I have been short of breath	0	1	2	3	4
B2	I am self-conscious about the way I dress	0	1	2	3	4
B3	One or both of my arms are swollen or tender	0	1	2	3	4
B4	I feel sexually attractive	0	1	2	3	4
B5	I am bothered by hair loss	0	1	2	3	4
B6	I worry that other members of my family might someday get the same illness I have	0	1	2	3	4
B7	I worry about the effect of stress on my illness	0	1	2	3	4
B8	I am bothered by a change in weight	0	1	2	3	4
B9	I am able to feel like a woman	0	1	2	3	4
P2	I have certain parts of my body where I experience significant pain	0	1	2	3	4

FACT-Cx ADDITIONAL

By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.

<u>ADDITIONAL CONCERNS</u>		Not at all	A little bit	Some- what	Quite a bit	Very much
Cx1	I am bothered by discharge or bleeding from my vagina	0	1	2	3	4
Cx2	I am bothered by odor coming from my vagina	0	1	2	3	4
Cx3	I am afraid to have sex	0	1	2	3	4
B4	I feel sexually attractive	0	1	2	3	4
Cx4	My vagina feels too narrow or short	0	1	2	3	4
BMT 7	I have concerns about my ability to have children	0	1	2	3	4
Cx5	I am afraid the treatment may harm my body	0	1	2	3	4
BL4	I am interested in sex	0	1	2	3	4
C7	I like the appearance of my body	0	1	2	3	4
Cx6	I am bothered by constipation	0	1	2	3	4
C6	I have a good appetite	0	1	2	3	4
BL1	I have trouble controlling my urine	0	1	2	3	4
BL3	It burns when I urinate	0	1	2	3	4
Cx7	I have discomfort when I urinate	0	1	2	3	4
HNI	I am able to eat the foods that I like	0	1	2	3	4

Serial No..... Hospital No..... Date of
interview.....

FACT-O ADDITIONAL

By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.

Serial No..... Hospital No..... Date of
interview.....

<u>ADDITIONAL CONCERNS</u>		Not at all	A little bit	Some- what	Quite a bit	Very much
O1	I have swelling in my stomach area	0	1	2	3	4
C2	I am losing weight	0	1	2	3	4
C3	I have control of my bowels	0	1	2	3	4
O2	I have been vomiting	0	1	2	3	4
B5	I am bothered by hair loss	0	1	2	3	4
C6	I have a good appetite	0	1	2	3	4
C7	I like the appearance of my body	0	1	2	3	4
BMT5	I am able to get around by myself	0	1	2	3	4
B9	I am able to feel like a woman	0	1	2	3	4
O3	I have cramps in my stomach area	0	1	2	3	4
BL4	I am interested in sex	0	1	2	3	4
BMT7	I have concerns about my ability to have children	0	1	2	3	4

FACT-En ADDITIONAL

By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.

<u>ADDITIONAL CONCERNS</u>		Not at all	A little bit	Some- what	Quite a bit	Very much
O1	I have swelling in my stomach area	0	1	2	3	4
O3	I have cramps in my stomach area	0	1	2	3	4
Hep 8	I have discomfort or pain in my stomach area	0	1	2	3	4
ES6	I have vaginal bleeding or spotting	0	1	2	3	4
ES4	I have vaginal discharge	0	1	2	3	4
Hep 1	I am unhappy about a change in my appearance	0	1	2	3	4
ES1	I have hot flashes	0	1	2	3	4
ES2	I have cold sweats	0	1	2	3	4
ES3	I have night sweats	0	1	2	3	4
HI7	I feel fatigued	0	1	2	3	4
ES8	I have pain or discomfort with intercourse	0	1	2	3	4
En1	I have trouble digesting food	0	1	2	3	4
B1	I have been short of breath	0	1	2	3	4
Cx6	I am bothered by constipation	0	1	2	3	4
B12	I urinate more frequently than usual	0	1	2	3	4
En2	I have discomfort or pain in my pelvic area	0	1	2	3	4

FACIT-F ADDITIONAL

By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.

<u>ADDITIONAL CONCERNS</u>		Not at all	A little bit	Some -what	Quite a bit	Very much
HI7	I feel fatigued	0	1	2	3	4
HI 12	I feel weak all over	0	1	2	3	4
An1	I feel listless ("washed out")	0	1	2	3	4
An2	I feel tired	0	1	2	3	4
An3	I have trouble <u>starting</u> things because I am tired	0	1	2	3	4
An4	I have trouble <u>finishing</u> things because I am tired	0	1	2	3	4
An5	I have energy	0	1	2	3	4
An7	I am able to do my usual activities	0	1	2	3	4
An8	I need to sleep during the day	0	1	2	3	4
An 12	I am too tired to eat	0	1	2	3	4
An 14	I need help doing my usual activities	0	1	2	3	4
An 15	I am frustrated by being too tired to do the things I want to do	0	1	2	3	4
An 16	I have to limit my social activity because I am tired	0	1	2	3	4

FACIT-Pal ADDITIONAL

By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.

ADDITIONAL CONCERNS

		Not at all	A little bit	Some- what	Quite a bit	Very much
PAL1	I maintain contact with my friends	0	1	2	3	4
PAL2	I have family members who will take on my responsibilities	0	1	2	3	4
PAL3	I feel that my family appreciates me	0	1	2	3	4
PAL4	I feel like a burden to my family	0	1	2	3	4
B1	I have been short of breath	0	1	2	3	4
PAL5	I am constipated	0	1	2	3	4
C2	I am losing weight	0	1	2	3	4
O2	I have been vomiting	0	1	2	3	4
PAL6	I have swelling in parts of my body	0	1	2	3	4
PAL7	My mouth and throat are dry	0	1	2	3	4
Br7	I feel independent	0	1	2	3	4
PAL8	I feel useful	0	1	2	3	4
PAL9	I make each day count	0	1	2	3	4
PAL10	I have peace of mind	0	1	2	3	4
Sp21	I feel hopeful	0	1	2	3	4
PAL12	I am able to make decisions	0	1	2	3	4
L1	My thinking is clear	0	1	2	3	4
PAL13	I have been able to reconcile (make peace) with other people	0	1	2	3	4
PAL14	I am able to openly discuss my concerns with the people closest to me	0	1	2	3	4

FAACT ADDITIONAL

By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.

<u>ADDITIONAL CONCERNS</u>		Not at all	A little bit	Some- what	Quite a bit	Very much
C6	I have a good appetite	0	1	2	3	4
ACT 1	The amount I eat is sufficient to meet my needs	0	1	2	3	4
ACT 2	I am worried about my weight	0	1	2	3	4
ACT 3	Most food tastes unpleasant to me	0	1	2	3	4
ACT 4	I am concerned about how thin I look	0	1	2	3	4
ACT 6	My interest in food drops as soon as I try to eat	0	1	2	3	4
ACT 7	I have difficulty eating rich or "heavy" foods	0	1	2	3	4
ACT 9	My family or friends are pressuring me to eat	0	1	2	3	4
O2	I have been vomiting	0	1	2	3	4
ACT 10	When I eat, I seem to get full quickly	0	1	2	3	4
ACT 11	I have pain in my stomach area	0	1	2	3	4
ACT 13	My general health is improving.....	0	1	2	3	4

FACIT-Sp-Ex

Below is a list of statements that other people with your illness have said are important.

By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.

		Not at all	A little bit	Some- what	Quite a bit	Very much
Sp1	I feel peaceful	0	1	2	3	4
Sp2	I have a reason for living	0	1	2	3	4
Sp3	My life has been productive	0	1	2	3	4
Sp4	I have trouble feeling peace of mind	0	1	2	3	4
Sp5	I feel a sense of purpose in my life	0	1	2	3	4
Sp6	I am able to reach down deep into myself for comfort	0	1	2	3	4
Sp7	I feel a sense of harmony within myself	0	1	2	3	4
Sp8	My life lacks meaning and purpose	0	1	2	3	4
Sp9	I find comfort in my faith or spiritual beliefs	0	1	2	3	4
Sp10	I find strength in my faith or spiritual beliefs	0	1	2	3	4
Sp11	My illness has strengthened my faith or spiritual beliefs	0	1	2	3	4
Sp12	I know that whatever happens with my illness, things will be okay	0	1	2	3	4
Sp13	I feel connected to a higher power (or God)	0	1	2	3	4
Sp14	I feel connected to other people	0	1	2	3	4
Sp15	I feel loved	0	1	2	3	4
Sp16	I feel love for others	0	1	2	3	4
Sp17	I am able to forgive others for any harm they have ever caused me	0	1	2	3	4
Sp18	I feel forgiven for any harm I may have ever caused	0	1	2	3	4
Sp19	Throughout the course of my day, I feel a sense of thankfulness for my life	0	1	2	3	4
Sp20	Throughout the course of my day, I feel a sense of thankfulness for what others bring to my life	0	1	2	3	4
Sp21	I feel hopeful	0	1	2	3	4
Sp22	I feel a sense of appreciation for the beauty of nature	0	1	2	3	4
Sp23	I feel compassion for others in the difficulties they are facing	0	1	2	3	4

FACIT-TS-G

Please evaluate your experience on this treatment:

(name of treatment)

If you have not completed your treatment, please answer the questions the best you can. All of your answers will be kept confidential.

Please mark one answer for each of the following questions.

		A lot worse	A little worse	About the same	A little better	A lot better
TS1	Compared to what you expected, how do you rate the <u>effectiveness of the treatment</u> so far?	0	1	2	3	4
TS2	Compared to what you expected, how do you rate the <u>side effects of treatment</u> so far?	0	1	2	3	4
		No, not at all	Yes, to some extent	Yes, for the most part	Yes, completely	
TS3	Did your doctor(s) help you evaluate the effects of your treatment so far?	0	1	2	3	
TS4	Do you feel you received the treatment that was right for you?	0	1	2	3	
TS5	Are you satisfied with the effects of this treatment so far?	0	1	2	3	
		No	Maybe	Yes		
TS6	Would you recommend this treatment to others with your illness?	0	1	2		
TS7	Would you choose this treatment again?	0	1	2		
		Poor	Fair	Good	Very Good	Excellent
TS8	How do you rate this treatment overall?	0	1	2	3	4

Thank you! Do you have any comments?

FACIT-TS-PS

These questions are about the quality of the health care services you are currently receiving. All of your responses will be kept confidential.

Your opinions may refer to your last visit or to several visits.

Please mark one box to choose the visit(s) you would like to rate:

1	My most recent visit.....	1	<input type="checkbox"/>
	Several of my most recent visits.....	2	<input type="checkbox"/>
	My experience in general.....	3	<input type="checkbox"/>

Please mark one answer for each of the following questions.

<u>Explanations</u>	No, not at all	Yes, but not as much as I wanted	Yes, almost as much as I wanted	Yes, and as much as I wanted
TS 9	Did your doctor(s) give explanations that you could understand?			
	0	1	2	3
TS 10	Did your doctor(s) explain the possible <u>benefits</u> of your treatment?			
	0	1	2	3
TS 11	Did your doctor(s) explain the possible <u>side effects or risks</u> of your treatment?			
	0	1	2	3
TS 12	Did you have an opportunity to ask questions?...			
	0	1	2	3

Interpersonal

TS 13	Did you get to say the things that were important to you?	0	1	2	3
TS 14	Did your doctor(s) seem to understand what was important to you?	0	1	2	3
TS 15	Did your doctor(s) show genuine concern for you?	0	1	2	3

		No, not at all	Yes, but not as much as I wanted	Yes, almost as much as I wanted	Yes, and as much as I wanted
<u>Comprehensive Care</u>					
TS 16	Did your doctor(s) seem to understand your needs?	0	1	2	3
TS 17	Did you feel that the treatment staff worked together towards the same goal?	0	1	2	3
TS 18	Were you able to talk to your doctor(s) when you needed to?	0	1	2	3
TS 19	Did the treatment staff discuss how your health and treatment may affect your <u>normal work</u> (including housework)?	0	1	2	3
TS 20	Did the treatment staff discuss how your health and treatment may affect your <u>normal daily</u> activities?	0	1	2	3
TS 21	Did the treatment staff discuss how your health and treatment may affect your <u>personal</u> relationships?	0	1	2	3
TS 22	Did the treatment staff discuss how your health and treatment may affect you <u>emotionally</u> ?	0	1	2	3

Technical Quality

TS 23	Did you feel your doctor(s) had experience treating your illness?	0	1	2	3
TS 24	Did you feel your doctor(s) knew about the latest medical developments for your illness?	0	1	2	3
TS 25	Was the treatment staff thorough in examining and treating you?	0	1	2	3

Serial No..... Hospital No..... Date of interview.....

Decision-making

No, not at all Yes, but not as much as I wanted Yes, almost as much as I wanted Yes, and as much as I wanted

TS 26	Did your doctor(s) discuss other treatments, for example, alternative medicine or new treatments?	0	1	2	3
TS 27	Were you encouraged to participate in decisions about your health care?	0	1	2	3
TS 28	Did you have enough time to make decisions about your health care?	0	1	2	3
TS 29	Did you have enough information to make decisions about your health care?	0	1	2	3
TS 30	Did your doctor(s) seem to respect your opinions?	0	1	2	3

Nurses

TS 31	Did your nurse(s) give explanations that you could understand?	0	1	2	3
TS 32	Did your nurse(s) show genuine concern for you?	0	1	2	3
TS 33	Did your nurse(s) seem to understand your needs?	0	1	2	3

Trust

No, not at all Yes, to some extent Yes, for the most part Yes, completely

TS 34	Did you feel that the treatment staff answered your questions honestly?	0	1	2	3
TS 35	Did the treatment staff respect your privacy?	0	1	2	3
TS 36	Did you have confidence in your doctor(s)?	0	1	2	3
TS 37	Did you trust your doctor(s)' suggestions for treatment?	0	1	2	3

Serial No..... Hospital No..... Date of interview.....

Overall

No Maybe Yes

TS
38

TS
39

Would you recommend this clinic or office to others?

0 1 2

Would you choose this clinic or office again?

0 1 2

Overall

Poor Fair Good Very Good Excellent

TS
40

How do you rate the care you received?

0 1 2 3 4

Thank you! Do you have any comments?

APPENDIX IV: PATIENT CONSENT FORM

WE ARE CONDUCTING A STUDY ON WOMEN WHO ARE ILL WITH SIMILAR DISEASES LIKE YOU.

WHILE SOME OF THE PROBLEMS WOMEN WITH THESE DISEASES MAY HAVE BEEN NOTED IN OTHER COUNTRIES IN THE WORLD, THIS IS NOT THE CASE IN OUR COUNTRY. IT IS FOR PURPOSES OF UNDERSTANDING THE VIEWS HELD BY WOMEN WITH THESE CONDITIONS THAT A STUDY LIKE THIS IS INTENDED AND WE ARE REQUESTING FOR YOUR PARTICIPATION. YOUR VIEWS WOULD FACILITATE BETTER UNDERSTANDING AND MANAGEMENT OF WOMEN WITH A SIMILAR DISEASE. THE SINCERE AND CORRECT INFORMATION YOU GIVE US WILL ALSO HELP IN GIVING APPROPRIATE ADVICE TO HEALTH CARE PLANNERS AND PROVIDERS ON HOW BEST TO DELIVER SERVICES NEEDED BY WOMEN WITH A SIMILAR DISEASE LIKE YOURS. THE INFORMATION WOULD ALSO HELP IN DESIGNING COMMUNITY EDUCATION PROGRAMMES IN ORDER TO ENHANCE THEIR UNDERSTANDING OF THE DISEASE AND MANAGEMENT OF PATIENTS HAVING THE DISEASE. THE INFORMATION YOU GIVE US WILL HOWEVER BE TREATED WITH STRICT CONFIDENTIALITY.

WE INTEND TO ASK YOU SOME QUESTIONS AND TAPE RECORD OUR CONVERSATION WITH YOU. WE WOULD ALSO LIKE TO ASK YOU TO CHECK THE CORRECT ANSWERS TO SOME SET QUESTIONS.

IN CASE YOU DECLINE TO OFFER INFORMATION, YOU WILL NOT BE VICTIMISED IN ANY WAY. HENCE NONE OF YOUR RIGHTS AS A PATIENT WILL BE DENIED BY PARTICIPATING OR NOT PARTICIPATING IN THIS STUDY.

SIMILAR MEETINGS WITH YOU IN THE FUTURE WILL BE SCHEDULED.

I HAVE UNDERSTOOD THE EXPLANATION GIVEN TO ME REGARDING MY PARTICIPATION IN THIS STUDY, AND WILLINGLY WANT TO PARTICIPATE.

SIGNATURE _____ THUMB PRINT _____

DATE _____.

WITNESS _____ RELATIONSHIP _____

DATE _____

APPENDIX V: TIME SCHEDULE

DATES	ACTIVITIES
I MAY 04 – MARCH 05	Proposal Preparation
II APR - JUNE 05	Proposal Submission for Approval and Registration.
III JULY 05–JUNE 07	Data Collection, Processing and Analysis
IV JULY 07 – DEC 07	Write up the Report
TOTAL 4 YEARS	

APPENDIX VI: BUDGET

STATIONARY, SUPPLIES AND EQUIPMENT

Photocopying paper	40 reams @500/=	20,000
Ruled Paper	20 reams @400/=	8,000
Ball pens	100 pieces @20/=	2,000
Pencils HB	100 pieces @25/=	2,500
Rubber	40 pieces @30/=	1,200
Ruler	40 pieces @ 20/=	800
Note Books	40 pieces @ 50/=	2,000
Electronic calculators	8 pieces @ 1,000/=	8,000
Transparencies	200 pieces @ 35/=	7,000
Computer desk top plus accessories		250,000
Sub total	301,500	

DATA COLLECTION

Travelling and Accommodation		
Accommodation/Subsistence Allowance		
Principal Investigator @3,750/=X12X7		= 315,000
Assistants @3,000 X16 X 24 months		= 1152,000
Travelling		
Principal Investigator 11,000 X 12		= 132,000

DATA ANALYSIS

Analyst @10,000 X 10 days		= 100,000
Secretary / Typist @ 18,000 X 5 months		= 90,000
Photocopying and Binding of report (10 copies)		= 20,000
Sub total		1809,000
Grand Total		2,110,500
+10% Contingencies		= 2,321,550
@ 76/= per dollar		= US\$ 30,547

APPENDIX VII: PERFORMANCE SCALE (ECOG AND KARNOFSKY)

ECOG	KARNOFSKY
0 Fully active, able to carry on all predisease performance without restriction.	100% Normal, no complaints, no evidence of disease
1 Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g. light housework, office work.	90% Able to carry on normal activity; minor signs or symptoms of disease.
2 Ambulatory and capable of all self care but unable to carry out any work activities; up and about more than 50% of waking hours.	80% Normal activity with effort some signs or symptoms of disease.
3 Capable of limited self-care confined to bed or chair more than 50% of waking hours.	70% Cares for self; unable to do normal activity or to do active work.
4 Completely disabled; cannot carry on self-care; totally confined to bed or chair.	60% Requires occasional assistance, but is mostly able to care for himself.
5 Dead	50% Requires considerable assistance and frequent medical care. 40% Disabled, requires special care and assistance. 30% Severely disabled, hospitalisation indicated; death not imminent. 20% Very sick, hospitalisation necessary active supportive treatment necessary. 10% Moribund, fatal processes, progressing rapidly. 0% Dead.