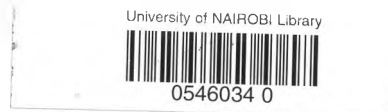


**THE CHALLENGES AND COPING STRATEGIES OF CERVICAL CANCER
PATIENTS AND THEIR FAMILIES IN KENYA**

BY

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**A THESIS SUBMITTED TO THE INSTITUTE OF ANTHROPOLOGY, GENDER
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OF MASTER OF ARTS IN ANTHROPOLOGY OF THE UNIVERSITY OF
NAIROBI**



NOVEMBER 2012

DECLARATION

This thesis is my original work and has not been presented for a degree in any other university.


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This thesis has been submitted with my approval as the university supervisor.


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Date

DEDICATION

This is dedicated to cervical cancer patients and their families.

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ABSTRACT

THE CHALLENGES AND COPING STRATEGIES OF CERVICAL CANCER PATIENTS AND THEIR FAMILIES IN KENYA

The study adopted an explorative descriptive study design that utilized qualitative research methods in the exploration of the *challenges and coping strategies developed by cervical cancer patients and their families*. In-depth interviews and key informant interviews were the primary data collection methods.

The overall objective of the study was to explore the challenges of cervical cancer patients and their families and the coping strategies they put into action to overcome those challenges. The study responded to two specific objectives namely; to establish the challenges faced by cervical cancer patients and their families; to determine the coping strategies that cervical cancer patients and their families have developed to counter the challenges of living with cervical cancer.

18 cervical cancer patients and 18 care givers were the key informants of this study. The study explored the lived experiences of cervical cancer patients and their families as a way of understanding challenges and the dynamics of living with chronic illnesses. Data was coded and analysed thematically. The themes were identified based on the study objectives.

The challenges identified through this study are; economic strain, access to health care, delayed diagnosis, lack of information on cervical cancer, anxiety and fear of death, family stress, sexuality as well as fear of stigmatization and avoidance .

The patients and families had over time put into action coping strategies to counter the challenges faced in living with cervical cancer. The coping strategies as identified in this

study include; turning to religion, family support, positive reinterpretation, and palliative care.

Based on the study findings there are indeed challenges faced by cervical cancer patients and their families, and to cope with these challenges the families and the patients have developed strategies but there is still a lot that needs to be done in addressing the challenges of living with cervical cancer. The study points out a few recommendations for policy, service delivery and further research. One of the recommendations is to improve health systems as a part of concerted efforts against cervical cancer. This is to facilitate more awareness creation on cervical cancer and screening leading to early diagnosis and treatment to this curable and preventable cancer.

In service delivery, the recommendation is to improve quality of life by meeting the patients' needs with holistic care (physical, psychosocial and spiritual support) through palliative care.

For further research, the study proposes research on the management tasks of patients with chronic illnesses including cervical cancer. Findings will better the understanding of caregivers' experience, and on how the adjustment to the care giver's role impacts on the ability to provide care to the cancer patient.

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LIST OF ACRONYMS/ABBREVIATIONS

ACCP: Alliance for Cervical Cancer Prevention

ACS: American Cancer Society

AKUH (N): Aga Khan University hospital

CAS: Centre for Adolescence Study

CTC: Cancer Treatment Centre

CC: Cervical cancer

ICO: Information centre

HPV: Human Papillomavirus

IARC: International Agency for Research on Cancer.

KNH: Kenyatta National Hospital

PATH: Program for Appropriate Technology in Health.

WHO: World Health Organization

CHAPTER 1: INTRODUCTION

This chapter introduces the study on the challenges and coping strategies of cervical cancer patients and their families in Kenya. The chapter consists of the introduction to the study, the problem statement, and the objectives of the study (general and specific objectives) and justification of the study.

1.1 Introduction

Cancer a chronic illness, is a leading cause of death worldwide and it accounted for 7.4 million deaths (or around 13% of all deaths worldwide) in 2004. More than 70% of these deaths occurred in low- and middle-income countries. Worldwide deaths from cancer are projected to continue rising, reaching an estimated 12 million deaths in 2030 (WHO 2008). Among women, cervical cancer is the second most common cancer after breast cancer worldwide. It is a preventable condition, which results from Human Papillomavirus (HPV) infection, a sexually transmitted disease. Each year, close to half a million women are diagnosed with cervical cancer, and approximately 270,000 mostly in the developing world die of the illness (ACCP 2004). In Kenya, current estimates indicate that every year 2,454 women are diagnosed with cervical cancer and 1,676 die from this chronic illness (WHO / ICO 2010).

Cervical cancer develops slowly after initial infection with Human Papillomavirus (HPV) (ACCP 2004). Women contract HPV in their teens and twenties. When exposed to HPV, a woman's immune system typically prevents the virus from doing harm. In a small group of women, however, the virus survives for years before it eventually converts some cells on the surface of the cervix into cancer cells (IARC 2007).

Over the past 40 years, widespread, routine use of Pap smear to test for the early signs of

the disease has resulted in a dramatic decline in cervical cancer deaths in developed countries. With early detection, women in developed countries are able to treat cervical cancer before it develops into a chronic illness and this has reduced mortality linked to cervical cancer.

Despite increased awareness for screening in the developing world, inequities among the different population groups make access to early detection difficult and women are usually diagnosed in the advanced stage of cervical cancer. At this advanced stage cancer has spread beyond the cervix. The most immediate need is for curative treatment in the form of pelvic surgery, radiotherapy, and chemotherapy, which are prohibitively expensive in these low resource settings. Consequently, most women do not receive curative treatment and face a protracted and difficult illness (Sellors *et al.* 2004). For these women palliative care remains the most viable option available to them (WHO 1990).

Palliative care is the “active total care of patients whose disease is not responsive to curative treatment.” Active total care involves the prevention and relief of suffering through early identification and assessment and treatment of pain, physical, psychological, social and spiritual problems affecting the patients and their families.

Palliative care aims to prolong life and improve the quality of life for the patients and their families (WHO 1990).

Cervical cancer like other chronic illnesses is therefore a real challenge for medicine and psychology. When an illness occurs, the patient is faced with the difficult task of adjusting to restrictions imposed by the disease itself. In particular, coping behaviours that exacerbate negative affective states have been correlated with reduced functionality,

increased physical and psychological morbidity and mortality (Williams *et al.* 1983; De Jong *et al.* 2005). Effective coping has been found to decrease morbidity and mortality related to chronic illness (Ashing-Giwa *et al.* 2004). This study seeks to explore the challenges and coping strategies of cervical cancer patients and their families and make recommendations to better the management and care of this chronic illness and prolong the life of women living with cervical cancer.

1.2 Statement of the problem

The number of detected cervical cancer cases in Kenya is on the rise given the increased awareness for screening services. There are now more women and families aware and faced with challenges of a chronic illness as cervical cancer ranks as the second most frequent cancer after breast cancer, especially among women between 15 and 44 years of age. About 38.8 % of women in the general population are estimated to harbour cervical HPV infection at a given time (WHO / ICO 2010).

Like other chronic illnesses, cervical cancer takes a long duration and progresses slowly. Having a long-term or chronic illness disrupts life in many ways. One may often be tired and in pain. The illness might affect one's appearance or physical abilities and independence. One may be unable to work, causing financial problems. Adjustment to the chronic illness is a complex process determined by both external factors (e.g. social support, life circumstances) and internal ones (e.g. personal resources, defence mechanisms, one's expectations and belief systems, strategies for coping with stress). Thus cervical cancer places a large burden on patients, their families, their communities, and their health care providers (Sellors *et al.* 2004). Management of cervical cancer poses unique physiological, psychosocial, economic, and medical challenges that cause

disruptions in the lives of the women and their families calling for coping strategies to adapt to the unique situation.

Although there are many studies on cervical cancer, most have focused on provision of palliative care (PATH 2004) as well as the knowledge and attitudes of women (Gatune and Nyamongo 2005). Studies have also looked at the barriers to Pap smear screening for prevention (Mati *et al.* 1994) as well as the risk factors to invasive cervical cancer infection (Williams *et al.* 1994). As a result there have been scaled up campaigns to create awareness and promote uptake of screening services towards prevention of cervical cancer.

Fewer studies have focused on the long term effects of cervical cancer on the women and their families and the coping strategies adopted by the families to enable the women to cope with their ill condition (ACCP 2004). This study therefore focuses on the challenges and coping strategies of cervical cancer patients and their families and aims to address the following questions.

- I) What are the challenges faced by cervical cancer patients and their families?
- II) What coping strategies have women and their families developed to counter the challenges of living with cervical cancer?

1.3 Objectives of the study

1.3.1. General Objective

The overall objective is to explore the challenges and coping strategies of cervical cancer patients and their families.

1.3.2 Specific Objectives

- I) To establish the challenges faced by cervical cancer patients and their families.
- II) To determine the coping strategies that cervical cancer patients and their families have developed to counter the challenges of living with cervical cancer.

1.3 Justification of the study

A study by WHO projects that by the year 2025, the number of cervical cancer patients in Kenya will have reached 2,955 per year (WHO/ICO 2010). As with other cancers in developing countries, cervical cancer is diagnosed in the advanced stage. While radiation therapy is the ideal treatment modality for advanced stage cervical cancer, its demand outstrips its availability in Kenya. Consequently, the patients face a difficult and protracted illness with palliative care as the only available treatment option (Sellors *et al.* 2004).

Palliative care involves holistic care to cater for the physical, psychosocial and emotional wellbeing of the patients and their families. This is important as patients with chronic conditions, such as cervical cancer, require programmes in which they are active partners. This entails their participation and collaboration in order to achieve the highest possible levels of well-being. Nevertheless, healthcare providers and hospitals in developing countries often do not take patients' experiences into account. Health providers either ignore the patients' perspectives or have little understanding of their experience (Mulemi 2008).

There is a need to explore the lived experiences of cervical cancer patients and their families as a way of understanding long term effects and the dynamics of living with chronic illnesses. Besides adding to existing anthropological literature on chronic illnesses, the study findings will inform policies aimed at better management and care of cervical cancer patients, and other chronic illnesses.

It will also inform health care providers, hospitals and existing palliative care programmes of the patients' experiences. With a better understanding of their patients' perspectives, healthcare providers will provide better services to prolong and improve the quality of life of the chronically ill patients. Such information will also be useful for setting up national control programmes, and support networks for cervical cancer patients.

CHAPTER 2: LITERATURE REVIEW

This chapter reviews literature on the challenges and coping strategies of living with cervical cancer. The chapter which starts with an introduction reviews the literature based on the study questions to highlight two broad areas i.e. the challenges of living with cervical cancer and coping with cervical cancer. The chapter also includes the theoretical framework which covers the theory of coping as a process, the relevance of the theory to the study, a conceptual framework, study assumptions and the definition of key terms.

2.1 Introduction

Cervical cancer is one of the most common cancers that affect a woman's reproductive organs. Various strains of the Human Papillomavirus (HPV), a sexually transmitted infection, play a role in causing most cases of cervical cancer. Cervical cancer occurs most often in women aged between 15 and 44 years (WHO / ICO 2010). In Kenya many girls engage in high risk sexual activities at an early age. At least 33 % of girls in secondary school have had sexual intercourse which is often unprotected. This high level sexual activity is associated with risks such as infection with sexually transmitted diseases including HIV/AIDS and HPV, teenage pregnancies and school dropout (CAS 2009). As such, 10.32 million women aged 15 years and above, are at a risk of developing cervical cancer (WHO / ICO 2010).

Cancer begins when healthy cells acquire a genetic mutation that turns normal cells into abnormal cells. The abnormal cells grow and multiply out of control, and they don't die. The accumulating abnormal cells form a mass (cancerous tumour). Cancer cells invade nearby tissues and can break off from an initial tumour to spread elsewhere in the body (metastasize) (Ferlay *et al.* 2001).

Cervical cancer occurs in four stages. Stage one is when cancer is confined to the cervix,

and may be evident only under microscopic evaluation (stage IA) or apparent by visible or physical examination (stage IB). Stage 2 is when cancer has spread beyond the cervix to involve the tissues surrounding the cervix (parametria) or the upper portion of the vagina. In stage 3, cancer spreads beyond the cervix to the lower vagina or to the sides of the pelvis, or causes a blockage of drainage from the kidney, a condition called hydronephrosis. Stage 4 which is the late stage cervical cancer invades structures adjacent to the cervix such as the bladder or rectum or has spread to other parts of the body such as the liver or lungs. Symptoms of advanced cervical cancer may include: loss of appetite, weight loss, fatigue, pelvic pain, back pain, leg pain, single swollen leg, heavy bleeding from the vagina, leaking of urine or faeces from the vagina, and bone fractures (Ferlay *et al.* 2001).

2.2 Challenges of living with Cervical Cancer

As a chronic illness cervical cancer presents with it a lot of challenges for the women and their families. The onset of a chronic illness is seen to irreversibly change the social status of an individual. Living with a chronic illness is seen as representing a potential loss of self, in which the individual struggles to maintain 'normality' over time, and in the face of the uncertainty associated with such degenerative and debilitating illness (Gerhardt 1989).

According to Bury (1991) the experience of chronic illness leads to a loss of confidence in the body, and from this follows a loss of confidence in social interaction or self-identity, a process he terms 'biographical disruption'. This concept brings into focus the meaning of illness for the individual, as well as the settings in which it occurs. The meanings of chronic illness are not simply personal. They are also the result of shared

experiences and interactions with others, which may involve 're-negotiating' existing relationships at work and at home.

The challenges of living with cervical cancer for the patients and their families can be looked at in two broad categories;

2.2.1 External Challenges

External challenges are brought about as a result of the interaction between the patient and her family and community. These include;

Family Stress: As a woman becomes very ill, depends a lot on her family and friends for care and support. Relationships within families have to change, and people need to take on new responsibilities. This can be difficult for everyone because people may not know how to take on these new roles or they may not want to change (Sellors *et al.* 2004).

Stigma and avoidance: Some family members and friends may avoid seeing or being with a very sick person if they are afraid that the illness may be contagious. The community may out of ignorance associate the illness with superstition and witchcraft and thus avoid contact with the cervical cancer patient and her family. Cervical cancer patients are also stigmatized because of bleeding and bad odor. People may not want to help because of their fears (Pollack *et al.* 2005).

Economic strain: The sick woman and her caregivers often need help to find ways to get food, pay for her housing, or pay for her medications and medical care. People from more disadvantaged social classes are more likely to experience financial, domestic and work-related difficulties as a result of their physical condition. This is because of the direct costs involved in altering the home, special dietary requirements, additional heating costs, the extra cost of using a taxi because of restricted mobility and access to public transport,

employing a home help etc. Not only may people with disabilities suffer loss of income through restriction or loss of paid employment, but their partner may have to give-up their job to become a full-time 'lay carer' (Pollack *et al.* 2005).

Sexuality: Because cervical cancer is a disease that affects a woman's reproductive system, it may change the way she feels about her body and even how she feels about being a woman. As the disease gets worse, the woman probably feels some pain or has vaginal discharge or bleeding that may cause her to decide that she no longer wants to have sex. Or she may not want to have sex because of how she feels emotionally (Sellors *et al.* 2004).

This affects the patient as well as her partner who may have to contend with unmet conjugal needs. Also if the woman was still in her reproductive years she can no longer reproduce and this also poses a challenge for the woman, her family and community in case the family still wanted more children.

Treatment: Treatment of cervical cancer is prohibitively expensive. Kenya lacks radiation therapy machines in district hospitals and patients are usually referred to KNH which has only 2 of such machines. Thus it may take a long time before therapy is initiated after diagnosis (Sellors *et al.* 2004). Many women succumb to anemia during this period with some of the patients being send home to look for blood. Due to high cost for radiation therapy and delays caused by high demand, as well as myths attached to cervical cancer a lot of women end up seeking alternative treatment in the folk sector.

2.2.2 Internal Challenges

Internal challenges include emotional, spiritual and physical challenges faced by the cervical cancer patient and her family. Like with any other chronic illness, when a

woman finds out she has terminal cervical cancer she may experience many strong emotions such as shock, anger, guilt, anxiety, and depression. This is from the fact that she has to undergo physical and psychosocial changes that affect her life entirely. Women with advanced cervical cancer may feel rejected, unclean, and even untouchable. Also the intensity of treatment therapies like radiotherapy and chemotherapy that she is to undergo, and a terminal illness and impending death (Pollack *et al.* 2005).

Depression is a common emotional reaction to losses in life. Depression is especially common when a person is dealing with death, either their own impending death or that of someone they care about (Sellors *et al.* 2004). When a woman becomes very ill, she loses control over her own life and decision making. Because she is in a situation where she cannot make sense of what is happening anger is a common reaction. She may be angry with herself or with others and may not always be easily understood by those around her (Sellors *et al.* 2004).

Anxiety and fear are usually caused when someone is unsure about a situation or unsure about how it will affect them. Anxiety and fear are common feelings that women and their caregivers may have when faced with cancer. A woman who is dying of cervical cancer may experience fear or anxiety because of:

- Changes in family roles and positions.
- Uncertainty about her relationship with her husband and friends.
- Loss of control over her everyday life.
- Lack of money for medications.
- Fear of suffering, pain, or death.
- Fear of the unknown.

A woman with cervical cancer may feel guilty if she thinks that she has done something bad that has caused her to have cervical cancer or that someone has placed a curse on her. She may feel guilty because other people have to take care of her or because her illness has made things difficult for people close to her. For example, she may feel badly about the family's lack of money and that her medical needs are using up the family's resources (Sellors *et al.* 2004).

When a woman is dying, religion and spiritual beliefs can be very comforting, but they also can be the source of questions and doubts. She may have thoughts and questions about her life and what will happen to her after she dies. She may believe that it is important to make peace with her god or do things to keep her soul or spirit safe after she dies (Pollack *et al.* 2005).

Most women with advanced cervical cancer will experience pain including backache at some time during their illness. Pain from late-stage cervical cancer may last until the sick woman dies. She may have more pain and backache and need more drugs as her disease gets worse. For this pain a woman needs to take drugs for which side effects may be severe (Sellors *et al.* 2004).

Women with cervical cancer may experience watery, straw-colored, bloody, or foul-smelling vaginal discharge. This discharge can be composed of blood, pus, tissue, urine, stool, or any combination of these. This symptom is often a result of bacteria that are attracted to the unhealthy cervical cancer tissue in the vagina. These bacteria produce particularly foul smelling gases. The bacteria cannot be eliminated permanently although efforts to relieve this symptom will have only temporary effect (Sellors *et al.* 2004).

The cancer may cause a fistula—a hole between the vagina and the bladder—causing

urine to leak uncontrollably from the vagina. Sometimes the hole is between the rectum and the vagina, and stool escapes from the vagina. No drugs can stop the leakage of urine or stool caused by a fistula. Surgery is usually not successful and is seldom performed for women with cervical cancer, especially since fistulae tend to occur during the late stage of illness (Sellors *et al.* 2004).

If severe, this symptom can be quite alarming for the patient and her family. Sexual intercourse or strenuous activity may provoke vaginal bleeding. It often subsides with simple bed rest. If needed, vaginal packs effectively control bleeding as well.

Nausea and vomiting is a possible sign of many different problems. Vomiting may result from sickness with high fever, severe pain, and infection in the stomach, or food poisoning from eating spoiled food. Nausea and vomiting may also be side effects of *opioid analgesics and of radiation or chemotherapy treatment. If constipation and impaction occur, they should be treated, since they cause nausea* (Sellors *et al.* 2004). If a person has dry, hard stools that are difficult to pass or she has gone much longer than her normal time without a bowel movement, she is said to be constipated. Constipation is a common side effect for women who are bedridden or taking opioids. Other physical challenges include: weakness and fatigue, appetite loss and wasting, leg swelling, bed sores, and cough or breathing difficulties (Pollack *et al.* 2005).

2.3 Coping with Cervical Cancer

The chronically ill and disabled person needs to be able to make some sense of their condition before they can begin the process of 'adjusting' to it. This can involve redefining ideas of what is 'good' and 'bad', such that the positive aspects of their lives are emphasized, and the negative impact of the illness lessened. As such Bury (1991)

emphasizes 'active coping' and term 'coping' in its relativistic sense, that is in terms of different kinds of adaptation rather than the normative use of 'successful' or 'unsuccessful' responses to living with a chronic illness.

Coping is thus recognized as an increasingly important consideration in the management of chronic illnesses like cervical cancer. Coping, as a multidimensional skill, can be conceptualized as the use of cognitive, behavioral, and affective strategies to change, tolerate, or avoid problematic or stressful events and situations in the context of a cultural norm (Camela *et al.* 2008). In coping there are coping strategies and coping resources. This study will give emphasis to the coping strategies as they entail the actual behavior of the cervical cancer patients and their families as they counter the challenges posed by cervical cancer.

2.3.1 Coping Strategies

Coping strategies are the actual behaviours or responses people use in dealing with stressful events. A variety of coping strategies have been identified among persons who experience life strains, including prayer, stoicism, physical activity, denial, withdrawal, and ignoring the problem (Corbin and Strauss 1988).

The two most common strategies for coping with long-term chronic illness and its debilitating effects, however, are normalization and the attribution of meaning. After the initial impact of the diagnosis of chronic illness wanes, family members are eager to resume their normal lives. Whatever the level of physical or mental impairment caused by the illness, most people do not want the illness to threaten the self-identities, social roles, or activities that they value, or to become the dominant factor in their interactions with others. To avoid this, they attempt to normalize the situation by minimizing the

illness and conveying the impression of normalcy to others. One normalizing strategy is to describe behaviours associated with the illness, such as pain, crying, fatigue, forgetfulness, diet changes, and drug therapies, as things that all people experience or engage in from time to time (Corbin and Strauss 1988).

In some cases chronically ill people invest a great deal of energy in their efforts to manage the impressions and responses of others; they may disguise symptoms, avoid embarrassing situations, or control the information available to others. Cross-sectional analysis of data from 3,617 participants found that participants with cancer were more likely to report seeking spiritual support in comparison to those reporting other chronic health conditions (Ferraro *et al.* 2000).

2.3.2 Coping Resources

Coping resources are the psychological and material assets available to individuals and their families in responding to stressful situations. At the individual level, coping resources include one's education, income, self-esteem, sense of mastery, and psychological hardiness, all of which affect one's ability to deal effectively with life strains. Integration and adaptability are seen as key family resources. Integration refers to having strong ties of affection, pride in family tradition, and a history of sharing in activities. Adaptability means having flexible social roles, sharing responsibility for performing tasks, and communicating openly (Corbin and Strauss 1988).

Coping is enhanced when the family does not blame itself for the illness, feels confident in its ability to manage the situation, and continues to be sensitive and responsive to the needs of all family members. Communication and emotional expressiveness, role relationships, available caregivers, and financial resources are all important resources in

managing chronic illnesses (Corbin and Strauss 1988).

2.3.3 Culture and Chronic Illnesses

Culture can be defined as encompassing learned beliefs and behaviours that are shared by a group and that influence how the individual perceives and shapes his or her world (Galanti, 1991). Cultural beliefs and behaviours influence the individual's perception of disease aetiology, illness, and disease labels.

Illnesses are culturally shaped by how people perceive, experience, and eventually cope with disease, based on their explanations of sickness. These are explanations specific to the social positions people occupy and systems of meaning they employ. These have been shown to influence the expectations and perceptions of symptoms the way people attach particular sickness labels to them and the valuations and responses that flow from those labels. How people communicate about their health problems, the manner in which they present their symptoms, when and to whom people go for care, how long people remain in care, and how they evaluate that care are all affected by cultural beliefs (Kleinman 1977).

Therefore, the individual seeking care for a chronic illness may have a different perception and understanding of his or her disease and illness than does his or her medical or social service provider, particularly if they do not share the same culture. Furthermore, these differences may, at worst, inhibit proper treatment and, at best, lead to minor misunderstandings in the doctor/patient encounter and the eventual outcome (Kleinman 1977).

Also the societal beliefs and the specific meanings attached to chronic illness and

disability strongly influences the societal expectations of what an individual is able to achieve. These aspects of meaning in illness are important to an understanding of the strategies that people employ. In essence, the experience of chronic illness involves testing structures of support and risking meanings within the practical constraints of home and work. Relationships do not guarantee particular responses...meanings change as they are tested and altered as they are put at risk' (Anderson and Bury 1988:92).

2.3.4 Conclusion from the Literature Review

The challenges of living with cervical cancer, as with other chronic illnesses, revolve around the daily lives of cervical cancer patients and their families. The challenges are both internal and external. The cervical cancer patients and their families now have to deal with physical changes in the women's bodies that cause pain and alter their physiology. The psychosocial, economic and emotional wellbeing of the patients and their families is also affected (Sellors *et al.* 2004). For each of these challenges the cervical cancer patients and their families develop coping strategies to ensure the wellbeing of both the patient and the family.

Aside from pain relief the needs of cancer patients can vary according to culture. A comparison of cancer patients from Kenya and Scotland found that while physical pain and financial worries dominated the lives of patients and their care givers in Kenya, Kenyan patients felt that the families and communities met their psychological and spiritual needs. In contrast, terminally ill patients in Scotland received adequate pain relief but their non physical needs were unmet (Murray *et al.* 2003).

Thus it is imperative to take culture and the social space into account in exploring the

challenges and coping strategies of cervical cancer patients and their families in the developing world and avoid generalizations on the already available literature on the same for developed countries.

2.4 Theoretical Framework

At its most fundamental level, theory is a possible explanation or description of the relationship between various ideas or actions. At a more complex level, theory can describe the nature of these relationships and can be used to predict outcomes. Theory is an extremely useful tool for understanding, predicting, and/or changing human behaviour. This study adopted the theory of coping as a process, which is described in detail as below.

2.4.1 Theory of Coping as a Process

The concept of coping has been with us for a long time, though it began to come into its own formally during the 1960s and 1970s, along with the burgeoning interest in stress-related studies. In the late 1970s a major new development in coping theory and research occurred in which the hierarchical view of coping, with its trait or style emphasis, was abandoned in favor of a contrasting approach, which treated coping as a process. From a process perspective, coping with illness, or stress changes over time and in accordance with the situational contexts in which it occurs (Richard 1993). The proponents of this theory include American Psychologist Lazarus S. Richard and Folkman S. Judah (1985).

According to the theory, coping thoughts and actions under stress must be measured separately from their outcomes in order to examine, independently, their ability to adapt or their inability to adapt. There may be no universally good or bad coping processes,

though some might more often be better or worse than others (Richard 1993). Also, coping strategies depend on whether, at any given time, the patients and their families are dealing with one or another of the diverse threats engendered by the illness. Thus, what a person does to cope depends on the context in which the disease occurs, and this will change over time because what is attended to, and the threats themselves, also change (Richard 1993).

The theory of coping as a process emphasizes that there are at least two major functions of coping, problem-focused and emotion-focused. The distinction is subscribed to widely by coping researchers.

The function of problem-focused coping is to change the troubled person-environment relationship by acting on the environment or oneself. The function of emotion-focused coping is to change either a) the way the stressful relationship with the environment is attended to (as in vigilance or avoidance) or b) the relational meaning of what is happening, which mitigates the stress even though the actual conditions of the relationship have not changed. The latter involves a more benign or less threatening reappraisal, as illustrated, for example, in denial and distancing (Richard 1993).

2.4.2 Relevance of the theory to the study

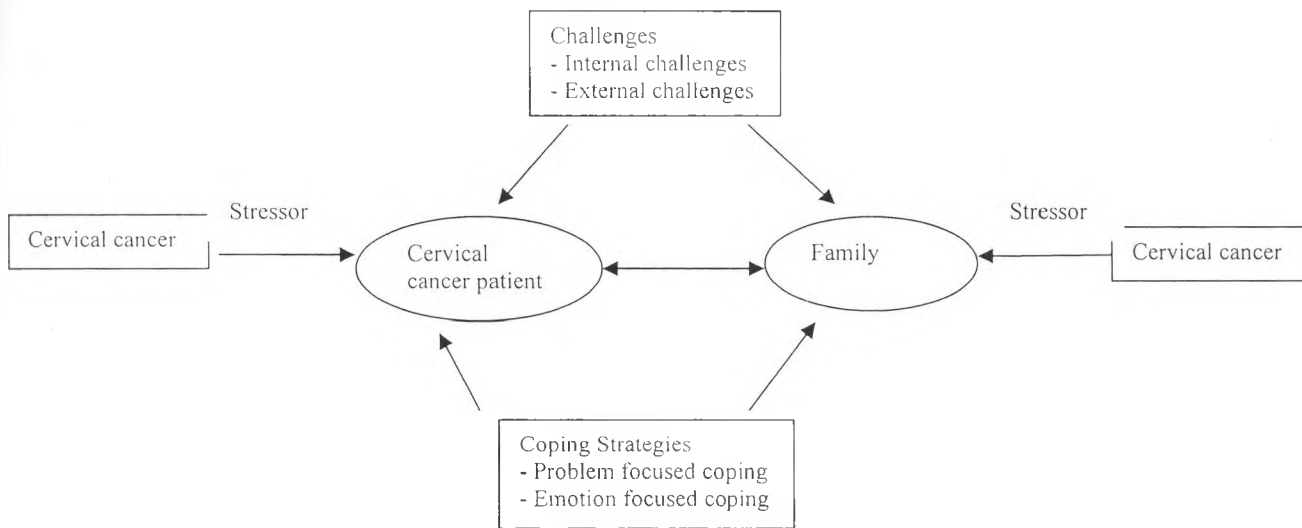
The theory of coping as a process is relevant to the study of the challenges and coping strategies of cervical cancer patients and their families. The theory defines coping as ongoing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the cervical cancer patient and her family (Richard 1993). The external and or internal demands in this study are the challenges of living with cervical cancer for the woman and her family, and the

coping strategies developed are the ongoing cognitive and behavioral efforts of the patient, and her family to cope with the illness. The theory will examine the problem focused coping and the emotion focused coping to bring out the experiences of cervical cancer patients and their families.

2.4.3 Conceptual Framework

Conceptually, the cervical cancer patients and their families may be seen as occupying a central position in the management of cervical cancer. Cervical cancer creates challenges to both the patients and their families, for which they have to come up with coping strategies. Literature review on the theory enabled the researcher to conceptualize the study as explored using the theory of coping as a process in a model as below;

Figure2. 3: The Conceptual Framework for the theory of coping as a process as applied in exploring the challenges and coping strategies of cervical cancer patients and their families



The challenges faced by cervical cancer patients and their families involve the interaction of the patient and her family and community. These challenges may include but are not limited to;

1. Internal challenges: These internal challenges include lack of or inadequate social

support, physical disability.

2. External challenges: They include strained family resources, high cost of management of cervical cancer, one's expectations and belief systems, family expectations, stress, inadequate health care, stigma and avoidance.

For these external and internal challenges both the patients and their families have to develop strategies to cope and ensure the wellbeing of the patient and of the family. The coping strategies may be problem-focused or emotion-focused. Problem-focused and emotion-focused coping strategies developed by cervical cancer patients and their families include but are not limited to;

1. Problem-focused coping strategies: These include seeking treatment in the professional, folk and also popular healthcare sectors to manage the health condition, family finding income generation activities to supplement the family income and cater for the medical expenses.
2. Emotion-focused coping strategies: These include joining a support network to mingle with other cervical cancer patients and draw strength from their experiences, going for counselling (both the patient and family) and turning to religion.

2.5 Study Assumptions

1. Cervical cancer patients and their families face challenges that they deal with on a regular basis.
2. Cervical cancer patients and their families adopt strategies which enable them to cope with their status as cervical cancer patients.

2.5.1 Definition of key terms

Cervical Cancer: is a preventable chronic illness that affects the cervix of a woman and is caused by the Human Papillomavirus (HPV), a sexually transmitted infection.

Challenges: are difficulties or hurdles (internal and/or external) a person deals with when faced with a particular situation in this study the particular situation is cervical cancer.

Coping strategies: are techniques (cognitive, behavioral and affective) applied by an individual to change, tolerate or avoid problematic or stressful events and situations in the context of a cervical cancer.

Care givers: an adult family member preferably the spouse taking care of the cervical cancer patient.

Medically stable: this refers to a cervical cancer patient who is not in pain or medication that can interfere with their ability to objectively participant in the study.

Lived experience: are the day to day happenings in the life of the cervical cancer patient as well as in the lives of her family members as they constantly interact with and adjust to manage the cervical cancer condition.

Palliative care: is a form of care usually given to chronically ill patients. It involves holistic care to cater for the physical, psychosocial and emotional wellbeing of the patients and their families.

Key Informant Interview: a qualitative data collection method. It is a loosely structured conversation with people who have specialized knowledge about the topic you wish to understand.

In- depth interview: is a qualitative data collection method that involves conducting intensive individual interviews with a small number of people to explore a situation.

CHAPTER 3: METHODOLOGY

This chapter outlines the methodology applied in the study of the challenges and the coping strategies of cervical cancer patients and their families in Kenya. The chapter details where the data was collected, from whom data was collected, how the data was collected, coded and analyzed to respond to the study objectives highlighted in chapter one. The chapter as such describes the study site, study design, study population, study sample and sampling procedure. It also explains the data collection methods used as well as data processing, analysis and presentation. Ethical considerations are also outlined in this chapter.

3.1 Study Site

The research site was Kenyatta National Hospital (KNH) and Nairobi Hospice in Nairobi, Kenya. The patients' families were accessed through interaction with the care givers of the cervical cancer patients.

3.1.1 Description of the study site

The two hospitals are located in Nairobi County.

The Kenyatta National Hospital (KNH) is the oldest and largest public national referral and teaching hospital in Kenya. The hospital receives patients of chronic illness from all corners of the country, and even across the Kenya national border. The adult cancer ward admits patients with all forms of cancers (Personal communication with Dr. Anselmy, department head CTC, KNH). The ward has five rooms with a bed capacity of 32. Kenya lacks radiation therapy machines in district hospitals and patients are usually referred to KNH which has only 2 of such machines. Thus it may take a long time before therapy is

initiated after diagnosis (Sellors *et al* 2004). This makes KNH a suitable site as the cervical cancer patients come from all over Kenya.

The Nairobi Hospice was the first hospice to be opened in East Africa. It is a modest building built by voluntary effort in the grounds of the Kenyatta National Hospital. It caters for terminally ill patients including cancer patients. Its location thus demonstrates to ordinary people that it is intended for everyone, not just those who can pay for private medicine. It consists of a single storey building with a reception area, two small offices for medical and nursing staff, three rooms for day clinics and seeing patients and a meeting room (Dr. Lang'o, Nairobi Hospice).

3.2 Study Design

The study adopted an explorative descriptive study design that utilized qualitative research methods in the exploration of the challenges and coping strategies developed by cervical cancer patients and their families.

The study utilized qualitative data collection methods, namely, in-depth interviews and key informant interviews. The field was the hospital facility where I first recruited the cervical cancer patients, and later with the patients consent recruited their care givers. I spent three months in the field, starting from May to July 2011. The first two weeks were for recruiting of the patients. I made follow ups and during the subsequent hospital visits the patients and later their care givers were interviewed.

3.3 Study Population

The population included cervical cancer patients and their care givers at the Nairobi Hospice and KNH Nairobi, Kenya. It also involved the health providers and community health workers working with the cervical cancer patients. The unit of analysis was the cervical cancer patient.

3.4 Study Sample

The study targeted cervical cancer patients at the Nairobi Hospice and KNH who are medically stable to give verbal and informed consent and are willing to participate in the study. Every year 2,454 women are diagnosed with cervical cancer, approximately 204 women every month (WHO/ICO 2010). Given the advanced stage of diagnosis which requires radiotherapy treatment, many of the patients are referred to KNH, which treats chronically ill patients from all over the country (Sellors et al, 2004). The Nairobi hospice also handles terminally ill patients from all over the country. Cervical cancer is one such terminal illness. Therefore 18 patients are roughly 36% of the cervical cancer patients diagnosed monthly, all over the country. The sample population number was arrived at with this in mind.

Furthermore, the study being qualitative in nature aimed at getting in-depth information from each of the study participants, and as such a small number was manageable. The total sample population was 36 i.e. 18 cervical cancer patients and 18 care givers (adult family members) of cervical cancer patients.

The inclusion criterion for identifying the 18 cervical cancer patients;

- I) Cervical cancer patients at KNH and / or Nairobi hospice.
- II) The patients were assessed by the health care provider and confirmed to be medically stable.
- III) The patients also had to voluntarily agree to participate in the study and give verbal and written consent.
- IV) Patients who gave verbal and written consent had a member of their family interviewed.

The exclusion criterion was any cervical cancer patient who was not medically stable to

participate in this study. Any cervical cancer patient who did not consent to participate in the study and have their care givers interviewed was also excluded. 18 cervical cancer patients were involved.

Families of these cervical cancer patients, namely, their care givers were interviewed. The cervical cancer patients were specifically requested allow for a member of their family to be interviewed. The family member regarded in this study as the care giver was informed on the study and written and verbal consent sought. 18 care givers, one for each cervical cancer patient were interviewed.

Members of staff working with cervical cancer patients in the 2 health facilities were interviewed as key informants. Six staff was identified based on their constant interaction with the cervical cancer patients.

3.5 Sampling Procedure

Purposive non probability sampling was used to select the sample population of 18 cervical cancer patients. The staff in charge in the health facilities helped identify the cervical cancer patients under their care, who are medically stable to participate in the study.

Once identified by the clinical staff as medically stable, I then talked to each cervical cancer patient individually, away from their healthcare provider. The researcher informed each of the patients on the study objectives, their role as key respondents, as well as ethical considerations. The ethical considerations included ensuring maximum comfort of the patients during the study, their voluntary engagement in the study, as well as no direct benefits to the patients of their families for participating in the study. In addition the researcher noted how important the information the participants gave was in informing

the study. The confidentiality of the participants would be maintained and acknowledgements would be made to appreciate their resourcefulness in informing the study. Having informed the study participants on the details of the study, the researcher requested their voluntary participation. The cervical cancer patients were also informed of the involvement of their families by way of interacting with their care givers. Verbal and written consent was sought from each of the participants. Once they agreed, the cervical cancer patients were then recruited as participants for the study. 18 cervical cancer patients who were medically stable to give verbal and written consent were selected and engaged as participants in in-depth interviews.

Convenience non probability sampling was used to identify 18 care givers. These are adult family members preferably spouses of the cervical cancer patients as participants in in-depth interviews.

Six staff working in any of the two sites was identified using purposive non probability sampling and interviewed as key informants. The inclusion criterion for the staff was that they worked with and frequently interacted with the cervical cancer patients in any of the two sites. These included but were not limited to clinicians, social workers, community health workers and counsellors working with the cervical cancer patients.

3.6 Data collection methods

3.6.1 In-depth Interviews

In-depth interview was the main data collection method in this study. This method is appropriate for sensitive topics (Bernard 1995). Cervical cancer is a gynaecological chronic health condition and the patients and their families must be handled with caution. The In-depth interview guide contained open ended questions that made it possible to

probe for thorough and detailed information on the challenges and coping strategies of cervical cancer patients and their families. In-depth interviews were used to interview the cervical cancer patients and their family members. In-depth interviews involve conducting intensive individual interviews with a small number of people to explore a situation. Two separate in-depth interviews were administered; one for the cervical cancer patients and the other for a care giver i.e. adult member (preferably the spouse) of the family.

The in-depth interviews for the cervical cancer patients gathered information on the experiences of the women. The experiences refer to the challenges faced by the cervical cancer patients and coping strategies they have developed to counter these challenges. 18 cervical cancer patients were interviewed.

The in-depth interviews for the families were administered to an adult member of the family preferably the spouse. They captured information on the challenges faced by the families of cervical cancer patients and the coping strategies adopted by the families to cope with the woman's health condition and ensure her well being as well as that of the family. 18 care givers i.e. adult members (preferably the spouse) of the family were interviewed. The interviews were tape-recorded for transcription.

3.6.2 Key Informant Interviews

Key informants are people believed to be knowledgeable on the topic under investigation (Nkwi *et al* 2005; Fetterman 1989; Bernard 1995). The Key Informant Interviews were conducted with the hospital staff working with the cervical cancer patients. Four members of staff were interviewed at KNH and two from the Nairobi Hospice. The staff included two doctors, one social worker, two nurses and one counsellor working with the

cervical cancer patients. The Key informant interviews gathered additional information on the challenges and coping strategies of cervical cancer patients and their families. The interviews were tape-recorded for transcription.

3.7 Data Processing Analysis and Presentation

Qualitative data from the in-depth interviews and key informant interviews was transcribed and analyzed thematically. The themes revolved around study objectives. The broader themes are; Challenges of cervical cancer patients and their families and; Coping strategies of cervical cancer patients and their families.

Socio demographic data on the study participants was presented in tables and graphs.

3.8 Ethical Consideration

The explorative descriptive study explored the challenges and coping strategies of cervical cancer patients and their families. Qualitative data collection methods were utilized and a sample population of 18 cervical cancer patients was involved. The study population comprised of medically stable cervical cancer patients at Kenyatta National Hospital and Nairobi Hospice.

The study adhered to the code of ethics to ensure that the study did not harm the participants in any way. Informed verbal and written consent and acknowledgement of the study participants were sought and the informants retained a copy of the written consent. Names of the informants remained anonymous through use of pseudonyms (Bernard 1995). In the analysis the pseudonyms which were mainly numbers were used.

The study is aimed at ensuring minimum distress on the patient and her family. The patients were evaluated by the hospital staff to ensure that they were medically stable to participate in the study. The study participants were given details of the study including

any fore seen or anticipated risks and how to tackle them in case they occur, and any benefits or compensations beforehand. To ensure maximum comfort for the study participants, the researcher worked closely with the health care providers of the study participants to ensure that the patients were attended to and any required assistance and support availed.

Ethical clearance for the study was obtained from the KNH/UoN-Ethics & Research Committee (ERC), (Ref: KNH-ERC/A/96). A research permit was also obtained from the National Council for Science and Technology (NCST), Ministry of Higher Education, Science and Technology (MoHEST) (Research permit No. NCST/RR1/12/1/MED-011/22).

3.9 Scope and limitation of study

This study was conducted at 2 sites, namely: Kenyatta National Hospital and Nairobi Hospice Nairobi, Kenya. The patients were to be followed to their homes in order to gain access to their families. The focus was on the challenges and coping strategies of cervical cancer patients and their families. The study population was the cervical cancer patients.

Limitation: Given the qualitative nature of the study as well as the sensitivity of the research topic, only a small number of participants were involved and this limits the generalization of the study results.

Solution: A small sample size was selected to enable in-depth information on the topic to be explored and inform the study. The participants were interviewed over a period of time as a way of gaining a fuller understanding of the challenges of living with cervical cancer and coping mechanisms adopted by these patients and their families.

Limitation: During fieldwork, the cervical cancer patients could not be followed to their homes to gain access to their families as earlier anticipated in the research proposal. The patients come from all over the country and limited time and resource could not allow for them to be followed home.

Solution: The cervical cancer patients are usually accompanied by their care givers on all hospital visits. The care givers were interacted with during the hospital visits and as such the patients' families were accessed.

Limitation: While the cervical cancer patients consented to participate in the study and have their families involved as well, when later approached, some of the care givers declined enrolment in the study despite their patients having been interviewed already.

Solution: The researcher accepted the decision of care givers who declined to be interviewed despite having their patients already interviewed and as such excluded the cervical cancer patient from the study sample. As a result cervical cancer patients whose care givers consented to participate in this study were enrolled until the sample size was attained. The information however remained relevant to the study findings.

Limitation: The data collection process was hectic and often emotionally draining. The hospital as the field exposed the researcher to interacting with terminally ill patients and their families as well.

Solution: The researcher remained objective. Keeping sight of the study objectives helped the researcher endure the new environment and collect data for the study. Also the will to go on in life that most of the cervical cancer patients manifested was a constant source of inspiration.

CHAPTER 4: THE CHALLENGES AND COPING STRATEGIES OF CERVICAL CANCER PATIENTS AND THEIR FAMILIES

This chapter presents the study findings as compiled from the data collected through in-depth interviews of 18 cervical cancer patients and their 18 care givers as well as key informant interviews of 6 health care workers from the KNH and Nairobi Hospice. The data was coded and analysed thematically based on the study questions. Sociodemographic characteristics of the study participants i.e. 18 cervical cancer patients and their 18 care givers is described and represented in a table in the first section of this chapter. (See table 4.1)

This chapter is divided into three sections focusing on: The socio-demographic characteristics of cervical cancer patients and their families; the challenges of cervical cancer patients and their families and; the coping strategies of cervical cancer patients and their families.

4.1 Sociodemographic Characteristics

These characteristics include: age, marital status, number of children, occupation and residence of the cervical cancer patients. The relationship of the cervical cancer patients to their care givers was also documented. (See Table 4.1)

Age: The age range of the cervical cancer patients was 35 to 80 years, with an average of 57.5 years. Four were aged below 50 years i.e. 35, 38, 40 and 45 years respectively. Four others were aged 51(2), 52 and 53 years. The remaining cervical cancer patients were aged between 60 and 80 years old i.e. 61(3), 62, 67, 68, 70(3) and 80 years respectively. (See Table 4.1)

Marital status: All of the cervical cancer patients were either married (12) or widows (6). One of the 12 married cervical cancer patients was separated from her spouse at the

time of the study due to illness, while the 11 were still living with their spouses. (See Table 4.1)

Number of children: All the cervical cancer patients had children ranging between one and twelve children each. Four patients had four children each, one had two children and three had three children respectively. (See Table 4.1)

Two other patients had eight children each while two had nine children each. One other patient had seven children. One patient had only one child, two had five children each, and one other patient had six children. One other cervical cancer patient had twelve children. The average number of children for the cervical cancer patients was five children each. The children were aged between 7 years and 51 years respectively. (See Table 4.1)

Residence: The cervical cancer patients came from six different regions in Kenya. Fourteen (77.8%) of the cervical cancer patients reside outside Nairobi, namely Central, Western, Eastern, North Eastern and Nyanza region. Four others (22.2%) reside within Nairobi region and its environs, namely Kawangware, Pangani, Kasarani and Kitengela. Seven ethnic communities were represented in this study namely, Embu, Mbeere, Luo, Luhya, Kamba, Kikuyu and Borana. (See Table 4.1)

Occupation: Most (16 out of 18) of the cervical cancer patients were involved in economic activities before the onset of their sickness. They had however stopped working (temporarily or permanently) to focus more on the treatment and management of the cervical cancer condition. Two (11.1%) of the cervical cancer patients were not involved in any economic activities due to their advanced age. Nine (50 %) of the

cervical cancer patients were small scale farmers, who planted cereals, coffee, vegetables and also kept cows, goats and sheep.

Three (16.7%) others were businesswomen who also engaged in subsistence farming. After diagnosis with cervical cancer and onset of treatment they had stopped working but had resumed business after completing treatment. They no longer engaged in subsistence farming.

Four (22.2%) others were businesswomen. After diagnosis, they stopped working for some time. At the time of the study, these four women were fully back in business. (See Table 4.1)

Relationship of care giver to cervical cancer patient: The care giver in this study is an adult family member who takes care of the cervical cancer patient. Ten (55.6%) of the care givers were female while were 8(44.4%) male. The female care givers comprised seven daughters, two sisters and one granddaughter respectively. The male care givers comprised five spouses and three sons of the cervical cancer patients. (See Table 4.1)

Occupation of the care giver: The care giver provided for and cared for the needs of the cervical cancer patient. The care givers' occupations were diverse. They included 6 (33.3%) business people, 3(16.7%) teachers, 2(11.1%) bankers, 3(16.7%) farmers, 1(5.6%) doctor, 1(5.6%) pastor, 1(5.6%) nurse, and 1(5.6%) house wife. (See Table 4.1)

Table 4.1 Sociodemographic characteristics of the cervical cancer patients and their care givers (N=36)

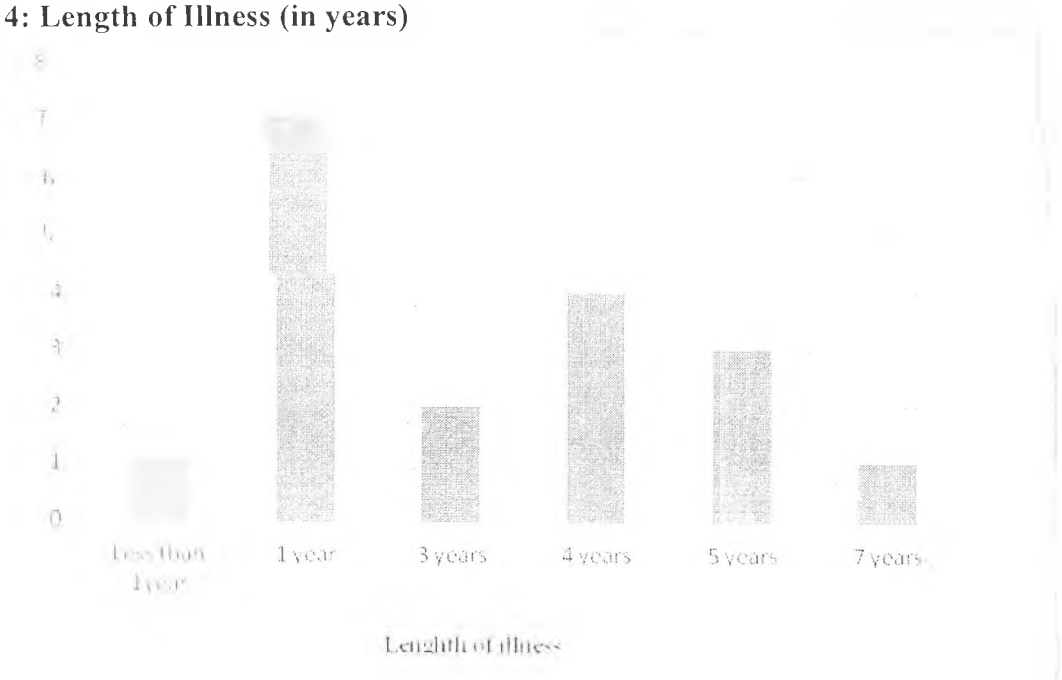
Variable	Frequency (patients)	Variable	Frequency (Care givers)
Number of children			
1-3	5		
4-6	7		
7-9	5		
10-12	1		
Age(years)		Age(years)	
30-39	2	20-29	2
40-49	2	30-39	4
50-59	4	40-49	9
60-69	6	50-59	2
70-79	3	60-69	1
80-89	1		
Residence-By region			
Nairobi	4		
Central	5		
Eastern	5		
N. Eastern	1		
Nyanza	1		
Western	2		
Occupation		Occupation	
Business/ farming	3	Business	6
Business	4	Teacher	3
Farming	9	Banker	2
None	2	Farmer	3
		Pastor	1
		Doctor	1
		Housewife	1
		Nurse	1
Marital Status		Marital status	
Married	12	Married	12
Widowed	6	Single	6
		Relationship to patient	
		Spouse	5
		Daughter	7
		Son	3
		Sister	2
		Granddaughter	1
		Gender	
		Male	8
		Female	10

4.2 Challenges faced by cervical cancer patients and their families

4.2.1 Length of Illness

The cervical cancer patients had lived with cervical cancer for periods ranging from 6 months to 7 years since diagnosis as shown in figure 4.1. Only one of the patients had been diagnosed in the last six months while seven had known their diagnosis of cervical cancer for one year at the time data was collected. Two had lived with cervical cancer for three years since diagnosis, while four had been diagnosed four years back. Three others had been diagnosed five years back while one had lived with cervical cancer for seven years.

Figure 4. 4: Length of Illness (in years)



Over the period of living with cervical cancer, the patients and their families had faced a number of challenges. The challenges faced by the patients or their families are discussed below:

4.2.2 Anxiety and Fear of death

Almost all the cervical cancer patients and their care givers mentioned anxiety and fear of death as the first and most recurrent challenge they faced. Since cancer has over time been associated with no cure, once diagnosed the cervical cancer patients reported having to battle with feelings and emotions that expressed anxiety and fear of death. The following excerpts illustrate this:

I have also lost so much weight. I fear that I will die soon. (Patient#18, 70years, Widow)

At first when I was told I had cancer, I did not believe it! Of all sicknesses, cervical cancer? I thought I was going to die. I was so worried. (Patient#16, 67 years, Widow)

The families of the cervical cancer patients were also faced with the challenge of anxiety and fear as reported by the caregivers. Families of the cervical cancer patients have to come to terms with the chronic condition a family member is ailing with as illustrated below:

As I had told you earlier we were finding it very difficult to accept mother's condition. This was our greatest challenge as a family. In as much as we will all die some day, when a terminal illness comes, the situation is worse (Caregiver # 14, Daughter, 35 years)

When mother was diagnosed the whole family was in shock. Cancer of the cervix? You know the perception we have of cancer is that once you have it you die (Care giver #16, Daughter, 45 years)

One of the health workers at the Kenyatta National Hospital in her responses as a key informant pointed out that one of the greatest challenges for the patients is the anxiety and fear of death associated with cervical cancer as a terminal illness:

The patients and their families are usually fearful that diagnosis with cancer is a death warrant. Even as I disclose the biopsy results to my patients I make a point to explain the condition in detail and the possible intervention to restore well being as a way of encouraging the patients (Health care worker #1, KNH)

4.2.3 Economic strain

The cervical cancer patients and their care givers reported economic strain as a major challenge of living with cervical cancer. They noted that when the cervical cancer patients fall sick, the patients usually stopped working to pay more attention their condition. The shift in priorities to focus more on the treatment and management of cervical cancer may be temporary or permanent. The net effect of this withdrawal from work often affected the overall family income. This is illustrated by the following excerpt from one of the patients:

We are business people, me and my husband. We sell clothes in Busia. Now when I fell ill I stopped working. This is the first challenge we encountered. I could no longer work alongside my husband, and we have school going children and now I am sick we need money for hospital. I left my husband and came to Nairobi where my other family members can look after me until I get better. (Patient#3, 35 years, Married)

It is further reinforced by the following excerpt by one of the care givers:

The greatest challenge is money. Especially in the beginning, you know my wife became sick and before then she was contributing to the family upkeep [the wife stopped working because of her sickness]. The burden [providing for the family and take care of his wife's treatment] was left on me and it was hard. We initially sold everything to offset her medical bills. Although now she is recovering it [financial strain brought about by his wife's cervical cancer condition] is still rubbed on our finances as a family. (Care giver#1, Spouse, 59 years)

Furthermore, resources have to be diverted toward the treatment and management of cervical cancer. They often require substantial resources to access treatment which includes antibiotics, pain relievers, radiotherapy and chemotherapy; as well as other items used in the management of cervical cancer including, diapers and sanitary towels.

Excerpts by two cervical cancer patients support this:

When the doctor confirmed that I had cervical cancer and recommended that I commence treatment, I did not have money so I went back home... That is when they [my husband and children] knew of my condition. They had to sell a few of

our belongings and we came back [to hospital]... This [the treatment] was very expensive. It left us without anything. (Patient#1 51 years, Married)

One thing I have learned is that treatment is very expensive. If you do not have money you will surely die of cervical cancer. Drugs are also expensive as well as the tests one needs to undergo. I thank God because while going through all this I have never lacked anything. (Patient#4, 40 years, Married)

Similarly, care givers illustrated the high cost of treatment and management of cervical cancer with the following excerpts:

The initial costs were a challenge. Chemotherapy and radiotherapy are very costly, but we managed. Even now mother needs pain relievers constantly, and these drugs are expensive. No matter the cost; I wanted to see my mother get better. (Care giver#2, Son, 32 years)

They [doctors] then recommended that my mother start on chemotherapy and radiotherapy. When they quoted the price, it was too expensive and I could not raise that kind of money so we just went home... [A month later we returned to hospital] I asked the doctors to help us but they said without money they could not start her [the cervical cancer patient who is the mother of the care giver] on chemotherapy and radiotherapy treatment. (Caregiver #11, Daughter, 43 years)

I will admit that the cost of treatment of cervical cancer as well as other forms of cancer is a bit expensive and usually a burden to the patients and their families. The costs keep piling from the initial tests done to confirm a diagnosis, to surgery, chemotherapy and radiotherapy as well as purchase of prescribed medication for the patients. (Health care worker #3, Kenyatta National Hospital)

Transport and accommodation were reported as an added expense to the treatment of cervical cancer, as the cervical cancer patients and their care givers mostly travelled from outside Nairobi. Fourteen out of the eighteen cervical cancer patients reside outside Nairobi where the referral hospital is located. The regular hospital visits for treatment and follow up for which the cervical cancer patients were accompanied by their caregivers required transport and accommodation arrangements. This was an extra expense on their already strained budgets. The following excerpts illustrate this:

The greatest challenge is coming to the hospital. The very first time she [the cervical cancer patient, the care giver's mother] had to be airlifted to Nairobi

because she was diagnosed in Kisumu and was very weak, so she could not travel all that distance by bus. That arrangement was very expensive. After her radiotherapy treatment we were then referred again to Kampala, Mulago Hospital. We [the care giver and other family members] had to again arrange transport and accommodation plus the treatment costs. I wish this treatment was available in Nyanza it would be less costly. (Care giver # 9, Son, 41 years)

Coming to hospital is a great challenge. We live in Kirinyaga, coming all the way and that I have to always come with someone, the fare sometimes is too much. (Patient#5, 52years, Married)

Being a referral hospital, KNH interacts with patients referred from all over the country. Some cervical cancer patients come from far and often are accompanied by their family members due to their health condition, the transport and accommodation costs become an added expense on their already constrained budgets (Health care worker # 1, KNH)

4.2.4 Family stress

The cervical cancer patients and their care givers reported that the sickness led to family stress. The stress was manifest in the relationship between the patient and other family members, or could result in disagreements on how the bills will be paid. In one instance, a cervical cancer patient noted that her health condition had caused a strained relationship with her mother-in-law. The mother-in-law developed a negative attitude towards her ailing daughter-in-law, as illustrated below:

My mother-in-law is the one who has been on my case [has been constantly picking arguments with me] since I started ailing. Initially I was affected by her attitude such that I even developed High Blood Pressure. She has been very negative about my situation sickness. But I have learnt to let go of her negative attitude. I never take to heart what she says. (Patient#11, 62 years, Married)

The strained family relationships would also come about in a situation where the patients and their care givers disagreed on the treatment and management of cervical cancer. For instance, a care giver opted for palliative care for her mother who is the cervical cancer patient. For the care giver, chemotherapy and radiotherapy were too intense for her mother's well being. Palliative care was affordable and it would not have any side effects

on the care giver's mother. On the other hand, the cervical cancer patient (the care giver's mother) wanted chemotherapy and radiotherapy but her daughter could not meet the costs.

The care giver and the patient fail to agree and the care giver pays for the treatment option that in their opinion is affordable and most suitable, against the patient's wish. The result is strife between the patient and care giver as illustrated by the following excerpt by one of the care givers:

My mother seems unhappy with the treatment I opted for her [the cervical cancer patient is the care giver's mother]. She [the patient] is now on palliative care but she wanted *achomwe* [radiotherapy and chemotherapy] which I [care giver] refused. I am her care taker and I saw it better for her to be getting treatment for her pain and then we just leave the rest to God. *Kama ameandikiwa* [If this is her destiny] – cervical cancer- then let it be but without complicating it. However this is my opinion. My mother does not like it at all. She even says that I have refused to pay for her treatment. She does not understand that the money is more than what I can afford. (Caregiver#18, Daughter, 45 years)

This is further reinforced by the following excerpt from the patient herself, confirming what her daughter had said:

The doctor recommended that *nichomwe* [radiotherapy and chemotherapy]. My daughter said we did not have that kind of money and we went home. When I went back home I kept on feeling worse and we came back to KNH, and they referred us to Nairobi hospice... [The patient is on palliative care]. My daughter says this [palliative care] was the best she could afford ...but I am not happy with this [palliative care as the treatment option] (Patient#18, 70 years, Widow)

4.2.5 Access to health care

The cervical cancer patients and their caregivers reported that accessing health care was a challenge. They noted that distance and time taken to see the doctor were hindrances to accessing health care which was by referral at KNH. Most (14 out of 18) of the cervical cancer patients resided from outside Nairobi, the location of the referral hospital. The patients and their care givers had to travel long distances to get to the hospital. The

patients reported that if by chance one missed their set appointment, it would be very difficult to see the doctor. Further, they noted that once at the hospital more time was taken before the cervical cancer patient could see the doctor, as illustrated in the following excerpt:

We [the care giver and the cervical cancer patient] live in Western Kenya and that is where my mother was diagnosed. We however were referred to Nairobi for treatment. Coming here and the whole process before one get to see the doctor it is hectic. You can take up to a whole day before you are attended to. Like today we came without an appointment and we have been here since very early in the morning. The place is congested and we need to see the doctor. (Care giver#14, Daughter, 35 years)

The patients and their care givers reported that many patients with all forms of cancer queued for treatment, yet there was only one radiotherapy machine at KNH. They noted that a cervical cancer patient could delay starting treatment for up to 3 months, due to the high demand for the services. This aspect made access to timely health care a major challenge as illustrated in the following excerpts:

The machines here have disappointed us more than once. You know my mother was scheduled to start treatment in May 2010 but due to demand she was delayed until July 2010. May be if the treatment had been initiated immediately she would be much better. (Caregiver#17, Son, 31 years)

After her [the cervical cancer patient] radiotherapy treatment we were then referred again to Kampala. They [doctors] told us that the machine here at KNH was broken down. This was a new development altogether. It is really difficult to get your patient to hospital especially if you come from outside Nairobi. KNH happens to be the only hospital with the facilities for cancer treatment. Then now with the broken down machine sending patients to Kampala... (Caregiver#1, Spouse, 59 years)

Additional information from the key informants further highlights access to health care as a challenge:

Patients referred to KNH from provincial and district hospitals have to wait for months before they can access services. Here at KNH weekly attendance includes about 40 new patients, 120 confirmed cases on follow up, 150 cases on

radiotherapy and 80 cases on chemotherapy. There are only three machines (Cobalt 60) to cover 40 million people against a background of inadequate specialized manpower. (Health care worker # 2, KNH)

The country only has four radiation oncologists, six medical oncologists, four paediatric oncologists and no trained surgical oncologists. The picture is even worse when one looks at the supportive staff. There are only five radiation therapy technologists, two oncology nurses and two medical physicists. There are no peripheral (provincial) cancer treatment centres. (Health care worker # 2, KNH)

4.2.6 Inadequate information on cervical cancer

The cervical cancer patients reported that they had no prior knowledge of cervical cancer until diagnosed. The patients noted that the symptoms of cervical cancer were not obvious to them. They often confused the symptoms as minor issues that would soon go away, for example lower abdominal pains. It is until advanced symptoms like heavy bleeding manifested, that the patients reported to have sought treatment. They noted that lack of information on cervical cancer was a challenge as it prolonged their suffering as they sought for diagnosis, yet the cancer was advancing. Citations from two cervical cancer patients exemplify this:

I started having lower abdominal pains... Then after we had sex with my husband I would bleed. This is when I went to hospital [in 1998]. I however just used to be treated and given medication without knowing what was wrong with me. It was only in 2008 that I came to know that I had cervical cancer. (Patient#10, 45 years, Married)

My problem started in 2008. I used to have back pain and at times I would bleed a lot [like menstruation]. For the blood [menses] it would come and go and I would think it is menses of old age, so I did not bother about it. I only came to know that it cervical cancer when the bleeding increased and I was admitted in hospital where the diagnosis was later made. If I at least knew the signs and symptoms maybe I would have suspected early enough before the cancer became serious (Patient#14, 61 years, Married)

The caregivers also reported that they did not know much about cervical cancer until someone from their family was diagnosed with the condition. They noted that the information on cervical cancer, its risk factors, prevention, intervention and treatment was not readily available to the public. This is illustrated by the following excerpts:

I wish people can be educated more on cervical cancer. What are the signs and symptoms? What causes it and the risk factors associated to cervical cancer. May be if my mother had this knowledge she would have been diagnosed early before her situation got to where it is now. This way early diagnosis can be ensured. (Caregiver#17, Son, 31 years)

Information on the nature and treatment on cervical cancer was the greatest challenge. You know the initial idea one gets when they hear cancer is impending death. However when we saw the doctor and we were explained to us the staging of cervical cancer, and the stage at which my wife's was, I got relieved since I understood the condition better and know that she will be ok. People need to be educated more on cervical cancer. (Caregiver #4, Spouse, 44 years)

The health care workers also reported inadequate information as one of the challenges facing cervical cancer patients as illustrated in the following excerpt:

Because of physical limitations and low- level of awareness on cancer among the public in terms of signs and symptoms and treatment options, risk factors and prevention measures, most patients present at an advanced stage. (Health care worker # 4, Nairobi Hospice)

4.2.7 Delayed diagnosis

The cervical cancer patients reported delayed diagnosis for their condition as a major challenge. The patients reported taking time before going to hospital. Once at the hospital, the patients reported having been treated for different illnesses on several occasions before they were later diagnosed with cervical cancer. The patients and their care givers noted that it took years and repeated hospital visits before proper diagnosis was made. A citation from one of the cervical cancer patients illustrates this:

My problem started with bleeding. The bleeding was irregular and whenever I went to hospital I would be given family planning pills to correct this. The doctors

kept on saying that I had hormonal imbalance. However despite taking the pills my situation became worse... Then last year I decided to seek specialized treatment... The doctor conducted a biopsy. After taking the specimen it was taken to Aga Khan Hospital for analysis and it took some time before the results were back. It took three weeks. [Before the results were back she became very sick and went to KNH]. At KNH I was send back home to wait for the results, despite being very ill. There wasn't much that could be done to help the situation until the results were out... [Results were later released] I had cervical cancer! (Patient#6, 38years, Married)

This is further reinforced by a care giver's account:

You know mother had been treated for several illnesses before she was later diagnosed with cervical cancer. I now feel that all this while she was being misdiagnosed. While she was taking medication for those other illnesses, the cervical cancer was becoming serious. If only she had been discovered earlier [sigh] (Caregiver#15, Daughter, 38 years)

Additional information from health care workers also reinforced the challenge of delayed diagnosis as in the excerpt below:

Cervical cancer in developing countries like Kenya, presents late when very little can be done in the form of definitive treatment by surgery or radiotherapy. Yet only 46 per cent of provincial hospitals in sub-Saharan Africa have capacity to surgically operate on patients with cervical carcinoma in East/Central Africa. Only 21 per cent have gynaecologists able to perform the operation. For example, in Kenya, there are only two gynaecological oncologists. (Health care worker #5, Nairobi Hospice)

4.2.8 Sexuality

The cervical cancer patients reported that their sense of womanhood had been affected by cervical cancer and this affected their sexuality. The cervical cancer patients reported that the nature of treatment of cervical cancer sometimes required surgery which removed their uterus. They also noted that the intensity of radiotherapy and chemotherapy usually left the women in their reproductive age infertile and physically scarred a factor that greatly affected their sexuality. The following excerpts from a cervical cancer patient and a health care worker illustrate this:

Losing the ability to have children has been a hard thing to reconcile myself with. This resulted from my treatment which involved removal of my uterus through surgery as well as radiotherapy and chemotherapy. I know I have children already, but losing my uterus is like being stripped of one of the things that

defines me as a woman. Because of this, I feel like I have lost a large part of my identity as a female. (Patient#6, 38 years, Married)

In cases where the cervical cancer in a patient is diagnosed in the early stages, then surgery is usually the form of treatment given. In the case of surgery, at times the whole uterus is removed rendering the woman infertile. The patients often find the situation damaging and it takes a lot of follow up, counselling and re assurance for a patient to feel whole again after such a procedure. (Health care worker #3, KNH)

The cervical cancer patients and their care givers also reported that the sickness had impacted on their sexuality in terms of how the patients now related sexually with their spouses. Once on treatment, the cervical cancer patients had to disengage from any sexual activities until assessed as fit by a health practitioner. The following excerpts by spouses of cervical cancer patients illustrate this:

I even at times fear that I will hurt her [his wife if they have sex]. It has taken me [spouse] several trips with her [cervical cancer patient] to the clinic so that I can ask the doctor again and again about cervical cancer and whether it is okay to engage in marital affairs [sexual activities]. (Care giver #4, Spouse, 44 years)

Our sex life had to come to a stop when my wife became sick. But you know after all these years of marriage, we need each other even without sex, and as you can see we are old and that is no longer a necessity. Once in a while we try, my wife is now okay. (Care giver#10, Spouse, 50 years)

In addition, the symptoms of cervical cancer which included bleeding and pain during sexual intercourse were reported as making intercourse less desirable. Since cervical cancer is a gynaecological condition, sexual relations are further affected with spouses afraid of infection as illustrated by the following excerpts:

You know even after my wife was okay I could not bring myself to... [Have sex with her]... you know, because I was afraid of getting infected or something. (Care giver #6, Spouse, 42 years)

Cervical cancer? How did she get it? You know I wanted to know if it was sexually transmitted, may I also have gotten it... We talked a lot about her illness and we even went for a HIV test which came out negative...This affected our sexual relationship a lot. (Care giver#12, Spouse, 63 years)

The other challenge is that her husband's family seems to have a problem with my sister's illness. The husband is supportive but his family... [Sigh] they have been talking so many bad things about my sister and her condition but we are supporting her. They haven't even come to see her, not even once. This even made our family ask her to come to Nairobi so that we could take care of her closely. We know she will be okay, and then we will see what those in-laws will now say. (Caregiver#3, Sister, 41 years)

4.3 Coping strategies of cervical cancer patients and their families

The cervical cancer patients and their care givers noted that coping with the challenges presented by cervical cancer was necessary for the patients' well being. Since most of the challenges were long term given the chronic nature of cervical cancer, the patients and their care givers reported that they devised coping mechanisms to counter the challenges. The coping strategies reported in this study include; family support, positive reinterpretation, palliative care and turning to religion.

4.3.1 Family Support

Family support was the most and first mentioned coping mechanism by both the cervical cancer patients and their care givers. Although the diagnosis with cervical cancer condition brought anxiety and fear of death initially, the cervical cancer patients reported that their families became a support network.

I was devastated [When given the cervical cancer diagnosis]; I did not know where to start. However I gained strength from my husband. He has been very understanding and my source of encouragement. Actually since my illness my husband has become more loving, caring and supportive. With such support I have come to accept my condition. (Patient#6, 38 years, married)

I had to relocate from my home in Karatina. I now stay with one of my sons in Isiolo. With the help of his siblings he takes care of me. All my children know of my sickness and they are very supportive. You know when one is sick they want to be helped. They want many things, treatment, medication, support. This is hard for those taking care of a sick one but I am thankful to God, my children are providing this. (Patient#2, 51 years, Widow)

The care givers reported that families provided financial as well as psychosocial support for the cervical cancer patients. The care givers noted coming together as a family to

support a loved one was good for both the patient as the family as it strengthened family unity. As the patient goes through the illness experience, she is not alone; her family is there with her, as exemplified by the following excerpts:

I decided to stand by my wife and walk her through this illness. It has not been easy, especially since the children do not know. But as I see my wife getting better, I get encouraged that things are going to be alright. Her side of the family knows and they are very supportive. (Caregiver#4, Spouse, 44 years)

I am also the one who takes care of her expenses. I bring her to hospital and buy her medicine. I usually take a day off on her clinic days. I have had to adjust my lifestyle to cater for my mother's needs. I take care of everything. My other sister also helps but most of the time I am the one who is in charge as she has children in college. This is very straining for me, but I am not complaining. It is enough that her health is improving. (Caregiver#8, Daughter, 45 years)

4.3.2 Turning to religion

After family support, turning to religion was the second most popular coping mechanism reported by the cervical cancer patients and their care givers. The cervical cancer patients reported believing in a higher power in control of their lives. Especially after diagnosis with cervical cancer, the patients reported becoming prayerful and trusting their well being to a higher power. The following excerpts by three cervical cancer patients illustrate this:

I thank God for everything. My faith has helped me. I believe that God will see me through this and I will be well again. You know I am a believer and I trust that I will be fine. (Patient#5, 52years, Married)

I find refuge in God. I know He has numbered my days and He knows how long I will be here on earth. Cancer does not determine the length of my life. God does. (Patient#13, 53 years, Widow)

But most important for me is that, God is in control. I will live my life the way God has planned it out. (Patient#9, 61 years, Married)

The care givers also reiterated the important role religion played in coping with cervical cancer for the patients and their families as well. The following excerpts illustrate this further:

How we manage is by believing in God. I know God can heal. I have also gotten encouraged by the treatment here. I have seen my wife move from a bedridden person to a whole person again. (Care giver #4, Spouse, 44 years)

Cancer and our children are still very young. I thought she would leave us. When she started treatment she became even weaker and I got even more worried. But after Kampala she is now better. God knows how much we have prayed for her restoration and I am happy our prayers have not been in vain. (Caregiver#6, Spouse, 42 years)

4.3.3 Palliative care

The care givers and the cervical cancer patients reported that palliative care was helping them to cope with cervical cancer. They noted that through palliative care the patients and their families were now able to look at life with hope for tomorrow. They noted that psychosocial care and sensitization on cervical cancer offered under palliative care was helping them overcome their fears as illustrated by the following excerpts:

The hospice has also been helpful. I usually bring her to hospital. We live with her and since I run my business with my husband and one of my sons, I leave them and accompany her here. I have been educated a lot on her condition and been encouraged. Especially this group sessions you know I have met families with patients some even young kids and talking with them brings hope and reassurance that we are not alone. I also get my questions answered. (Care giver#3, Sister, 41 years)

Initially I was afraid about dying but with frequent visits to the Nairobi Hospice, I have begun to have a different perspective of life. I now take life one day at a time. I live for today and know that tomorrow is in God's hands. He is the one who gives life. When my day comes I will leave this world with or without cervical cancer. (Patient#3, 35years, Married)

When I went back home I kept on feeling worse and we came back to KNH.... I started coming to the hospice and here they talk to me, ask how I am feeling and give me medication. The medication has helped, however I have lost so much weight. Just look at my arms they way I am so thin. I do not know if I will ever be okay, but I am not going to lose hope. (Patient#18, 70years, Widow)

I have handled patients who walked into the hospice desperate and lost out on hope for living. But with the holistic care we offer our clients and their families, we have seen many women rise up from their sick bed and begin to recollect their lives yet again. (Health care worker #4, Nairobi Hospice)

Additional information from the key informant interviews however established that although palliative care services were also available at KNH, fewer patients were able to access the free of charge services. Cervical cancer patients could only attend palliative care upon referral from the health care worker in charge of their treatment. Only patients whose cervical cancer condition was regarded as terminal by the health care worker were referred to the palliative care unit.

Upon referral, not all patients readily accepted these services. Some of the cervical cancer patients explained that they could not bring themselves to go for palliative care. They noted that in their opinion embracing palliative care was like resigning themselves to death. According to the patients going for radiotherapy and chemotherapy treatment was a better option as with treatment one would always get well. The following excerpts illustrate this:

I have been postponing going for a group therapy session at the palliative care unit. You know after my treatment [chemotherapy and radiotherapy] I had been doing okay and then I was send to Kampala for further treatment... After Kampala, I started leaking urine. It has been like this for three months. I went back to hospital and the doctor told me that there is nothing that can be done about this complication. The next visit to hospital doctor recommended that I go for palliative care, for which I have not yet done. I just have this feeling my condition is not treatable and for me this is hard to come to terms with it [that the condition is terminal]. [Going for palliative care] I feel like I am giving up on life and just accepting to die just like that.” (Patient#14, 61 years, Married)

I know my daughter [the care giver]; if she wanted she could have found money for chemotherapy and radiotherapy. I am unhappy with palliative care, *hii siyo matibabu* [This is not treatment], Just look at my arms I am so thin I do not know if I will ever be okay....(Patient#18, 70 years, Widow)

4.3.4 Positive reinterpretation

The cervical cancer patients reported that accepting their ill condition helped them cope with their ill health. They explained that alongside the treatment, accepting one's

condition helped them put into proper perspective their health condition. The cervical cancer patients reported that constant support from family and friends as well as counselling and religion had helped them accept their cervical cancer condition. This is illustrated by the following excerpts by cervical cancer patients:

I also have accepted my condition, because I know that cancer can affect anyone. I know I will be better. When I knew I had cancer of the cervix, I thought my life was ended. But with treatment, I have become better and my life is back to normal (Patient#4, 40years, Married)

So when I got news of my diagnosis I feared that my days were numbered. I got so distressed. But with encouragement a from my children especially my daughter, I have come to see things differently. I take every day at a time. I have accepted to live with my illness. (Patient # 13, 53years, Widow)

You see these beautiful mats and cards, these are made by women who have understood their health condition, accepted themselves and adopted a positive attitude for life. They have come together in a support group and meet weekly to encourage each other as well as make some handiwork to acquire skill to enable them to sustain a livelihood. Their attitude towards life is such an inspiration. (Health care worker # 6, Nairobi Hospice)

As reported, their positive attitude towards life helped the patients live through the cervical cancer experience.

CHAPTER 5: DISCUSSION OF THE STUDY FINDINGS

This chapter tackles the discussion of the study findings. The discussion has been guided by the research questions of this study. The findings are therefore discussed under two major themes namely; challenges of living with cervical cancer and coping with cervical cancer.

Challenges of living with cervical cancer as discussed in this chapter are; access to health care, delayed diagnosis, anxiety and fear of death, family stress, fear of stigmatization, sexuality, lack of information on cervical cancer as well as economic strain. Coping with cervical cancer has also been tackled in the discussion with the following strategies being expounded; positive reinterpretation, palliative care, family support and turning to religion.

5.1 Challenges of living with cervical cancer

The cervical cancer patients and their care givers cited challenges of living with cervical cancer. The challenges reported by the patients and their care givers included, economic strain, access to health care, delayed diagnosis, lack of information on cervical cancer, anxiety and fear of death, family stress and sexuality as well as fear of stigmatization and avoidance. Challenges facing cervical cancer patients have been reported in other studies (Sellors *et al* 2004; Mulemi 2008; World bank 1993; Sherris *et al* 2001; IARC 2007; WHO 1990; ACCP 2004)

5.1.1 Economic strain

Majority of the respondents cited economic strain as a major challenge for cervical cancer patients and their families. The high cost of cancer treatment has been reported elsewhere (e.g. in a study on the lived experiences of patients in a cancer ward in Kenya).

In that study patients reported that money for admission and treatment was a challenge (Mulemi 2008). Cervical cancer patients are exposed to a lifestyle of illness which renders them partially or permanently inactive. This happens in a situation where the women are contributing to the overall family income before diagnosis resulting in a strained family budget (Sellors *et al* 2004).

Treatment options for cervical cancer are; surgery or chemotherapy and radiotherapy depending on the stage of the disease at diagnosis. Drugs to go alongside the treatment and for pain alleviation are necessary. Some of the cervical cancer patients need supplies like diapers and sanitary towels regularly. The treatment and management of cervical cancer is expensive.

Transport costs for the frequent hospital visits and accommodation arrangements were adversely mentioned by the cervical cancer patients and their care givers as additional costs. A 1993 World Bank analysis estimates that the cost of screening cervical cancer every five years is US\$ 100 per disability adjusted life year (DALY) gained compared with US\$2600 per DALY for treatment and palliative care of invasive cervical cancer (World Bank, 1993).

5.1.2 Access to health care

Although many developing countries have expended their scarce resources on providing surgical, radiotherapy and chemotherapy services, only a small proportion of women with cervical cancer benefit. Most of the cervical cancer patients have to endure a difficult and protracted illness since the treatment options, if available, are not accessible or affordable. Little can be done for most cancer patients but provide palliative care (Sherris *et al* 2001). Palliative care gives total care for patients dying of chronic illnesses

such as advanced cervical cancer. The overall goal of palliative care is to achieve the best quality of life for the patients and their care givers (WHO 1990).

The cervical cancer patients and their care givers in this study reported access to health care as another major challenge. They reported distance from the health facility, time taken to see the doctor once at the health facility, as well as high demand for the treatment services as hindrances' to accessing health care. Access to healthcare for cancer patients in developing countries remains a major challenge (Sherris *et al* 2001).Cervical cancer is the third most common cancer worldwide...is the opening statement from Beyond our borders: Cervical cancer in the developing world (Sherris *et al* 2001).Cervical cancer is the leading cause of death in women from cancer in developing countries, causing approximately 190,000 deaths worldwide each year (Sherris *et al* 2001). Up to 80% per cent of these deaths occur in the developing world where access to appropriate and timely cervical cancer treatment is a challenge.

Treatment of cervical cancer will depend on factors such as stage of the cancer, size of the growth, how far it has spread, age and whether the cervical cancer patient desires more children. In some cases, various methods may be combined. These methods include radiotherapy, chemotherapy and surgery. For the cervical cancer patients the immediate action would be curative treatment in the form of pelvic surgery, chemotherapy and radiation (Sherris *et al* 2001).

Majority of the cervical cancer patients involved in the study had undergone chemotherapy and radiotherapy. Due to the overall higher cost of these services at the private hospitals including Aga Khan University hospital (Nairobi) cervical cancer patients diagnosed in private facilities prefer to access treatment from the public health

facilities and as such end up at KNH. In Kenya there are only two radiotherapy machines within the public health sector and they are at the KNH (WHO/ICO 2010).

Being the only public health facility with radiotherapy machines, patients with all types of cancers and from all walks of life are referred to KNH to access these services. This makes the demand for the services much higher than their availability. As such a cervical cancer patient may be queued to start treatment for up to two months. While waiting for treatment, their health condition is not improving, making it more challenging for the patients and their families. Similar findings were reported in another study on the lived experiences of cancer patients (Mulemi 2008).

In addition, for cervical cancer patients, besides the radiotherapy and chemotherapy treatment therapies, usually the patients require brachy therapy. In Kenya the only brachy therapy machine in the public health sector placed at the KNH is broken down. As such patients are referred to Mulago Hospital in Kampala, Uganda for treatment. This is considerably cheaper than accessing the same service from a private health facility here in Kenya.

5.1.3 Delayed diagnosis

The cervical cancer patients reported to have taken time before seeking medical attention regarding their health condition. At the onset of the symptoms the women reported having taken pain killers to relieve back pains. They also reported having dismissed initial bleeding as being menstrual period, despite most of them having reached menopause. It is when adverse symptoms manifested that the cervical cancer patients went to hospital. At the hospital several diagnosis were made and the women were treated for different illnesses before they were diagnosed with cervical cancer. The

illnesses commonly diagnosed included hormonal imbalance for the bleeding and for the back pains they were given pain relievers. By the time a proper diagnosis is made, majority of the women have advanced cervical cancer. Similar findings have been reported elsewhere (Sherris *et al* 2001).

In Sub Saharan Africa, more than 50 percent of the women seeking treatment have advanced cervical cancer (ACCP 2004). Patients who present with excessive bleeding are often treated to reduce the bleeding. This may go on for a long time without proper diagnosis in the case of cervical cancer being made. As time goes on without proper diagnosis resources are wasted on wrong treatment while the condition keeps getting worse. If cervical cancer is not detected early enough, it keeps on progressing and beyond stage III it is untreatable (ACCP 2004).

In the treatment process, delayed diagnosis and referral, and unforeseen interruptions often result in poor outcomes (Mulemi 2008). In the developing world, despite the increased awareness for screening services, inequities among the different population groups make access to early detection difficult and women are usually diagnosed in the advanced stage of cervical cancer (Sellors *et al* 2004). The current estimates indicate that every year in Kenya, 2,454 women are diagnosed with cervical cancer and 1, 676 die from this chronic health condition. Yet, this debilitating condition is almost entirely preventable and, indeed, 100 per cent curable when detected early (WHO/ICO 2010).

5.1.4 Inadequate information on cervical cancer

Until they become cervical cancer patients, the study respondents reported that they had little if any previous knowledge of this condition. If diagnosed early cervical cancer is

treatable yet most of the patients are unaware of the risk factors of cervical cancer and its signs and symptoms (WHO/ICO 2010). Majority of the patients had no prior knowledge of cervical cancer before diagnosis. Cervical cancer becomes a reality to the patients and their families upon diagnosis.

Similar findings on the knowledge of cervical cancer were reported in an ethnographic study of cervical cancer among women in rural Kenya (Gatune and Nyamongo 2005). In this study, women were asked questions to assess their knowledge, attitudes and practices of cervical cancer. About 35% had never heard of cervical cancer. Forty respondents (25%) had heard about cervical cancer but could not explain anything about the disease (Gatune and Nyamongo 2005). In the present study respondents felt that if they has prior knowledge on cervical cancer, it would have helped in early diagnosis and their health condition would have been treatable.

5.1.5 Family stress

From the study findings it is evident that the family faces difficulties in taking care of the chronically ill person who becomes a lot more dependent. A once active mother, sister, daughter or wife becomes sickly and dependent for even basic things. Pain resulting from their condition at times leaves their families feeling helpless. As the cervical cancer patients undergo the treatment therapies, the intensity of the treatment drains energy leaving them almost motionless and in need of a helping hand every now and then. Spouses, children, parents and siblings have to adjust to the shifting priorities, duties and responsibilities for the well being of their ailing family member. Sometimes these

shifting priorities may bring in strained relationships, causing family stress (Sellors *et al* 2004).

In some cases the spouse has to refocus and now offer more care to the cervical cancer patients. Since the spouse may also be the sole breadwinner, then a helping hand is sought to help in the care. For older cervical cancer patients, they move in with their children for better observation and care. In isolated cases the cervical cancer patients move back to their maternal homes for care. This shift in household arrangement and responsibilities strains the family unit. In other situations the shifting priorities and responsibilities may work out for the better and result in better family relationships as was reported by some study respondents.

As the patient goes through treatment which most often leaves them wasted, the family only hopes that she will be better (Sellors *et al* 2004).

The treatment therapies fill the patients with the hope of getting better. However given the advanced stage diagnosis, nothing much can be done to remedy the health condition. The situation is chronic with death as the end and the burden of the sickness causes family stress. Some family members are unable to come to terms with the chronic condition of their loved one.

The possibility of losing a loved one puts pressure on both the patient and the family with even some families opting for radiotherapy and chemotherapy treatment which are very costly and declining palliative care which is offered free of charge. To them palliative care is given to dying people and a lot of them are opposed to the idea. This is in spite of the fact that majority of the patients actually need the holistic care provided through palliative services to be able to better cope with cervical cancer (Murray *et al* 2003).

5.1.6 Sexuality

Most of the patients in the study mentioned that they had been left with scars on their bodies during the treatment and that this had affected how they felt about themselves. The scars affected the cervical cancer patients physically and psychologically. Physically some had no uterus, they could no longer reproduce. They felt less feminine. Also the intensity of radiotherapy and chemotherapy rendered the women infertile. Weeks (2003), defines sexuality as an historical construction which brings together a host of different biological and mental possibilities and cultural forms. Sexuality is the quality of being sexual- ability to admire, to experience or to portray oneself- or having sex. That this form of cancer affects a woman's reproductive system, it makes the condition sensitive. The woman's sexuality is affected.

The cervical cancer patients who were still in their reproductive ages, felt that cervical cancer had stripped them of this capability. All the patients had scars resulting from the treatment therapies and they no longer felt as attractive and most were less confident. The cervical cancer treatment had left permanent marks on their bodies; A constant reminder of their health condition. For the cervical cancer in sexual relationships, these scars left them less confident of their outlook.

The early stages of cervical cancer do not usually manifest any symptoms. Symptoms tend to occur when the disease is more advanced. Painful sexual intercourse, pain in the pelvic area and lower abdomen and bleeding after sexual activity are symptoms of cervical cancer. The odour from the vaginal discharge and bleeding are also symptoms (Ferlay *et al* 2004). These symptoms affect the sexual life of the cervical cancer patient. If she is married or in a sexual relationship, this also affects the spouse as they can no

longer engage in sexual activity without pain or bleeding, making it less pleasurable (Sellors *et al* 2004).

Cervical cancer treatment is intense and it often affects the woman's desire for sexual intimacy. Surgery involves the removal of the cancerous cells and tissue in the cervix. In some situations, complete removal of the cervix and uterus is necessary --a hysterectomy--prompting menopause. Menopause brings with it symptoms such as hot flashes, vaginal dryness, and night sweats. These symptoms can make sex less comfortable or desirable. In some women, surgery can lead to a sense of loss, which affects the relationship and feelings of intimacy of the cervical cancer patient and the partner (IARC 2007).

At the time of their diagnosis, twelve of the patients were married and living with their spouses. For some of the cervical cancer patients, who had disengaged from sexual activity when they fell sick, had to come with their spouses for clinics and consultation. Some of the spouses were understanding and even seemed more concerned with the well being of their loved ones than with their conjugal needs.

5.1.7 Fear of stigma and avoidance

It is the constant association of cancer with death that often contributes to stigma and avoidance (Sellors *et al* 2004). The family and friends of the cervical cancer patients resign to waiting for their loved ones to die. Some family and friends even count days. This outlook as reported in the study causes some cervical cancer patients and their families to keep to themselves.

The bleeding and odour from the discharge also makes most of the cervical cancer patients keep to themselves for fear of being stigmatized. When people know that a

woman is having such symptoms, they avoid their company. Some caregivers in the study reported initial fears of handling personal effects of the cervical cancer patients for fear of infection. These fears were later replaced with correct information on cervical cancer. Wives keep the condition from their spouses for fear of how they would react to it. Some husbands have after diagnosis abandoned their wives as they think that the condition is contagious. This was a recurrent theme in the study findings. The community may out of ignorance associate the illness with superstitious causes like witchcraft (Sellors *et al* 2004).

5.2 Coping with cervical cancer

Further, the cervical cancer patients and the care givers reported that most these challenges were long term. As a result the patients and their families usually developed coping strategies to counter the challenges and enable them endure and survive the illness experience. As the patients and their families come to terms with the sickness, they develop strategies to cope with the challenges they encounter. Coping is recognized as an increasingly important consideration in the management of chronic disease. Effective coping has been found to decrease morbidity and mortality (Camela *et al* 2008). The role of care givers emerged as a coping mechanism in coping with cervical cancer. Turning to religion, family support, positive reinterpretation, and palliative care were reported as coping strategies throughout the study.

5.2.1 Family support

Families have come together and provided a strong pillar for the cervical cancer patients. The study respondents repeatedly cited family support as a means of coping with the illness experience. Despite the financial constraints, family members put the health of the

patient first and desire to see her getting better. They pull resources together and provide not only financial but also the much needed emotional support for the patient (Sellors *et al* 2004).

Accepting the patient and providing for her treatment and upkeep were reported as important in ensuring the wellbeing of the patient. Similar findings were reported in another study on the comparison on cancer patients in Kenya and Scotland (Murray *et al* 2003). In the study, while physical pain and financial worries dominated the lives of patients and their care givers in Kenya, Kenyan patients felt that the families and communities met their psychological and spiritual needs. In contrast, terminally ill patients in Scotland received adequate pain relief but their non physical needs were unmet (Murray *et al* 2003).

5.2.1.1 Role of care givers in coping with cervical cancer

With medical advances in cancer screening and treatment, cervical cancer has become a chronic rather than an acute disease with the result that patients survive longer with cancer (Nijboer *et al* 1998). As a result, there has been a push towards outpatient care in recent years (Nijboer *et al* 1998). ; Adams *et al* 2009; Golant *et al* 2008). Consequently, informal caregivers are now taking on the responsibility of caring for a loved one with cancer. Informal caregivers have become so essential that they are estimated to provide an average of 55% of the care needed (Nijboer *et al* 1998).

Informal caregivers are a major form of support for the cancer patient because they provide most care outside of the hospital environment. Due to the typically late onset of cancer, caregivers are often the spouses and/or children of patients, but may also be parents, other family members, or close friends. This support includes: Physical support:

management of side effects and late effects of treatment (Given & Sherwood 2006; Haley 2003; Kim & Given 2008; Nijboer *et al* 1998) and assistance with personal tasks such as bathing (Kim & Given 2008; Nijboer *et al* 1998). Emotional (Haley 2003; Kim & Given 2008; Nijboer *et al* 1998). Financial assistance: helping cover the expenses associated with cancer treatment (Kim & Given 2008; Nijboer *et al* 1998). Practical assistance: treatment monitoring, (Given & Sherwood 2006; Haley 2003; Kim & Given 2008) assistance with decision making (Nijboer *et al* 1998) and assistance with non-personal tasks such as grocery shopping (Nijboer *et al* 1998). Spiritual support (Kim & Given 2008).

The caregiver's relationship to the patient can be an important factor in their adjustment to care giving. Spouses, followed by adult daughters, are the most likely family members to provide care (Haley 2003). Spouses generally tend to have the most difficulty adjusting to this experience (Haley 2003; Nijboer *et al* 1998), although adult daughters also tend to express difficulty. However, this may be a factor of age more-so than the relationship to the patient in that spouses tend to be older caregivers than adult children. These findings were reiterated in this study as daughters were the most likely caregivers, followed by spouses.

5.2.2 Positive reinterpretation

Cervical cancer patients who accept their condition and will to live are able to cope with their health condition as reported in this study. Being a terminal illness the reality of cervical cancer comes with fear of death. Patients get encouragement through counselling and also improvement on their condition through treatment. They also get to interact with other cancer patients and share their experiences. Over time, the patients learn to take one

day at a time and as they get treatment they desire to get better and live longer (Sellors *et al* 2004).

Whatever the level of physical or mental impairment caused by the illness, most people do not want the illness to threaten the self-identities, social roles, or activities that they value, or to become the dominant factor in their interactions with others. To avoid this, they attempt to normalize the situation by minimizing the illness and conveying the impression of normalcy to others (Corbin and Strauss 1988).

Majority of the cervical cancer patients reported resuming work once they finished treatment and regained energy. They take up roles in economic activities like business, while avoiding strenuous work like farming. Household chores which they had initially stopped due to poor health are also duties these women engage in heartily. The elderly ones also put work into their time by taking care of their grandchildren or young one in the family. This is a way of coping for the cervical cancer women who feel relevant and useful. Working gives the cervical cancer patients something to look forward to and it helps the family see their loved ones determined to overcome the illness episode.

5.2.3 Palliative care

Palliative care was a service enabling the cervical cancer patients to cope with their health condition. Palliative care involves holistic care to cater for the physical, psychosocial and emotional wellbeing of the patients and their families. This is important as patients with chronic conditions, such as cervical cancer, require programmes in which they are active partners (WHO 1990).

Through palliative care, the patients are counselled and prepared for any eventualities including death. They get free pain relievers, diapers as well as dressing of wounds.

Information regarding their illness is availed and most of their questions given answers. Their families and care givers are also counselled and encouraged to accept the health condition of their loved ones. Patients are better able to understand their health condition and cope. Their families are also put in proper perspective as care givers. They are also prepared for the death of their loved one (WHO 1990).

However, not all respondents embraced palliative care. Actually some patients would decline accessing these services upon referral. In such a case a patient would continue with the other forms of treatment without palliative care. In a case where the care givers were also informed of the need for palliative care for the patients, some readily agreed and encouraged their loved ones to go for counselling, group therapy and even day care services. Some care givers on the other hand would refuse to have their patients' access palliative care even if the patients were willing. This is because the study respondents felt that going for palliative care was like giving up the possibility that their loved ones would defeat cancer. It was resigning to death. This was a recurrent theme as respondents talked about palliative care as a coping strategy.

Palliative care is available in the health facilities free of charge or at a highly subsidized fee. Most patients at the referral hospital go to the palliative care unit on referral from their doctors. Not all patients on cancer treatment go for palliative care clinics. As long as a patient has proof of a terminal illness, they are attended to free of charge. The hospice also offers palliative care to cancer and HIV/AIDS patients at a subsidized fee. Cervical cancer patients access these services as well. Despite the palliative care services being offered free of charge or at a highly subsidized fee not many cervical cancer patients reported accessing them.

5.2.4 Turning to religion

Religious coping activities such as prayer, attending church, and seeking comfort and strength from God, are often reported by individuals undergoing the stress of physical illness (Koenig *et al* 2001).

Respondents of this study reported religion as a way of coping with the challenges and fears of living with a chronic illness such as cervical cancer. For the families and care givers they keep hope alive knowing that cancer is not in control. God is. This hope helps the families live with and care for the cervical cancer patients taking each day at a time without many anxieties of what next.

Giving up their life and health to a higher power gives the cervical cancer patients the strength to carry on with life without so much fear of death from their health condition.

A growing body of research literature has found that measures of religious coping are often positively associated with improved mental and physical health outcomes for medically ill patients. Cross-sectional analysis of data from 3,617 participants found that participants with cancer were more likely to report seeking spiritual support in comparison to those reporting other chronic health conditions (Ferraro *et al* 2000).

In some cases however, turning to religion is a negative coping strategy. When a woman is dying, religion and spiritual beliefs can be very comforting. For some however, these beliefs also can be the source of questions and doubts. She may have thoughts and questions about her life and what will happen to her after she dies. She may believe that it is important to make peace with her god or do things to keep her soul or spirit safe after she dies (Sellors *et al* 2004). From the study findings, cervical cancer patients who had turned to religion had developed a positive outlook to cope with their health condition.

CHAPTER 6: SUMMARY, CONCLUSION AND RECOMMENDATIONS

This chapter is divided into three sections namely, summary, conclusion and recommendations. The summary gives an overview of the study, highlighting the title, study objectives, theoretical framework applied in this study, methodology, study findings as well as the discussion.

In the conclusion, the study focuses on the study assumptions in comparison to the study findings and discussion. The findings concur with the study assumptions and the challenges of living with cervical cancer and coping strategies are identified and discussed and recommendations are made.

6.1 Summary

The study on the challenges and coping strategies of cervical cancer patients and their families in Kenya is a descriptive exploratory study. Kenyatta National Hospital and the Nairobi hospice located in Nairobi County were the study sites. Non probability sampling mainly purposive and convenience methods were used to select the study sample comprising 18 cervical cancer patients and 18 care givers. In-depth interviews and key informant interviews were the primary data collection methods. Secondary data was also reviewed to build up the discussion.

Data was coded and analysed thematically.

The two broad themes identified from the findings are; challenges of living with cervical cancer for the patient and her family; coping with cervical cancer (strategies devised by patients and their families to counter challenges of living with cervical cancer).

6.2 Conclusion

There are challenges faced by cervical cancer patients and their families as established in this study. These include; economic strain, family stress, access to healthcare, inadequate information on cervical cancer, fear of stigmatization and avoidance, anxiety and fear of death and sexuality. From the study findings the challenges were found to load a heavy burden on the cervical cancer patients and their families as well. Similar challenges have been reported in other studies (Sellors *et al* 2004; Mulemi 2008; World bank 1993; Sherris *et al* 2001; IARC 2007; WHO 1990; ACCP 2004).

Further, the study identified coping strategies devised by the families and the cervical cancer patients to counter the challenges of living with cervical cancer. The patients and their families have developed strategies to enable them cope with cervical cancer. The coping strategies developed by the patients and their families as identified through the study include, family support, positive reinterpretation, turning to religion and palliative care. These coping strategies concur with findings from other studies (Corbin and Strauss 1988; WHO 1990; Sellors *et al* 2004; Ferraro *et al* 2000; Haley 2003; Nijboer *et al* 1998).

From the study findings it is clear that cervical cancer places a large burden on patients, their families, their communities, and their health care providers. Management of cervical cancer poses unique physiological, psychosocial, economic, and medical challenges that cause disruptions in the lives of the women and their families calling for coping strategies to adapt to the unique situation. However, to make the experience of living with cervical cancer more bearable a lot needs to be done. Below are a few recommendations

6.3 Recommendations

6.3.1 Recommendation for policy and service delivery

6.3.1.1 Improving health systems as part of a concerted effort against cervical cancer

:

Positive results for chronic diseases like cervical cancer can only be achieved when patients, families, societies and healthcare teams join their efforts in an organized and motivated way. Health systems in Kenya and the developing countries need to be developed to meet the needs of the healthy and the sick. This is through developing comprehensive cancer control programs that seek to prevent, detect early, cure and care.

To promote prevention and early detection of cervical cancer in Kenya, educating women of reproductive age is fundamental. Information of cervical cancer should be available at all levels. Women should be made aware of the need to screen for cervical cancer and where to go for screening. With the information available and the services improved for accessibility more women would then access the screening and also vaccination services. Early detection of cervical cancer would also result from a more informed population, easily accessing screening services. Early detection of cervical cancer opens an opportunity for cure and as such fewer women would succumb to this curable cancer.

6.3.1.2 Improving the quality of life by meeting patients needs

More people are diagnosed with cancer including cervical cancer and need adequate care. For instance, in Kenya current estimates indicate that every year 2,454 women are diagnosed with cervical cancer and 1,676 die from this chronic illness (WHO / ICO 2010).

Most of the cancer patients especially in the developing world present in the very late stages of whatever form of cancer. For most of them the best form of care is palliative

care that is the physical, psychosocial and spiritual support that can considerably improve their quality of life and that of their families by relieving unnecessary suffering (Globocan 2000).

Palliative care is not only the end of life care but is part of the continuum of care from the time cancer is diagnosed throughout the course of the disease alongside treatment. It becomes more intense towards the end of life as the treatment interventions become less effective. Palliative care also goes beyond death and involves bereavement care for the families (Globocan 2000).

Palliative care is already available in Kenya yet from the study findings, not as much terminally cervical cancer patients go for the care offered. More education on the importance of palliative care for the patient and their families is necessary. This awareness is for all stakeholders to ensure that more patients and their families can access the care and cope more easily with cervical cancer as a chronic condition.

6.3.2 Recommendation for further research

For years, research has been reporting the physical, psychological, financial, social, and spiritual repercussions of cancer on the patient. This study explored this challenges specific to cervical cancer patients. Further research in this area is necessary; to better understand the patients' illness experience.

With the discovery of the distress, particularly psychological, that cancer could cause in patients, researchers also began to investigate whether caring for someone with cancer could have similar effects on informal caregivers. Over the years, many stressors have been identified and the effects of caring for a loved one with cancer are becoming well documented.

Cancer as a chronic illness presents complex problems for patients and their families and has not always received adequate attention in intervention research. Although considerable information about self management by patients with heart, cancer, respiratory disease, arthritis and diabetes is available, very little exploration of management tasks by patients with these conditions is available.

Research in this area is of importance not only to better understand the caregiver's experience, but also to learn how their adjustment to the caregiver role impacts their ability to provide care to the cancer patient.

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APPENDICES

Appendix 1: In-depth Interview Guide I for the cervical cancer patients

Instructions

Introduce yourself to the participant. My name is.....I am carrying out a study on the challenges and coping strategies of cervical cancer patients and their families. If literate give her the statement of consent. If not read it out to them and seek their consent. Clarify as much as possible.

If she consents to participating then ask them the following questions. Let her know that her responses are confidential. If she does not consent, terminate the interview and thank her for her time.

QUESTIONS

1. How old are you?
2. What are your interests?
 - a) What sorts of things do you like to do?
 - b) What are you able to do?
3. Could you tell me some of the things your family expects you to do?
 - a) At home?
 - b) As relates to work?
 - c) In your relationships?
4. When were you diagnosed with cervical cancer?
 - a) How did the diagnosis come about? Had you gone to hospital specifically for cervical cancer treatment?
 - b) What was your initial reaction? *Probe more.* How exactly did you feel?

- c) After diagnosis what next? *Probe*. Did you start treatment immediately?
 - d) How did your family know of your condition? Did you confide in anyone first?
5. In what ways has this illness affected your health? *Probe*. How exactly?
6. What are some the challenges that you have faced?
- a) External challenges? By these I mean, in regard to your illness and the interaction between you and your family, friends, workmates, community?
 - b) Are you married? If yes, how has your condition affected your relationship with your husband?
 - c) Do you have any children? If yes, do they know of your condition? How are they taking it?
 - d) Does anyone else in your family (nuclear and extended) know of your condition? How are they taking it?
 - e) Do your friends or colleagues know of your condition? How do they treat you? Is it any different from before you were diagnosed?
 - f) Do members of your community know that you have cervical cancer? If yes, how do they treat you?
 - g) Internal challenges? *Probe*. Pain, fear of death e.t.c.
 - h) Have these challenges varied over time?
7. Has your condition affected your lifestyle over the years? How exactly?
- a) Things you used to do that you have now stopped?
 - b) Things you have had to start doing?
8. How is your family dealing with your health condition?
- a) Who takes care of you? How?

- b) What are your needs?
- c) How are these needs met?
- d) Have things changed for you and your family? If so, in what ways?

9. How are you able to handle these challenges resulting from your health condition?

What do you do? *Probe to identify the problem focused and emotion focused coping strategies the patient practices.*

10. Where do you go for care and treatment?

- a) What services do they offer you?
- b) How regular are your clinics?
- c) Are you in any support group network? What do you do at the network?
- d) Any recommendations for cervical cancer management? What should be done differently?
- e) Anything else you would like me to know? Is that all?

Thank you for your participation.

Appendix 2: In-depth Interview Guide II for adult family member.

Instructions

Introduce yourself to the participant. My name is.....I am carrying out a study on the challenges and coping strategies of cervical cancer patients and their families. You have been identified as one of the family members of a cervical cancer patient. If literate give him or her the statement of consent form. If not read it out to him or her and seek his or her consent. Clarify as much as possible. If he or she consents to participating give him or her a demographic questionnaire to fill out. Once they finish, ask him or her the following questions. Let him or her know that his or her responses are confidential. If he or she does not consent, terminate the interview and thank her for their time.

QUESTIONS

1. Could you tell me the nature of the relationship between you and the patient?
 - a) Are you the husband?
 - b) Sister
 - c) Mother
 - d) Daughter
 - e) Other? Specify

2. Kindly explain how the family does get its livelihood. What is the main source of the household income?
 - a) Who is the primary breadwinner?
 - b) How many members are in this household?
 - c) What is your monthly household income?

- d) How much is spent on the care and treatment of the patient?
3. How did you learn of her condition?
- a) What was your initial reaction?
 - b) How long ago was this?
 - c) And how are you taking it presently?
 - d) Who else in the family knows of her health condition?
 - e) What is their reaction to her condition?
4. Who takes care of the cervical cancer patient?
- a) What is it like to take care of a cervical cancer patient?
 - b) What are her needs?
 - c) How are these needs met?
 - d) What is your role in her care and treatment?
5. Are there any challenges of caring for cervical cancer patient? If yes, which ones?
- Probe to find out the internal and external challenges
- a) Have things changed for the family? If so, how?
 - b) Does her condition affect your lifestyle? If yes, in what ways?
 - c) Has her condition affected your relationship? *Probe*. In what ways?
 - d) Economically?
 - e) Does the community (extended family, friends, and neighbours) know of her condition? If yes, how do they react to it?
 - f) Any other challenges?
 - g) Regarding her health condition, are there any fears you and the family have? If yes, which ones?

6. How do you and the family cope with her health condition?

- a) Any specific things you do to tackle the challenges brought about by cervical cancer in the family? *Probe to bring out the problem-focused and emotion focused coping strategies of the family*

Thank you for your participation.

Appendix 3: Key Informant Interview Guide for the hospital staff

RESPONDENT NAME..... TITLE.....

HOSPITAL.....

1. How many cervical cancer patients do you have? Are they inpatient or outpatient?
2. What are the costs for;
 - a) Inpatient cervical cancer patients?
 - b) Outpatient cervical cancer patients?
 - c) At what point in the illness do you admit the cervical cancer patients?
3. At what stage was the prognosis for each of the cervical cancer patients in your care made?
 - a. Were they all diagnosed here? If so, when was this?
 - b. Had they come to specifically seek cervical cancer treatment?
 - c. If not, were they referred? If yes, from where?
 - d. Did you prepare them before disclosing their prognosis? If so, how?
4. What services do you offer cervical cancer patients?
 - a) What structures are operational in your institution for cervical cancer care?
 - b) Apart from medication to relieve pain and take care of other physical challenges, do you offer them any other form of care?
 - c) Do you have a support network for the cervical cancer patients in your care?
5. Are there challenges of handling cervical cancer patients? Which ones?

6. How do you involve their families in their care?

a) Do you have a support mechanism for the families of cervical cancer patients? If so, what does it offer?

7. Are there any success stories you would like to share?

Have you lost any patients to cervical cancer in the last five years? If so, how many and when?

8. What recommendations would you make regarding treatment and care of cervical cancer patients? Is that all? Anything else you would like to add?

Thank you for your cooperation.

Appendix IV: Statement for consent for the cervical cancer patient.

Title: The challenges and coping strategies of cervical cancer patients and their families.

Introduction

“Hello, my name is Mariah Ngutu a Masters of Arts (Anthropology) student from the University of Nairobi. I am carrying out a study on challenges and coping strategies of cervical cancer patients and their families. You have been identified as one the key respondents in this study, and I hope that you will feel free to discuss with me.

You will also be followed to your home so as to gain access to your family and interview one adult member of your family identified as your care giver. Do you agree to this?

This study will explore the lived experiences of cervical cancer patients and their families as a way of understanding long term effects and the dynamics of living with chronic illnesses. I am interested in your experiences, in terms of the challenges and coping strategies of living with cervical cancer.

The explorative descriptive study will explore the challenges and coping strategies of cervical cancer patients and their families. Qualitative data collection methods will be utilized and a sample population of 36 (18 cervical cancer patients and 18 care givers) is targeted. The study population comprises of medically stable cervical cancer patients at Kenyatta National Hospital and Nairobi Hospice.

Objectives of the study

The overall objective is to explore the challenges and coping strategies of cervical cancer patients and their families. The specific objectives are;

- I) To establish the challenges faced by cervical cancer patients and their families.
- II) To determine the coping strategies that cervical cancer patients and their families have developed to counter the challenges of living with cervical cancer.

Benefits

No specific direct benefits will accrue to you and your family. However, the information you provide will help to better understand the experience of living with cervical cancer. This information will be used to make recommendations that may help improve the management of cervical cancer patients.

Risks

No specimen will be obtained for this study. No invasive procedures will be conducted on you. As such minimum risk is anticipated. After your initial consent, the researcher will work closely with the health care provider to review you after the interview sessions. Constant counselling and evaluation by your health care provider will help minimize the possibility of any psychological harm.

No embarrassing questions will be asked neither will the researcher express shock or disgust on any of the responses given.

Voluntarism

Your participation in this study will be on a voluntary basis. You are free to skip any question you feel uneasy to respond to. You are also free to withdraw your participation at any given time. Your participation or lack of participation in the study will not in any way affect your care and treatment.

Confidentiality

Pseudonyms will be used to keep the identity of the informants private. The study will ensure the confidentiality and privacy of study participants by keeping any information shared between the researcher and the study participants confidential.

The information will be taken in great confidence and only used for this research. The recommendations will be availed to the KNH and Nairobi Hospice to ensure better service delivery to the cervical cancer patients. People who have informed the study will be acknowledged in the study findings.

Contacts:

In case of any questions you can contact;

Ethical Review Committee, KNH. Hospital Rd, along Ngong road

P.O.Box 20723, Nairobi.

Email: KNHplan@KEn.Healthnet.org

Phone no.: 726300-9

Fax: 725272

Supervisor: Prof. Isaac K. Nyamongo

Email: inyamongo@uonbi.ac.ke

Researcher: Mariah Ngutu Peter

Email: mariahngutu@gmail.com

Phone no.: 0723 839 619

The results from the study will be used to obtain a Masters of Arts degree in Anthropology from the University of Nairobi. The findings will also be used to make recommendations aimed at improving treatment and care offered to cervical cancer patients countrywide. The recommendations will be available for KN H and Nairobi Hospice to improve palliative care targeting cervical cancer patients.

Do you have any questions? Thank you”

DECLARATION:

RESEARCHER

I Mariah Ngutu Peter, declare that I have given full information regarding this study to
..... before seeking verbal and written consent.

Date:

Signature:

STUDY PARTICIPANT

Ihave been fully informed of this study and
have agreed to be a study participant out of my own free will. I therefore give my verbal
and written consent. I have also been informed of the subsequent home visit to interview
my care giver and I also give consent to this.

Date:

Signature:

Appendix V: Statement for consent for the care giver.

Title: The challenges and coping strategies of cervical cancer patients and their families.

Introduction

“Hello, my name is Mariah Ngutu a Masters of Arts (Anthropology) student from the University of Nairobi. I am carrying out a study on challenges and coping strategies of cervical cancer patients and their families. You have been identified as one the key respondents in this study given your relationship with

(Name of CC patient) as the care giver. I hope that you will feel free to discuss with me.

This study will explore the lived experiences of cervical cancer patients and their families as a way of understanding long term effects and the dynamics of living with chronic illnesses. I am interested in your experiences, in terms of the challenges and coping strategies of living with cervical cancer.

The explorative descriptive study will explore the challenges and coping strategies of cervical cancer patients and their families. Qualitative data collection methods will be utilized and a sample population of 36 (18 cervical cancer patients and 18 care givers) is targeted. The study population comprises of medically stable cervical cancer patients at Kenyatta National Hospital and Nairobi Hospice.

Objectives of the study

The overall objective is to explore the challenges and coping strategies of cervical cancer patients and their families. The specific objectives are;

- I) To establish the challenges faced by cervical cancer patients and their families.
- II) To determine the coping strategies that cervical cancer patients and their families

have developed to counter the challenges of living with cervical cancer.

Benefits

No specific direct benefits will accrue to you and your family. However, the information you provide will help to better understand the experience of living with cervical cancer. This information will be used to make recommendations that may help improve the management of cervical cancer patients.

Risks

No specimen will be obtained for this study. No invasive procedures will be conducted on you. As such minimum risk is anticipated. Constant counselling and evaluation of your patient by the health care provider will help minimize the possibility of any psychological harm. No embarrassing questions will be asked neither will the researcher express shock or disgust on any of the responses given.

Voluntarism

Your participation in this study will be on a voluntary basis. You are free to skip any question you feel uneasy to respond to. You are also free to withdraw your participation at any given time. Your participation or lack of participation in the study will not in any way affect the care and treatment of your patient.

Confidentiality

Pseudonyms will be used to keep the identity of the informants private. The study will ensure the confidentiality and privacy of study participants by keeping any information shared between the researcher and the study participants confidential.

The information will be taken in great confidence and only used for this research. The recommendations will be availed to the KNH and Nairobi Hospice to ensure better

service delivery to the cervical cancer patients. People who have informed the study will be acknowledged in the study findings.

Contacts:

In case of any questions you can contact;

Ethical Review Committee, KNH. Hospital Rd, along Ngong road

P.O.Box 20723, Nairobi.

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Supervisor: Prof. Isaac K. Nyamongo

Email: inyamongo@uonbi.ac.ke

Researcher: Mariah Ngutu Peter

Email: mariahngutu@gmail.com

Phone no.: 0723 839 619

The results from the study will be used to obtain a Masters of Arts degree in Anthropology from the University of Nairobi. The findings will also be used to make recommendations aimed at improving treatment and care offered to cervical cancer patients countrywide. The recommendations will be available for KNH and Nairobi Hospice to improve palliative care targeting cervical cancer patients.

Do you have any questions? Thank you”

DECLARATION:

RESEARCHER

I Mariah Ngutu Peter, declare that I have given full information regarding this study to before seeking verbal and written consent.

Date:

Signature:

STUDY PARTICIPANT

Ihave been fully informed of this study and have agreed to be a study participant out of my own free will. I therefore give my verbal and written consent. I am (Name of Cervical cancer patient's) care giver.

Date:

Signature: