EFFECTS OF CHRONIC DEBILITATING DISEASES ON LIVELIHOODS AND COPING STRATEGIES: A CASE OF WORKING-AGE CANCER PATIENTS AT KENYATTA NATIONAL HOSPITAL.

BY

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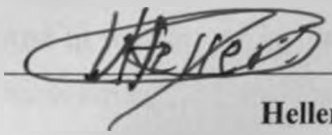
DECLARATION

I do hereby declare that, this project paper is my own original work and has not been presented either wholly or in part for a degree in any other University.



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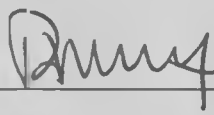
This project paper has been submitted for examination with my approval as University supervisor.



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DEDICATION

This project paper is dedicated to my beloved husband Jared Maaka for his never ending support and encouragement. Thank you so much. To my three daughters Mosaisi. Bonareri and Bisieri. You gave me humble time during my study period. May you grow up with passion and desire for knowledge and pursue it to the highest level. And in memory of my late father Francis Wabomba, 'for the foundation he laid still holds strong'.

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ABBREVIATIONS

CTC	Cancer Treatment Centre
ERC	Ethics and Review Committee
IAEA	International Atomic Energy Agency
KNH	Kenyatta National Hospital
KEMRI	Kenya Medical Research Institute
MOPH	Ministry of Public Health
NCDs	Non-communicable Diseases
MOMS	Ministry of Medical Services
NCI	National Cancer Institute
NCR	Nairobi Cancer Registry
NHIF	National Health Insurance Fund
WHO	World Health Organization

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ABSTRACT

Cancer is the leading cause of death in economically developed countries and the second leading cause of death in developing countries. It has increasingly becoming an important cause of morbidity and mortality in all regions of the world as it has been found to cause more deaths than TB, malaria and HIV/AIDS combined. In 2000, cancer was responsible for 12 per cent of the 56 million deaths from all causes worldwide. In 2008, there was an estimate of 12.7 million new cases of cancer around the world of which 56 per cent were in the developing world. It was also reported that there were 7.6 million deaths from cancer in same year out of which 64 per cent occurred in the developing world. Assuming the underlying rates of cancer will remain unaltered, over the next two decades it is projected that by 2030, there will be almost 21.4 million new cancer cases diagnosed annually and there will be over 13.2 million deaths from cancer. In Africa, the cancer situation is alarming yet the general population have little or no information on cancer prevention and treatment options. Access to diagnostic and treatment facilities is hard and not affordable for a large part of the African population. In the context of competing priorities, limited resources and inadequately developed health care systems, countries in Africa face the harsh reality of cancer. The research was designed to examine the effects of chronic debilitating diseases on livelihoods and coping strategies.

The objectives of this study were: (i) To examine the effects of cancer in labour force participation; (ii) To examine the effects of cancer on other livelihoods; (iii) To find out strategies patient use to cope with cancer related effects.

The study used both primary and secondary data. In collecting primary data, both quantitative and qualitative methods of data collection were used. A total of 85 cancer patients within the working age bracket were purposefully selected for questionnaire survey. Also a total of 15 In-depth interviews were conducted with 15 purposefully selected cancer patients within the working age bracket. In addition, a total 5 Key informant interviews were conducted with cancer health care providers at the Cancer Treatment Centre in the Kenyatta National Hospital.

The study findings revealed that the effects of cancer on labour force participation and livelihoods are felt both by the cancer patients and their households. The disease affected negatively the labour force participation of the patients as well as the participation of other members of the household. Further, the disease greatly affected the livelihoods of the patients and those of their households through reduced earning, loss of income, reduced cultivation and use of household savings in seeking cancer care and treatment. Cancer patients were found to employ certain coping strategies in effort to mitigate cancer related effects on their livelihoods like sale of family assets, borrowing, asking for assistance from friends and relatives. Whereas these strategies help them in the first instances, they later serve to deplete the resource base of affected households and contributed to their impoverishment through asset loss.

The study concluded that Cancer contributes to household impoverishment by negatively affecting the labour force participation of the affected people. It also negatively affected the resource base and livelihood assets of affected households through assets disposal. Cancer affects health, income, education, family relations and social roles. It is a socio-economic development issue that if not adequately tackled can lead to increased vulnerability to affected households and their eventual impoverishment. Cancer is an issue that warrants special attention because of its major implication to households and the society at large.

CHAPTER ONE
INTRODUCTION AND BACKGROUND TO THE STUDY

1.0 Introduction

For many years, chronic non communicable diseases, also known as degenerative diseases were seen as diseases of the elderly in the developed world (Feachman et al, 1992). This was because it was thought to affect the wealthy and the old in the western world. Due to this believe countries in the developing world focused more on infectious diseases which were thought to affect them more and ignored chronic non-communicable diseases.

However, it's indicated that, this is not the picture of world health (Eckholm, 1977; Feachem *et al*, 1992; Gray, 1993). Chronic non communicable diseases like cardiovascular diseases, diabetes, respiratory diseases and cancer were found to be affecting people in the developing regions of the world much as it is affecting the developed world, (World Health Report 2005).

Low and middle income countries are undergoing what has been termed as epidemiological shift in which, acute infectious diseases are being replaced as dominant causes of morbidity and mortality by chronic diseases like cancer, diabetes, respiratory and cardiovascular diseases (King, 2009). An epidemic of chronic non-communicable diseases is growing in Africa, a continent that is still struggling with infectious and nutritional diseases, (Holmes and Dalai 2009). Several factors have been associated with this and they include unhealthy lifestyles that are becoming more common with a shift from agrarian to urban living, people switching from eating fresh to processes foods, replacing physical labour with sedentary habits and breath more polluted air, (WHO Report 2011). Cancer has been one of the mostly reported diseases emerging.

This project report presents the findings of a study that was undertaken to examine the effects of cancer, chronic non-communicable disease on the livelihoods and coping

strategies using the case of working-age cancer patients at the Kenyatta National Hospital. The project report is structured into six chapters. Chapter one gives a background of the trends of the emerging burden of cancer. It particularly presents a Statement of the Problem, Study Questions, Objectives and Justification of the study. Chapter two presents a review of existing literature and the conceptual framework that guided the analysis of the study findings. In literature review, the search for literature was done around research questions and considering several livelihood activities. Chapter three presents the methodology that was followed in this study. In brief, it describes the study design, site where the study was done, sampling procedures, and data collection methods and how the collected data was analysed. It also presents ethical considerations that were followed in carrying out this study and the challenges that were faced during data collection. Chapter four presents the socio-demographic characteristic of respondents who participated in this study and findings on the effects of cancer on labour participation and livelihoods. Chapter five presents the findings on the strategies patients use to cope with cancer related effects on their livelihoods and the last chapter six presents a summary of the study findings draws conclusions and makes recommendations based on the study findings.

1.1 Background of the Study

Cancer is a collective term used to refer to malignant tumours. The disease results from malignant transformation of normal cells causing them to enlarge and divide more rapidly without control than the normal cells. These abnormal cells then may spread to other parts of the body invading other tissues (WHO, 2005).

Cancer presents itself in different types. The type of cancer is usually named depending on the part of the body from which the cancer cells originate. For example prostate cancer originates from prostate glands whereas breast cancer originates from the breast muscles. Other types like neck cancer, blood cancer, skin cancer, brain cancer have their origin as their names suggest, (Springhouse, 2005).

Regarded as a disease for the elderly, studies done in developed countries have revealed otherwise. Cancer is affecting people in the developing countries much as it is affecting people in the developed countries. And that almost more than a half of people diagnosed of cancer are under the age of 65 years, (Short et al., 2005). Therefore it is not a disease for only the elderly and the wealthy as regarded earlier. In fact, according to WHO cancer is a major public health issue worldwide (WHO, 2005).

Cancer is the leading cause of death in economically developed countries and the second leading cause of death in developing countries (WHO, 2008). According to the global status report on non-communicable diseases, cancer has increasingly becoming an important cause of morbidity and mortality in all regions of the world. In fact, worldwide, cancer has been found to cause more deaths than TB, malaria and HIV/AIDS combined, (Barron, 2008, Toumi, 2010, WHO, 2010). For instance, in 2000, cancer was responsible for 12 per cent of the 56 million deaths from all causes worldwide, (WHO, 2010).

The International Agency for Research on Cancer and WHO reports that annual cases of cancer were expected to rise from 11 million to 16 million by 2020 (WHO, 2010). In 2008, there was an estimate of 12.7 million new cases of cancer around the world of which 56 per cent were in the developing world. According to Globocan 7.6 million deaths from cancer in 2008 and out of these 64 per cent occurred in the developing world, (Globocan, 2008).

Assuming the underlying rates of cancer will remain unaltered, over the next two decades it is projected that by 2030, there will be almost 21.4 million new cancer cases diagnosed annually and there will be over 13.2 million deaths from cancer (WHO, 2008). The most diagnosed cancers worldwide are lung 1.61 million which is 12.7 per cent of the total, breast 1.38 million which is 10.9 per cent and colorectal cancer 1.23 million which translates to 9.7 per cent. Also reports have indicated that African females are mostly affected by cervical and breast cancer while the males suffer from

Kaposi Sarcoma, liver, prostate, stomach, lung, oesophagus and bladder cancer (Globocan, 2008).

It was also reported that over 70 per cent of cancer related deaths occur in the developing countries (Toumi, 2010). The WHO argues that, burden of cancer is increasing in developing countries as a result of population aging and growth as well as increased adoption of cancer associated lifestyle choices including smoking, physical inactivity and westernized diets (WHO, 2011).

In Africa, the cancer situation is alarming yet the general population have little or no information on cancer prevention and treatment options. Access to diagnostic and treatment facilities is hard and not affordable for a large part of the African population. In the context of competing priorities, limited resources and inadequately developed health care systems, countries in Africa face the harsh reality of cancer. In view of the ever increasing cancer incidence trends, the disease is becoming an emerging public health issue (WHO, 2005).

In Kenya cases of cancer are on the rise, (Musibi, 2008; Karambu, 2010 and Neondo, 2010 MOPHS and MOMS, 2012). According to Pact Kenya Cancer Assessment in Africa and Asia about 80,000 cancer cases are diagnosed each year. In 2005, cancer was estimated to have killed 18,000 people in Kenya and many of these people diagnosed were under the age of 70 years, (MOPH & MOMS, 2010). These occurrence rates have increased and according to the National Cancer Control Strategy, there were 28,000 cancer cases that were diagnosed in the country and 22,000 deaths from cancer last year (MOPHS and MOMS, 2012).

Considering the high incidence rates of the disease in the developing regions of the world in which Kenya is included, it can no longer be ignored. Although the socio-economic effects of cancer in resource constrained countries can be difficult to estimate due to lack of country specific data, it can be agreed that it would be even disastrous to

add another burden of cancer on the economies of countries that are already crippled with the burden of infectious diseases.

Given that cancer is also affecting people of working-age, who are central to labour participation and bedrock of livelihoods the it can be said to have great socio-economic effects to those affected for instance due to premature deaths or disability. Despite these facts, the country does not have much documentation on socio-economic effects of cancer as it has on other diseases like HIV/AIDS and Malaria. It is against this background that this study was designed to explore the effects of cancer on livelihoods of the affected people to find out the strategies that affected people use to cape with these cancer related effects.

1.2 Statement of the Problem

In Kenya cancer is rapidly becoming a major epidemic often leading to death. The disease ranks third as a cause of death in the country after infectious and cardiovascular diseases. Data availability is scanty and is mainly hospital based. Therefore the true burden is unclear. A policy brief on the situational analysis of cancer in Kenya done in 2011 cites inadequate facilities, few specialists, high cost of treatment, lack of access to treatment, sedentary lifestyle, lack of cancer awareness, social inequity and unreliable cancer registry as the factors that were backtracking the fight against cancer in Kenya (GOK, 2010)

The cancer situation in the country is dire with more than 60 per cent of those diagnosed being under the age of 70 years. This constitutes a part of the population that should be actively participating in the labour force, (MOPHS and MOMS, 2011). Given this situation, it can therefore be argued that cancer is affecting peoples' labour participation and eventually affecting their overall livelihoods.

The country has been lacking a national cancer registry and as a result, there has not been the exact data on the number of people affected by cancer. The figures that have often been quoted have been estimates arrived at by the Nairobi Cancer Registry

(NCR) which is run by Kenya Medical Research Institute, (Karambu, 2010). According to Kenya Medical Research Institute Report (2008), the data on cancer that was available was scanty and only dated back to 2000. Although AMPATH - Oncology at Moi Teaching and Referral Hospital in Eldoret complemented the Nairobi Cancer Registry, the two cancer registries could not collect national wide data due to lack of country wide network for data collection.

The assenting to the Cancer control bill into law on 27th July 2012 was a major step towards collecting more data on cancer incidences in the country. The law, among other things, provided for the establishment of a National Cancer Institute (NCI). It also gave direction to all health care facilities to be depositing information on any cancer case diagnosed within 14 days to the National Cancer Institute. However, this is yet to take effect and this recent positive step in the fight against the emerging cancer pandemic also faces major challenges; for instance some patients may be misdiagnosed at mostly ill equipped health posts in the country to deal with cancer prevention and treatment. Other patients may remain at home without visiting health facilities. Because of these limitations, it is likely that the cancer burden in the country will remain underestimated due to hitherto lack of reliable statistical data.

Further, most healthy facilities in the country are not adequately equipped to deal with the burden of cancer. Currently, Kenyatta National hospital is the only National Public Referral Hospital that offers holistic cancer treatment. However, this facility is also not adequately equipped in terms of equipment and personnel. For instance, only two Radiation therapy machines are available but one is not very reliable as it often breaks down. Because of the unreliable machine and the increased number of patients, the waiting line is very long leading to belated treatment.

Moreover, the population in Kenya has not yet embraced the National health Insurance Fund (NHIF) whose policy is to subsidise the cost of health care through cost sharing. NHIF is only held by 2.7 million Kenyans which are less than 10 per cent of the total population. Given that the treatment of cancer is high (Global Medicine Report, 2011)

and there already exists socio-economic inequalities, bearing the cost alone becomes so expensive beyond the reach of many Kenyans who are already resource constrained making them not to seek help until it is very late when the treatment options are limited and not curative.

The impact of cancer is far reaching. In addition to the pain and suffering that cancer can cause to its patients, it also brings social and economic consequences. Other than increasing the demand on health care, it hampers the ability of an individual to generate income especially through increased absenteeism from work or by ultimately impeding peoples to work (Rocco et al, 2011). Further, the effects of cancer can cause distress to the family by affecting their social lives and livelihoods.

As such if cancer reduces employment and labour supply, it would cause an efficiency loss to the economy as a whole because the endowment of labour is not fully used. This could contribute to keeping the county's economy below its production frontier. If it hinders people from supplying labour to the economy, then it denies them or reduces their income level and this has implications to their livelihoods.

A review of available literature indicate that, studies that have been done are largely biomedical and have focused on the probability and timeliness return to work rather than identifying how the experience of cancer affects participation in labour and livelihood of affected patients. Further, most of the studies have been done in the developed countries, (Spelten, 2002; A de Boer 2008). However, in developing countries like Kenya, cancer occurs in a totally different social economic setting and yet there has not been adequate documentation on these effects. The aim of this study is to examine the effects of cancer on livelihoods of affected individuals and to find out the coping strategies that these people use. The study was done among patients of working-age at the Cancer Treatment Centre in the Kenyatta National Hospital.

1.3 Study Questions.

1.3 .1 Broad Question

The broad question that the study intends to answer is:

What are the effects of cancer on livelihoods and what are the coping strategies that patients use to cope with cancer related effects?

1.3.2 Specific study questions

In order to arrive at an answer to the broad question, the following specific questions were used.

1) What are the effects of cancer on the patient's labour participation?
2) What are the effects of cancer on the patients' other livelihoods?
3) What strategies do patients use to cope with cancer related effects?

1.4 Objectives

1.4.1 Overall objective

The overall objective of this study was to examine the effects of cancer on livelihoods and to find out coping strategies that the affected use using a case of working age patients at the Kenyatta National Hospital, Cancer Treatment Centre in Kenya.

1.4.2 Specific objective

1) To examine the effects of cancer on patients' labour participation.
2) To examine the effects of cancer on the patients' other livelihoods.
3) To explore the strategies used by patients to cope with cancer related effects.

1.5 Study Rationale

This study was justified on the basis of the following four reasons

First, for a long time the country Kenya has not been having a national cancer control law or policy; but now several efforts have been made within the country in the past decade to tackle the emerging cancer epidemic. These include most recently the enactment of a law in July 2012 that establishes the National Cancer Institute - a body which would deal with prevention, treatment and control of cancer. Despite these

efforts the goal of a nationwide, affordable, and sustainable program to control cervical cancer has yet to be achieved. This study intent to provide evidence based data that will help inform the ongoing process.

Second, countries in the developing world, including Kenya are experiencing an epidemiological shift from infectious diseases to chronic non-communicable diseases (NCDs). Due to this shift, there is a paucity of literature on the emerging socio-economic effects of these emerging diseases (diabetes, heart diseases, respiratory disease, and cancer). This study hopes to contribute to furtherance of knowledge on the social economic effects of chronic non-communicable diseases and in particular cancer.

Third, whereas the health burden caused by cancer is apparent and there is also adequate biomedical literature on cancer and its effects on the health status of a person, literature on non-health effects of cancer on patients' livelihoods has not been adequately documented. And, since the disease also affects people of working age - who are central to livelihoods and critical to social and economic stability households and the country, there is need for the documentation of non- health effects of cancer on patients and their households. This study seeks to provide evidence based information on the social and economic effects of cancer as reported by affected working age patients particularly on labour participation, livelihood and how the patients are coping with cancer related effects.

Finally, the relationship between health and development has been well documented, (World Bank 1993; Bhargava, 2001; Julio, 2004). Better health is central to human happiness and well-being and therefore makes contribution to economic development. By focusing on the effects of cancer, an obvious shock on the health endowment of human capital, the study will bring into perspective the complex relationship between health and development. Indeed, the study hopes to contribute to a better understanding of how poor health as a result of cancer can lead to increased vulnerability of patients' livelihoods and how this can drive the affected patients into poverty. These will help

inform the government and other stake holders on the importance of investing in the health sector, particularly in the prevention, control and treatment of emerging health threats like cancer for the purpose of economic development and poverty reduction.

CHAPTER TWO

LITERATURE REVIEW AND CONCEPTUAL FRAMEWORK

2.0 Introduction

This chapter contains a review of available literature. The chapter has been divided into two parts. The first part reviews literature on the effect of chronic disease on livelihoods and coping strategies and the literatures are organized around the study question. The second part of the chapter gives the conceptual framework that guided the study.

2.1 Effects of ill health on labour force participation

Although health is an important aspect of human capital (Mukere, 2006), it is rarely considered a contribution to labour quality. Labour quality is mostly identified narrowly and only with education and yet the health status of an individual affects labour participation.

The relationship between health status and employment may seem obvious, however unveiling causes and effects is complicated and ambiguous, (Barnay and Debrand, 2006). The effects seem to counteract each other such that on one hand working conditions may reduce health status and on the other poor health may result in departure from the labour market.

Gibbon observes that the health status of a population has a bearing on the success or failure of a country in providing for the most basic needs of its people, supply and productivity of adults in the labour force and enrolment and performance of children in schools. He argues that a health population is capable of actively participating in economic, social and political development and thus a great asset of the nation. (Gibbon, 1993)

Health status is therefore a crucial determinant of labour market decisions. Healthier works on the other hand are physically and mentally energetic; they are more productive and earn higher wages. Although it is argued that health may not be a sole determinant of people's work behaviour it however has some influence. Poor health is associated with reduced hours of work, lower wage rates, early retirement and disability (Mitchel, 1990).

Although Brandley and Bednark (2002) indicated that cancer patients are productive and perform well at the workplace, cancer has been found to have effects on people's decision concerning work. In her 2005 study among women with breast cancer patients, Brandley argues that a negative health shock decreases labour supply in women with breast cancer and in fact women with breast cancer were less likely to work 6 months after diagnosis (Brandley, 2005).
In another study of employment and cancer, Brandley et al, (2007) found the greatest reduction in labour supply 6 months following diagnosis and although at 12 and 18 months survivors were found return to work. (Spelten et al 2002) suggests that some cancer patients find it difficult to return to work after cancer treatment. In whichever the case, cancer will have affected patient's participation in the labour force.

Ill health may affect labour participation through absenteeism and presenteeism. Health people are less likely to be absent from work because of ill health or illness of their families (WHO, 1999). Cancer patient usually need time off to attend treatment sessions and this may affect labour force participation such that unless patients get jobs that are flexible enough to accommodate their health status they may quite work, (Kennedy, et al, 2007).

Unlike absenteeism where labour participation is directly affected by the number of hours and days lost, presenteeism involves being present at work but not performing up as expected due to illness. Cancer patients may have reduced capacity to perform at work (Gudbergsson et al, 2006) and therefore their participation may have a reduced productivity for example, when they have cancer related fatigue (Feuerstein et al,

2007), they may do work cut backs (Kessley et al, 2001. Henry et al, 2008) or even change their job role to less demanding ones, (Steiner et al, 2008).

The effects of cancer of labour force participation also depend on the type of work patients are involved into. In doing studies on the factors determining cancer patients decision concerning labour force participation. Kennedy, (2007), Taskila, (2007) and Hoffman. (2007) argues that whether the cancer survivor will continue to work during treatment. return to work after treatment or their ability to work will be limited depends on: cancer site. type of treatment. health status, education and physical workload.

Different types of cancer have been found to affect patients differently. In a study of men with testicular cancer, physical and mental impairment at work were least reported compared to those with prostate, lymphoma and breast cancer, (Taskila, 2007). In another study by De Boer, patients with leukaemia were found to have the lowest score in work ability compared to those with breast. cervical or gastrointestinal cancers, (De Boer, 2008).

Yet in another study, (Yabroff et al. 2004) found that patients with lung and gastrointestinal cancer reported most limitations at work when compared with those of breast, prostate or colorectal cancer. (Brandley et al, 2007) in a comparative study of men with prostate cancer and women with breast cancer, found out that those with breast cancer report difficulties in both mentally and physically demanding jobs. On the other hand men with prostate cancer mostly report difficulties in physically demanding work. All this studies have no consistence in their findings.

Studies have shown that, patients with a recent history of breast cancer, (Maunsell et al 2004, Brandley et al, 2007), brain cancer (Feuerstein et al, 2007), stomach cancer (Lee et al, 2008) prostate. colorectal, testicular and other cancers either report lower work productivity, impaired physical and mental work ability or reduced working hours.
However, (Taskila, 2007) found that there were no differences in work ability between those with cancer (breast, lymphoma, prostate and testicular) and those without the

history of cancer for both sexes. Brandley et a,l 2007 also did not find differences in working hours between those diagnosed with prostate cancer 6 months post- diagnosis and the comparison group of those without cancer.

The type of treatment one uses also has been found to have an effect. Chemotherapy for example, is a type of treatment that has been found to have strong association with work ability. (Taskila, 2007, De Boer, 2008, Henry et al, 2008, Steiner, 2008) suggests that treatment with chemotherapy is linked to poor work ability regardless of the type of cancer in those patients working during or following treatment.

The type of work an individual is involved in has power to influence the direction of how cancer affects labour participation. This is because of activity restriction and the disabling nature of cancer and other chronic diseases (Marks et al,.....). High labour intensive occupations are likely to lead to those with cancer to leave the work force. Brandley, at al, 2005 argues that some patients reported that cancer and its treatment interfered with their ability to perform physical and cognitive tasks at work 12 months after diagnosis.

Workers with well developed and portable skills may move into other jobs that accommodate their health status more easily than those with job specific skills. As argued by Grandy and Hayward (1986) for the same level of disability those with less skilled occupation show a greater rate of departure from the labour force as do those more physically demanding occupations.

Although Hoffman, (2005) study indicated that cancer survivors face few barriers to employment opportunities, Corotty et al, 2002 states that there is growing evidence that individuals with chronic conditions have difficulties in securing employment and are more likely to drop out of the labour force.

Literature available indicates that indeed cancer has effects on labour force participation. However, this literature is biomedical, presenting the effect of cancer on

employment from a medical perspective. Moreover the literatures are mostly from developed western countries with well developed insurance cover, better cancer detection strategies and modern treatment technology. Cancer in the developing countries like Kenya, do occur in socio-economically and policy different settings. There is no established insurance cover for people with cancer or any other disability and the socio-economic conditions are hostile to many people especially the poor.

The cancer treatment infrastructure in Kenya is inadequate and some cancer management options are not readily available and therefore people diagnosed with cancer may not survive long enough to recover. With this reality, one would expect differences on how cancer is impacting on labour force participation and these differences are what the study sought to find out.

2.2 The effect of ill health on other livelihoods

Livelihoods entail capabilities, assets and activities which are required for earning a means of living. The sustainable livelihoods framework posits that, there are five sets of livelihood assets- financial, physical, social, human and natural, (DFID/FAO, 2000; Neefje, 2000). Each of these assets is demonstrated to be impacted on, by ill health leading to their reduction.

The impact of ill health on human capital is identified as central to any effort to measure effects of an epidemic because, decline in human capital flows through the other assets. Deterioration in a person's health manifest in increased weakness often due to poor nutrition but also stress and disability and in the worst case death; which is the ultimate destruction of human capabilities. Disabling illness can be severe. However, Kyengombe, (2003) argues that it will depend on the nature of disability and whether its effects are temporary or permanent.

Disease or illness usually cause decline in livelihood assets. In the case of financial assets for example, income may be reduced due to the reduced participation in the labour force and other income generating activities, affecting individual's income

stability. When the financial assets are not enough to meet all the needs it is supposed to, an individual or a household run the risk of increased vulnerability to impoverishment.

In doing a research on the impact of HIV/AIDS on livelihood strategies (Cohen, 1993, Ragulema, 1999, HSRC 2001) argued that, the disease first affects individuals through illness and may be death. This in turn leads to diversion of resources from savings and investment into care. In another study, LoveLife, (2000) argues that one's a person develop AIDS, increases medical and other costs such as transport to and from the health facility occur simultaneously with reduced capacity to work creating a double economic burden to the person and the affected household.

Illness has also effects on the physical capitals. Health shock often requires individuals and household to diversify their physical assets, tools, equipment and other procession may be sold in times of dire need. Sometimes household goods are sold and resources redirected to meeting short term consumption or survival needs to the detriment of long term investment. This affects the future sustainability. In studies by Cohen, (1997) and Ayieko, (1998) it has been argued that households with AIDS suffer frequently seek to keep up with medical cost by selling livestock and other assets including land. Even if land is not sold off it may remain underutilized due weakened capacity to farm because of lack of finance and reduced labour force.

The effects of ill health on social assets cannot be overlooked. Social assets entail the social resources upon which people draw in pursuit of livelihood objectives. They include networks, membership of groups and relationships of trust, (Neefjes, 2000). Studies by Baier (1997) and Cohen (1998) draw attention to the manner in which HIV/AIDS can cause social exclusion and diminish the ability to cope with further crises. In Aliber (2001), Halkett argues that sometimes extended family network can collapse due to pressure of having to support orphaned children. While Marcus (2000) argues that HIV/AIDS has forced a change in household composition and weaken or break the youth adult's nexus between generations. This in turn exacerbates an already

existing social crisis of care especially of children and the aged causing social destitution. These findings are related to HIV and where as it is a chronic disease it is communicable. There still remains a gap in understanding the effects of cancer on the social livelihood assets.

2.3 Effects of ill health on agricultural livelihood

Even in the 21st century, agriculture remains fundamental to many economies. It is the backbone of Kenya's economy as many people depend on it for as their primary source of livelihood. It provides a chance for people to participate in the labour force, provide income and also provides food for both subsistence and for the market.

Asenso-Okyero et al, (2011), argued that in agricultural systems, the effects of ill health on farming households can be put in three categories; absenteeism from work due to morbidity and eventual mortality, family time is diverted to caring for the sick and loss of savings and assets in dealing with disease and its consequences, the long-term impact of ill health include loss of farming knowledge, reduction of land under cultivation, planting less labour intensive crops, reduction of crops planted and reduction of livestock. The ultimate impact of ill health is a decline in household income and possible food insecurity; this signifies a severe deterioration of household livelihoods.

Such findings were confirmed by Rugalema (1999) when he did a research in Tanzania. His arguments were argues that, illness affects time allocation and puts pressure on children to work so as to meet the living needs. However, studies of how ill health affects livelihoods have been done in the context of other disease like the HIV/AIDS pandemic. But how cancer affects livelihoods in the Kenyan situation has not been studies because cancer is just an emerging health threat in the country and this was one of the objectives that this study ventured to find out.

2.4 Strategies used in coping with the effects of ill health on livelihoods

Coping strategies are plans set out to successfully deal with a difficult situation. In the context of the proposed study it will be used to refer to ways and means that individuals resort to so at to regain, maintain or even surpass the initial livelihood condition prior to the incidence of a health shock.

People cope with illness in different ways. However, how they cope is influenced by the opportunities available to them, their capabilities and assets. Over time their assets may reduce and if individuals are unable to replace their asset base, they become vulnerable and may be forced to rely on insecure or harmful strategies.

Pryer, et al, (2003) identified some strategies which include; borrowing money, followed by diversification of income sources, women going to work, reducing expenditure, using savings, selling of assets, merging households, moving families to rural areas and finally begging.

Although these strategies are meant to help cope with the health shock they are self-exploitative and often result in further erosion of income security. Borrowing money for example has been found to be the first strategy individuals turn to in the face of hard economic times and agent medical bills (Pryer, 2003) when the income they get is not enough. Borrowing money especially for subsistence can seem a viable short term solution but in the long run it is not sustainable as they cause deepening and bad debts.

Other than depending on income which may not be enough or borrowing money, some individuals or households resort to diversification or changing livelihood strategies to meet the extra cost. Other times involving other family members such as children or older people who were not previously economically active. Rugalema, (1999) reports intensive use of child labour as a major strategy used by afflicted households during HIV/AIDS care provision.

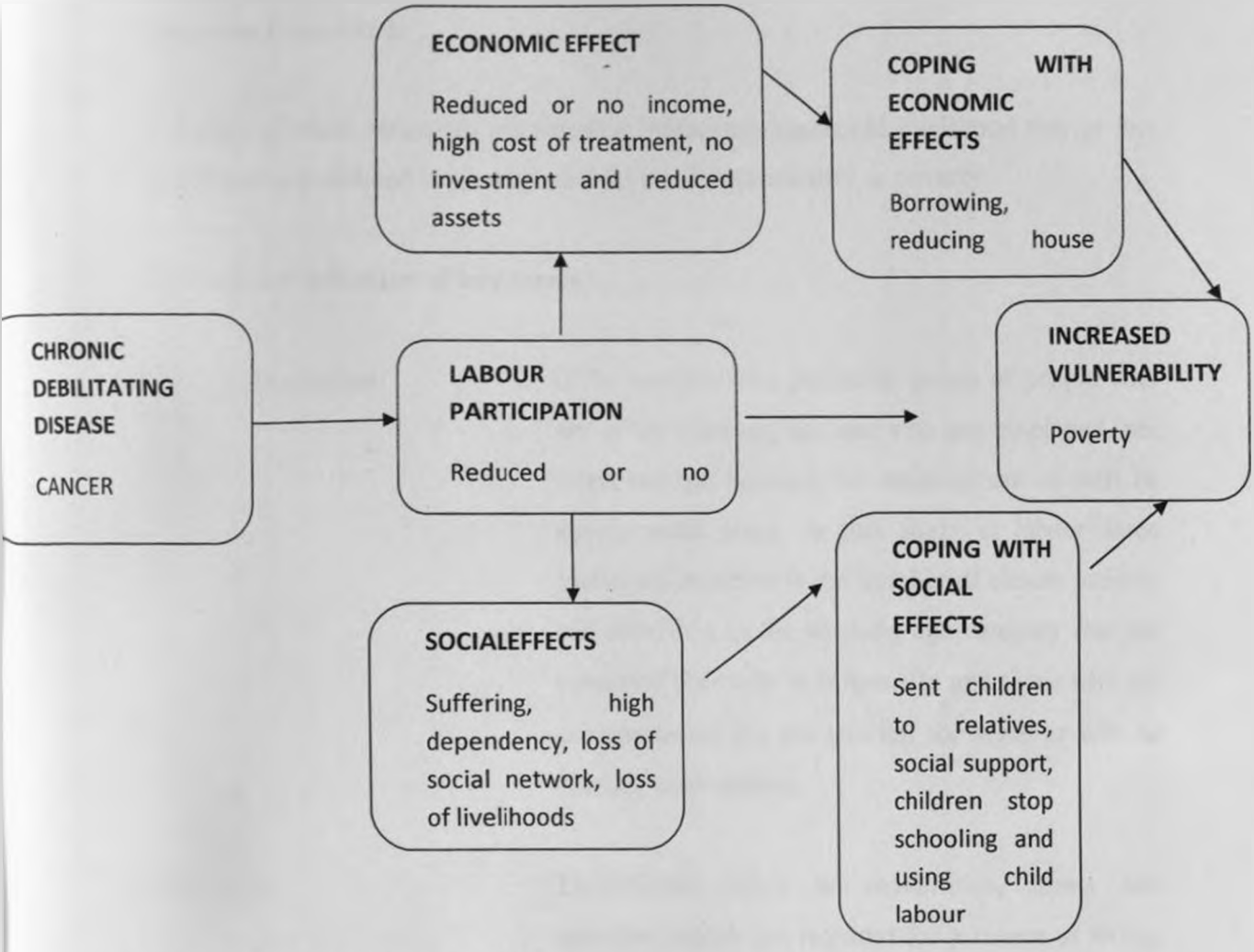
Children may also be taken out of school to fill the labour and income gaps when productive adults become ill and fail to participate in income generating activities. However in Kyengombe (2003), Pryer, (1993), Kabir, (1998) and Goudge and Gouender, (2000) argue that when children are taken out of school to participate in labour and help to meet consumption needs it contribute to poverty being transmitted across generations affecting the long term productivity and earning potential of those children. This study therefore seeks to find out the strategies that cancer patients to cope with cancer in relation to its effects on their livelihoods and to establish is it will corroborate with findings from other studies.

2.5 Conceptual framework

This study sought to examine the relationship between suffering from cancer and participation in livelihood activities. According to Mugenda (2008) a conceptual framework gives a set of lenses through which a researcher vies the problem. In this study, a conceptual framework is used to explain the relationship between ill health (suffering from cancer), livelihood activities (labour force participation) and coping strategies. Specifically, the study focuses on the effects of cancer on participation in the labour force, participation in other livelihood activities and strategies that affected individuals use cope with these cancer related effects.

The dependent variable in this study is suffering from cancer and the dependent variables are participation in livelihood activities and coping strategies. the hypothesis of the study is that suffering from cancer affects participation in labour and other livelihood activities and that coping strategies must be adopted to cope with these cancer related effects. The conceptual framework is explained in figure 1

Figure 1: Diagrammatic Representation of Conceptual Framework



Source: Researchers own modelling

From figure 1, it is suggested that cancer creates a vulnerability context that result in reduced or lack of participation in the labour force. This reduced or lack of participation in the labour force has both economic and social implications. Economically it will lead to reduced or lack of income, high cost of treatment, reduced assets, and lack of savings and use of savings. Socially, it will lead increased dependency, change in household functioning, loss of human capital and loss of social network. In the face of both social and economic consequences, patients resort to

certain coping strategies; selling some of their assets, borrowing money, asking for assistance, stopping children from schooling and using them to generate income and meet their living needs.

Although all these strategies are aimed at improving household livelihood they in fact contribute to livelihood insecurity and increased vulnerability to poverty.

Operational definition of key terms

Labour participation: Is the number of a particular group of people who are of the working age and who are employed, not employed but looking for employment or will be stating work soon. In this study is labour force participation refers to the number of cancer patients and survivors in the working age category that are employed formally or informally and those who are not employed but are looking for work or will be starting work shortly.

Livelihoods: Livelihoods refers to capabilities, assets and activities which are required for a means of living, livelihoods have also been defined as ways through which people earn their living. In the context of this study livelihoods' is taken to mean all those activities that cancer patients and members of their household are or used to engage in. either these activities helped them get food or extra money as earnings.

Coping strategies: These are sets of actions that aim to manage the cost of an event that threatens the welfare of individuals

or households. In the context of the proposed study coping strategies describe activities and behaviour that cancer patients and their households engage in to mobilize resources and which help them deal with how cancer has affected their livelihoods.

Working age cancer patients: This is the age group of people considered adults and thus employable. For the purpose of this study 18-59 years is the working age range chosen because those who fall into this bracket should be vibrant and energetic thus actively participating in the labour force and constructing livelihoods.

CHAPTER THREE
RESEARCH METHODOLOGY

3.0 Introduction

The previous chapter presented empirical literature, theoretical framework and the conceptual framework for this study. It also gave operational definition of basic concepts for the study. This chapter presents a description of the study design, the site where the study was carried out, the study population and sampling, methods of data collection, data analysis and ethical considerations during the study. It also points out to the challenge that was experienced during field work.

3.1 Research Design

The study used a case study design and carried out a cross-sectional survey. It utilized mixed method approach - using both quantitative and qualitative techniques in data collection. It further drew data from both primary and secondary sources. Primary data was collected though survey questionnaire, in-depth interviews and key informant interviews.

3.2 Study Site

The study was carried out at the Kenyatta National Hospital, Cancer Treatment centre. The Cancer Treatment Centre (CTC) was formerly called Radiotherapy Department located in the Old Hospital. It is adjacent to the theatre department to the North and orthopaedic clinic to the South. It was started as a temporary unit on research project of particular types of tumours by the Karolinksa Institute of Stockholm, Sweden and was officially handed over in 1968 to the government of Kenya. Charged with the role of provision of high quality specialised therapeutic radiation and patients' management of all cancer cases referred from other health institutions, the cancer treatment centre offers services both to in-patient and out-patients.

The Cancer treatment centre at the Kenyatta National Hospital was suitable as a study site first because; it is a referral hospital that offers holistic cancer treatment in the

country. Apart from serving both the rural and urban population of Kenya, it also serves other East African countries. Secondly, since the centre receives patients from diverse backgrounds, using the site for the proposed study will therefore provide an opportunity to explore the various contexts in which cancer is experienced.

Finally, the Cancer Treatment Centre was also a suitable area for the study because of its nearness to town and its accessibility by road. It was therefore possible for the researcher to travel to and from the facility during the research period and was able to complete field work within the stipulated time and resources that were available at the time.

3.3 Study Population and Sampling Procedure

Because of lack of specific statistics on the number of working age cancer patients at the Kenyatta National Hospital and considering the fact that it is a referral hospital, this study adopted a non probability purposive sampling strategy. This strategy was adopted because it allowed the researcher to use cases that had required information with respect to the objectives of the study. Therefore all Patients within the age range 18-60 years who were being treated at the Cancer Treatment Centre at the Kenyatta National Hospital during the time of the study constituted the sampling frame. From these, a total of 100 participants, 85 for survey questionnaire and 15 for In-depth Interviews were purposively recruited for the study. The purposive selection was to ensure that only those meeting the selection criteria for participation were selected.

Further, 5 Key informant interviews were conducted. Key informants are taken as people who have expertise information on the issue under investigation. In this respect, 2 oncology Doctors and 3 Nurses at the Cancer Treatment Centre were selected to participate in the study because they are involved in treatment care and management of cancer cases. They were therefore seen as having rich information that would greatly contribute to better understanding of the effects of cancer on the patients. The criteria for selection of Key informants are described in the section of specific method of data collection.

3.4 Data Collection Methods

Data collection was carried out from 18 June to 6 July, 2012. The study utilized mixed methodology in data collection; quantitative and qualitative methods. This mixed method methods complemented each other and helped to minimise bias created by each method on its own. The quantitative method of data collection intended to establish prevalence trends of cancer whereas, the qualitative methods of data collection were meant to collect data that would explain the effects of cancer on patients' livelihoods in a more deeply and exhaustively from individual experience. The approach gave respondents an opportunity to state how the disease had affected them and impacted on their livelihoods. The methods of data collection that were used included: Questionnaire survey, In-depth interviews, Key informant interviews and Observational method.

3.4.1 Questionnaire Survey

Survey Questionnaires were used to collect descriptive and exploratory data. This method as used to obtain primary data from a total of 85 respondents using both structured and unstructured questions (appendix ii). Recruitment of these participants was based on the suitability of the selected respondent to respond to fit in the selection criteria.

The selection criteria for the 85 participants included;

1. Patients between 18 and 60 years (period considered as appropriate working age for most people)
2. Present at the Cancer Treatment Centre
3. Full ability to communicate in English or Kiswahili
4. At least 6 months after cancer diagnosis
5. Agree to participate in the study and sign a written consent form

The Questionnaire was administered to the respondents on a face to face format by the researcher. Information sought using this method included: the socio-demographic characteristics of the participants; whether had affected their wok activities or not;

whether they had stopped working because of cancer; whether cancer had affected their income and savings; whether cancer had affected their social lives and that of their children; how they were managing to raise money for treatment and whether they have sought for financial assistance from anywhere.

3.4.2 In-depth Interviews

The second method of collecting primary data was In-depth Interviews using an In-depth Interview guide (Appendix iii). A total of 15 In-depth interviews (6 men and 9 women) were conducted with purposefully selected cancer patients. The selection criteria for the In-depth interviews included the following;

1. Gender (6men and 9 women)
2. Age between 18 and 60 years
3. Time that has passed since cancer diagnosis (at least 1 year)
4. Could communicate in Kiswahili or English
5. Agree to participate in the study and sign a written consent form.

Information solicited from In-depth interviews included; socio-demographic characteristics of the participants, individual's lived experience with cancer, effects of cancer on labour participation, effects of cancer on livelihood activities and the strategies they have been using to cope with cancer related effects.

These in-depth interviews provided detailed exploration of individuals' own experience of the effects of cancer. These provided examples of case scenarios that best illustrated how cancer had affected the participants' participation in livelihood activities and how they were coping. During these in-depth interviews, note taking was done and some quotations were used in verbatim quoting during data analysis.

3.4.3 Key informants

Key informant interviews involved face to face interviews with people who have knowledge about the situation of cancer, cancer symptoms, its diagnosis, treatment, management and care. In this regard, a total of 5 key informant interviews were

conducted with oncology medical experts. They included 2 oncology doctors and 3 oncology nurses at the Cancer Treatment Centre at the Kenyatta National Hospital.

Selection criteria for the health care providers included:

1. Oncology doctor or nurse
2. Available for interview
3. Involved in cancer care and management

Information collected included: common cancers diagnosed and treated at the facility, information on how different types of cancer affect patients' participation in the labour force, information on the effect of cancer on patients' knowledge and skills, information on the extent to which the timing of diagnosis and the type of treatment affect patients' work activities and information on if cost of cancer treatment was of concern. Key informant interviews were guided by key informant interview guide (Appendix iv).

3.4.4 Observation

Observation was another method of data collection that was used during this study. According to Babbie, (2000) Observation means watching and recording phenomena as they occur in nature with regard to cause and effect or mutual relation. Although this method had not been included in the original study protocol and the Observation checklist had not been developed, the principal researcher found it useful during field work especially in observing the deteriorated physical health of some of the study participants. The method was therefore included it in the data collection methods and during which field work observation note were taken and used during data analysis to complement In-depth interviews.

3.5 Secondary Data

Secondary was used to provide background information to the study focusing on cancer cases. The data was obtained from both published and unpublished materials including; relevant books, journals, papers and magazines. Also search on the internet was done to supplement existing information.

3.6 Data Analysis

Quality control measures were put in place to ensure that quality information was collected. The investigator for this study was charged with the overall day to day running of the study protocol and was supervised by two qualified social science researchers from the Institute for Development Studies, University of Nairobi.

Qualitative research allows the researcher to collect the first data and start analyzing them at the same time. It also allows them an opportunity to reformulate and modify the data collection protocol. Whereas this procedure was followed, the actual process of cleaning and analyzing data was done after the completion of the field work. Since qualitative methods of data collection yield masses of data, various qualitative findings from In-depth Interviews and Key-Informant Interviews were analyses thematically in relation to the study objectives and research questions. This was done by creating key themes around study objectives. The key themes that guided the analysis were; the effects of cancer on labour participation, the effects of cancer on livelihoods and strategies used by patients to cope with cancer related effects. Also during analysis, some quotations were extracted and presented in verbatim form as stated by study participants.

Quantitative data obtained from the study questionnaire was analyzed using statistical package for social science (SPSS). The data was then presented in the form of frequency distribution tables, charts and graphs which represent the most elementary way of summarizing and displaying data.

3.7 Ethical Considerations

The research involved human beings as study subjects. Despite this, the study did not present any physical dangers to the participants as neither was it a medical study nor did it include any interventions. However, ethical procedures in social science research were followed in order not to inflict pain of any form to study participants.

Potential issues expected included; psychological distress from talking about the disease. If this was to happen, the researcher was record such cases and report to medical officer immediately, however there was no such incident of psychological distress.

The participants were informed of the objectives and aim of the study. Their consent was sought for participation. They were also informed that they had a right to opt out even in the middle of the study and how their participation to the end was going to be appreciated. Consent for every interview conducted was also asked before note taking on the conversations was done during interviews. The respondents were assured that the note taken were going to be kept safely or destroyed after writing the final report of the research and that their names were not going to be included in the study's final report. They were therefore asked to sign a written consent form for accepting to participate in the study.

Confidentiality was assured to the study participants. Those participating in the study were assigned codes and these were used when referring to them instead of their names. These codes were used for transcription and verbatim quoting. No information obtained from the patients had a name tag and no revelation of who exactly said what was done.

The study protocol was submitted to the Kenyatta National Hospital, Ethics and Research Committee (KNH/UON-ERC) for ethical review and clearance and then presented to the National Council for Science and Technology for issuance of a research permit as required by the Ministry of Education and Kenya administrative authorities.

3.8 Challenge faced in the Field during Data Collection

Despite being told that participation in the study was voluntary and that there was no monetary incentive for participation, most of the respondents were eager to know and kept asking how they were going to benefit from the study. They expected to be

financial supported at the end of the interview session citing the high cost of cancer treatment.

The study followed the above outlined methodology and the study findings are presented in the next chapter.

CHAPTER FOUR

RESEARCH FINDINGS AND DISCUSSION

4.0 Introduction

This chapter presents the study findings on the effects of cancer, a chronic debilitating disease on livelihoods. It is organized into three sections. The first section of the chapter presents the socio-demographic characteristics of the study respondents. The second section of the chapter presents the effects of cancer on labour participation while the third section presents the findings on the effects of cancer on livelihoods. The chapter answers the first two specific study questions and drive at achieving the first two specific study objectives.

The findings of the study questionnaire, in-depth interviews and key informant interviews have been triangulated and most findings are reported in an integrated way. Data originating from the study questionnaire are mostly presented in percentages whereas data from in-depth interviews and those from key informant interviews have been analyzed thematically using themes developed around study questions. The results have been presented using the following thematic areas so as to meet the earlier stated study objectives.

1. Socio-demographic characteristics of study participants.
2. Effect of cancer on labour participation.
3. Effects of cancer on livelihoods.
4. Strategies used by patients to cope with the effects of cancer. (Chapter 5)

4.1 Socio demographic characteristics of survey participants

4.1.1 Age

Age is an important socio-demographic variable in this study. It indicates the range age during which people should be actively participating in the labour force. This study targeted respondents from the working age bracket (18-60) and from the findings all the respondents that were interviewed come from this age bracket. For the purpose of

this paper. age was grouped into 4 groups and the findings are as shown in the following table.

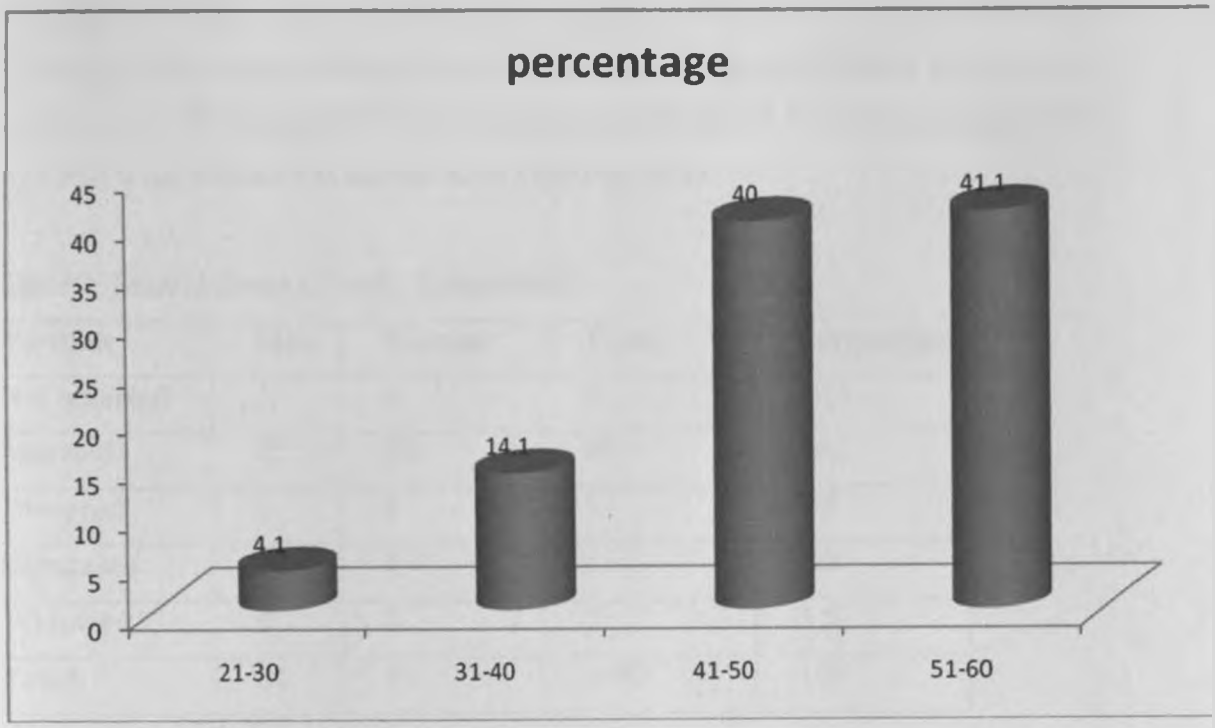
Table 1: Age and Sex of Study Respondents

Age	Men	Women	Frequency	Percentage
21-30	1	3	4	4.7
31-40	7	5	12	14.1
41-50	11	23	34	40.0
51-60	15	20	35	41.1
Total	34	51	n=85	100

Source: Field data, 2012

From these findings, the minimum age of patients who participated in the study was 26 years and maximum age of 60 years. The mean age of the participants was found to be 46.95 with a standard deviation of 8.099.The highest frequency was found between 50-60 years at 35 (41.1%) and this was closely followed by age group between 40-50 at 34 (40%). The age between 21-30 years had the lowest frequency of cancer incident at 4 (4.7%). The following graph shows the frequency of cancer incidences among the age groups.

Figure 2: Age of Study Respondents



Source: Feield data, 2012

From this study therefore, it can be said that chances of developing cancer increases with increase in age. Increase in age and before reaching retirement age represents people who should have worked for some time and thus have gained experience in the labour force. Based on these findings, it can be said that cancer affects experienced people in labour force.

4.1.2 Sex of Study Respondents

Sex was another socio-demographic variable that was measured in this study. This variable was important in exploring if cancer is affecting people from the two categories of Sex; Men and Women. From the study findings, out of 85 patients who participated in the study, 51 (60%) were women and 34 (40%) were men as show in Table 1.

4.1.3 Marital Status of Study Respondents

Marital status was another socio-demographic variable in this study. There were four categories of this variable including: Not married, Married, Divorced and Widowed. According to the study findings, out of 85 participants who participated in the study, 9 (10.6%) were Not married, 63 (74.1%) were married, 10 (11.8%) were divorced while 3 (3.5%) were widowed as shown in the following table.

Table 2: Marital Status of Study Respondents

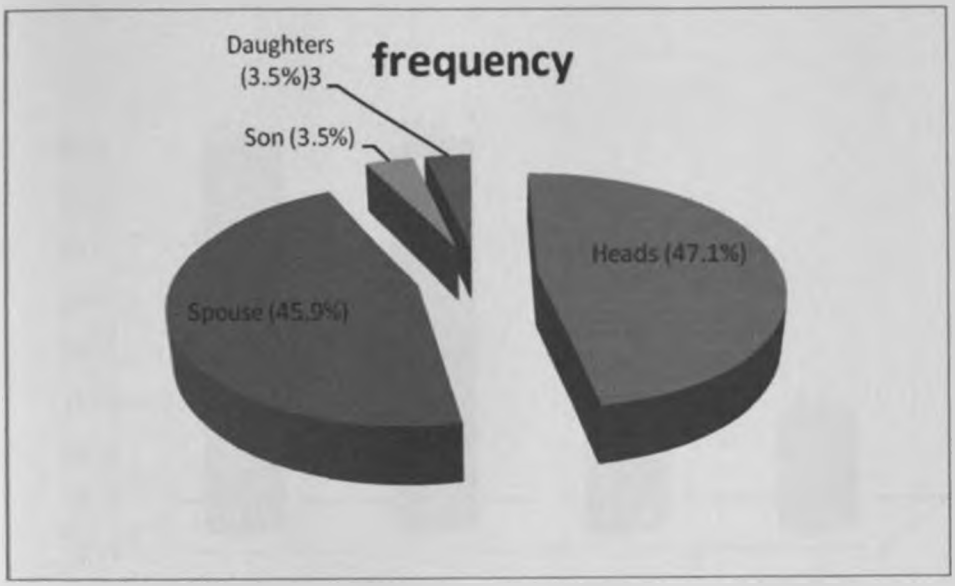
Variable	Men	Women	Total	Percentage
Not married	7	4	9	10.6
Married	25	38	63	74.1
Divorced	1	4	5	5.9
Separated	1	4	5	5.9
Widowed	0	3	3	3.5
Totals	34	51	n=85	100

Source: Field data, 2012

4.1.4 Household Relationship

Positions people hold in households was another variable that was measured. The study referred to this as household relationship and was categorised into four as follow; Head, Spouse, Son and Daughter. This variable was important as a position one holds in a household can help to indicate the extent of the effect if cancer for example affects a household head. From the study findings, out of the 85 patients who participated in the study, 40 (47.1%) were household heads ether married or not but responsible for heading a household. 39 (45.9%) were spouses and therefore responsible for providing support to household heads. 3 (3.5%) were adult son but still living in parents household while again 3 (3.5%) were daughters by virtue of not married and living in parent's house as shown in the following chart.

Figure 3: Household Relationships of Study Respondents



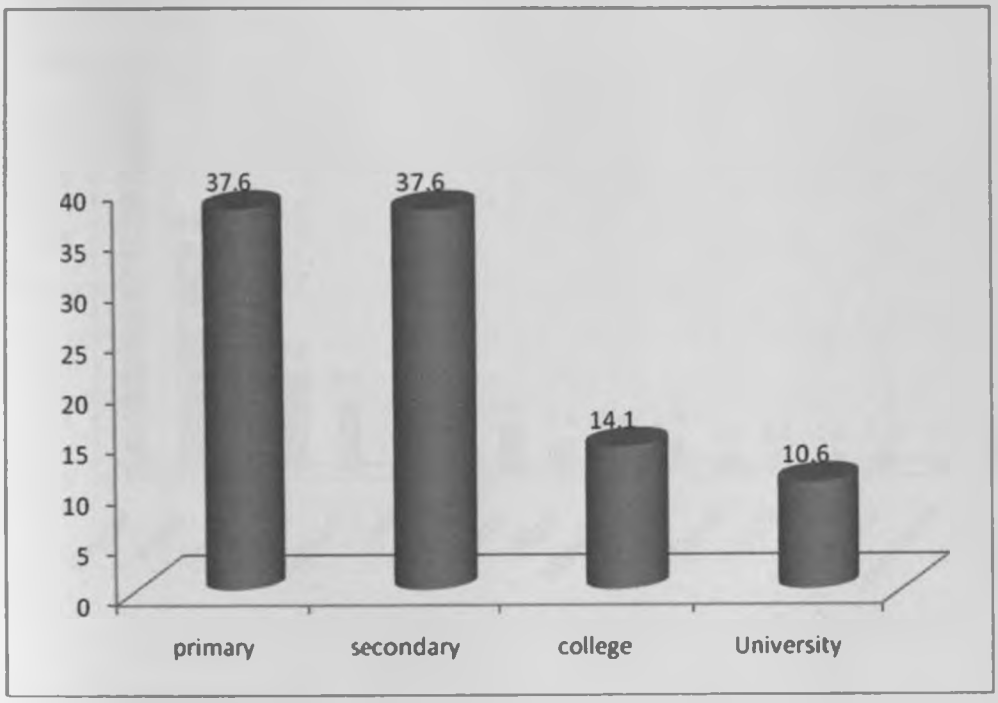
Source: Field data, 2012

4.1.5 Education Level of the Study Respondents

The education of participant was another variable that was measure in this study. It indicated the level of knowledge that participant had and could also indicate if at all there was any relationship between education and the occurrence of cancer. The variable was categorized into; Primary Level, Secondary Level, College Level and University Level.

From the study findings, out of 85 people who participated in the study, 32 (37.6%) had primary education level, 32 (37.6%) had secondary education level, 12 (14.1%) had college education level and 9 (10.6%) had university Education Level.

Figure 4: Education Level of study respondents



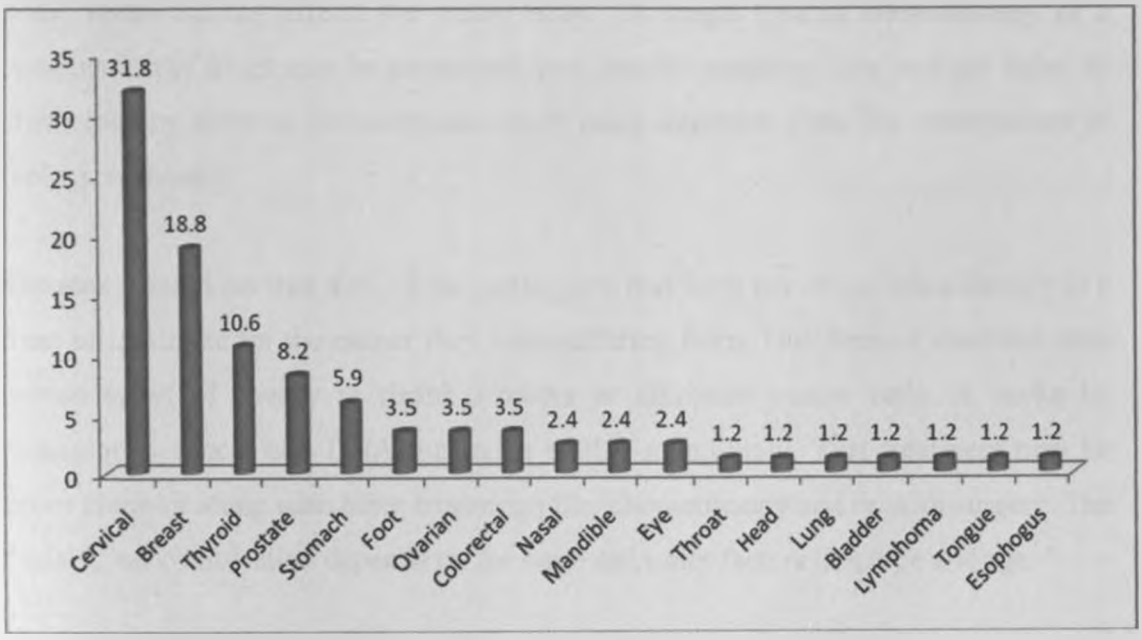
Source: Field data, 2012

4.1.6 Types of Cancers in the Study

This study established the most common types of cancers that working-age patients were being treated for at the Kenyatta National Hospital. Although the National Cancer Control Strategy 2011-2016 had indicated that in Kenya, the most common cancer in women were Breast, Oesophagus and Cervical cancer and Oesophagus, Prostrate and Kaposi Sarcoma in men, this study found out that among the 51 women who participated in the study 27 (%) had cervical cancer and 16 (%) had breast cancer. Among men, out of 34 patients who participated in the study 7 (%) thyroid cancer, 6 (%) had prostate cancer while 4(%) had stomach cancer. Overall cervical cancer had the highest frequency of 27 (31.8%). It was followed by breast cancer with the frequency of 16 (18.8%) and thyroid 9 (10.6%). Prostate cancer came fourth at 6 (7.1%) and stomach fifth with the frequency of 5 (5.9%).

The following graph gives a summary of the 21 types of cancer represented in the study and their frequencies

Figure 5: Types of Cancer in the Study



Source: field data, 2012

4.1.7 Treatment of Cancer at Kenyatta National Hospital

There are four standard methods of cancer treatment; Surgery, chemotherapy, radiation therapy and the biological therapy. These treatments are recommended to the patient by the doctor depending on the type of cancer, stage of development of the cancer, age and health condition of the patient. One treatment can be administered or a combination of two or more depending on the doctors' recommendation

The study found out that 2% of the patients had only had surgery to remove tumours as a form of treatment. This was done to prevent, treat, stage and diagnose cancer, in relation to cancer treatment, often performed in conjunction with other treatment modes like chemotherapy or radiation therapy and that explains why a few participants had had it alone.

8% of the participants were on chemotherapy as a treatment for the cancer they were suffering from. Chemotherapy is a type of treatment that uses drugs to eliminate cancer cells. Usually it is in the form of pills or intravenously injection in the body. It works

by targeting rapidly multiplying cancer cells. Unlike surgery which affects part of the body, chemotherapy affects the whole body. A single type of chemotherapy or a combination of drugs may be prescribed for a specific length of time and can either be chemotherapy alone or in combination with other treatment form like radiotherapy or biological therapy.

The study found out that 42% of the participants had been put on radiation therapy as a form of treatment for the cancer they were suffering from. This form of treatment uses certain types of energy to shrink tumours or eliminate cancer cells. It works by damaging a cancer cell DNA making it unable to multiply. This treatment may be given alone or along with other treatments like chemotherapy and or with surgery. The decision on combination depends on the stage and other factors like type and age.

Hormonal therapy is not popular and it is used for selected types of cancer and it is not readily available and not many people use it. Only 1% of the participants were found to have been treated by this treatment

Overall, the study found out that 50.6% of the surveyed patients were on a single treatment, 44.7% were on combined treatment of either two treatments or more than two. Only 4 (4.7%) had not started treatment yet but were waiting to start as shown in the table 5.

Table 3: Various treatments used by participants

Type of Treatment	Participants	Percentage
Hormonal treatment	1	1.2
Surgery	2	2.4
Not on any treatment	4	4.7
Chemotherapy	8	9.4
Radiation therapy	32	37.6
Combined treatment	38	44.7
Total	n=85	100

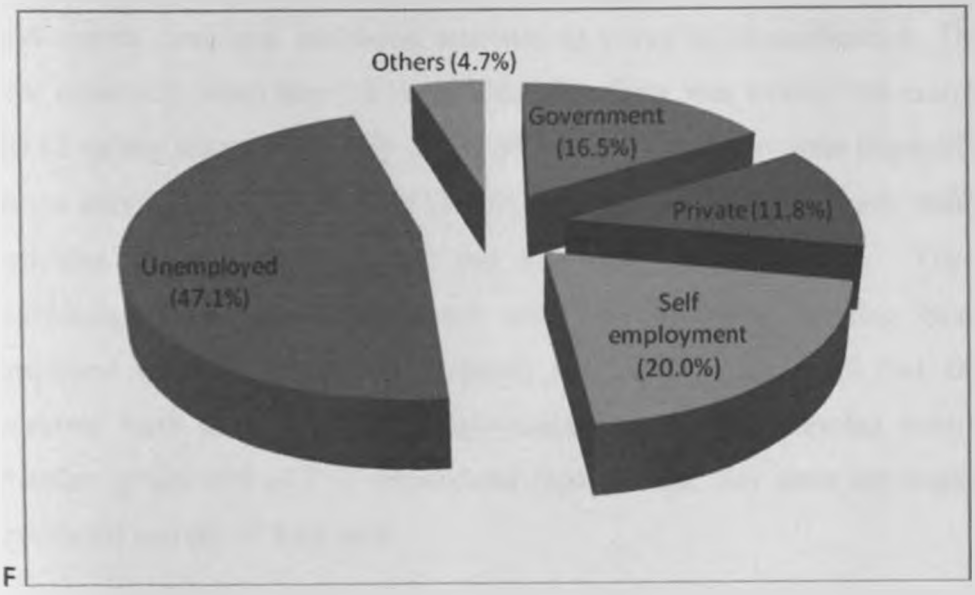
Source: Field data, 2012

4.1.8 Occupation of the Study Respondents

Occupation was another variable that was measure in this study. The variable was important knowing ones occupation helped in understanding the effects of cancer on labour participation. The variable was categorised into 5 as; employed by Government, Private sector, Self-employment, Unemployed and Others.

In this study, although 40 (47.1%) of the participants in this study reported that they were not employed, at least 14 (16.5%) reported that they were employed in the government, 10 (11.8%) were in the private sector, 17 (20.0%) were in Self-employed business and only 4 (4.7%) reported that they were doing other activities but did not mention them.

Figure 5: Occupations of Study Respondents



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Source: Field data 2012

4.1.9 Other livelihood activities

The study also measured other livelihood activities that patients were engaged in there participants were asked Name other activities that they were engaged in. From the findings, 46 (52.9%) of the participants said that they were engaged in Farming, 22 (25.9%) said that they were in Business, 3 (3.5%) said that they used to provide casual labour, 2 (2.4%) said that they got other income from Renting out their houses, 1

(1.2%) from providing Consultancy services while 11 (14.1%) said that they did not have any other source of income.

Table 4: Other Livelihoods of the Study Respondents

Other sources of income	Frequency	Percentage
Farming	46	54.1
No any other engagement	11	12.9
Business	22	25.9
Casual	3	3.5
Rent	2	2.4
Consultancy services	1	1.2
Total	**n=85**	**100**

Source: Field data, 2012

Considering this question and that on occupation, it was found out that some participants combined livelihood activities as a way of diversification. This was the case especially when none of the livelihood activity was secure. For example, out of the 85 survey respondents, only 27 (31.8%) reported that they were engaged in farming as the only source of income. 15 (17.6%) reported that they were only doing business activities and 6 (7.1%) reported that they only in employment. The rest were combining two or more livelihood activities like doing farming besides being employed were 14 (16.5%), employment and business were 7 (8.2%), farming and business were 4 (4.7%) while employment, business and farming were 8 (9.4%). Another group of 4 (4.7%) respondents reported that they were not engaged in any livelihood activity of their own.

4.1.10 Average income

Participant average monthly income was another variable that was measured. It was important in establishing if there was a relationship between cancer incident and income. From the findings, it was found out that cancer affected people both with low income and those with high income. The lowest participant report to earn an average of 1,000 per month and the highest had an average income of 65,000 per month. There were however 4 (4.7%) who said that they did not have any source of income and

depended on other family members and relatives for the living. the following table show average grouped income of those patients who participated in the study.

Table 5: Average Income

Income	Frequency	Frequency Percentage
0-10,000	45	52.9
11,000-20,000	20	23.5
21,000-30,000	8	9.4
31,000-40,000	4	4.7
41,000-50,000	6	7.1
51,000-60,000	0	0
61,000>	3	3.5
Totals	n=85	100

Source: Field data, 2012

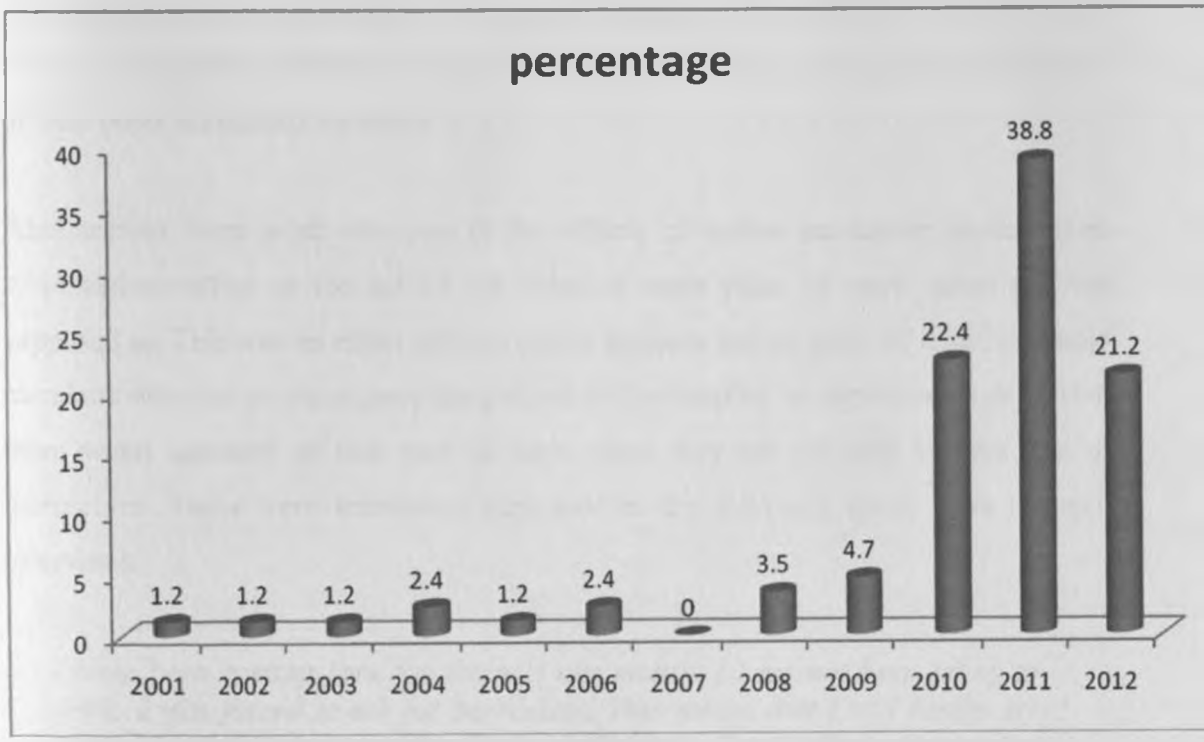
The findings from table 5 indicate that out of 85 patients who participated in the study 45 (52.9%) had a lower average income of 10,000 shillings or less and only 3 (3.5%) had an average income of above 60,000 shillings. From this finding, it can be said that cancer can affect people both with high or low income level. It cannot be conclusively said that cancer affects mostly people of low income levels because the low income levels may be due to cancer itself.

4.1.11 Year of diagnosis

The year of diagnosis was another variable that was measured. This was important in establishing the time that had elapsed since the person was diagnosed and was helpful in bringing out personal lived experience with cancer. From the findings, 10 Years was the longest time that people had survived cancer. Out of the 85 patients who participated in the study, 1 (1.2%) had been diagnosed in 2001. The year 2011 had the highest frequency of 33 (38.3%), 2010 was second with a frequency of 19 (22.4%) while 2012 had a frequency of 18 (21.2%). the highest frequency of cancer incidences in the year 2011 can be explained by the increasing incidences of the disease. 2012 is

expected to have the highest number of cases but only the study considered people who had been diagnose up to the month of March in the year 2012. the following chart shows the frequency percentage on number of cases per year.

Figure 6: Years of Cancer diagnosis of the Study Respondents



Source: Field data, 2012

4.2 Findings from In-depth Interviews

Of the 15 In-depth Interview participants, 6 were men and 9 were women. Their ages ranged between 32 and 59 years and at least one year had passed since their cancer diagnosis. Other socio-demographic characteristics of In-depth interview participant are presented in appendix v. Other findings from these In-depth interviews were triangulated with findings from the survey and reported in an integrated way. Finding from In-depth interviews were mostly used in verbatim quotation.

4.3 Effects of cancer on Livelihoods

4.3.1 Effects of cancer on labour participation

The main asset of most poor people is their bodies; they are much dependent on their physical ability as a source of income (Goudge and Govender, 2000). Labour participation is a livelihood activity that related to those who are employed or are employable but not yet employed. Suffering from cancer affects the physical ability of the patient and therefore affects labour participation. The effect of cancer on labour participation according to this study can be divided into three broad impacts: absenteeism from work for those who are still employed, inability to work for those severely affected and diverting time to seeking treatment both for the patients and some of their other household members.

Absenteeism from work was one of the effects of cancer on labour participation. Absenteeism refers to the act of not being at ones place of work when you are supposed to. This was an effect both on cancer patients and on some of their household members who had to accompany the patients to the hospital on appointment days, visit them when admitted or take care of them when they are not able to take care of themselves. These were sentiments expressed in the following quote from In-depth interviews.

> *I have been coming here for the past one month. I have not been going to work. I was forced to ask for permission. This means that I will forego my annual leave. I have foregone other activities too. Time spent on the waiting line is time lost and therefore money lost. (32 year old foot cancer respondent)*

Other than affecting those who were employed, it was also affecting those who were doing personal businesses and had not asked either a family member or a relative to run the business as they attend hospital appointments. This was capture in the following quote from in-depth interviews.

> *I cannot walk on my own. I was brought here by my wife and my brother. They did not go to do their work and they have to wait for me to be treated and take me home. (41 year old lung cancer respondent)*

Agriculture is the main economic activity in Kenya and in fact it is the country's backbone as revealed in this study 46% of the surveyed patients said that they were

engaged in farming. They reported absenteeism from farming activities saying that they were weak and could not participate in farming activities. Such led to loss of farming knowledge, reduction of land under cultivation, reduction of crop variety planted and reduction of livestock farmed. Ultimately it led to decline in household income and possible food insecurity.

Cancer was found to cause inability to work among these suffering from it. Many patients interviewed revealed that they could no longer physically jobs they had initially done. In addition to body weakness, the patients had pain and were fatigued by cancer. More so, the unpredictability of symptoms meant that only highly flexible employment was possible. Out of 85 patients who participated in the study, 83 reported that cancer had affected their ability to work. They reported that because of suffering from cancer, they could not engage in labour activities because of deteriorating physical ability. This was can be captured by the following two quote from In-depth interviews.

> *I had to leave the teaching profession. I had lost almost all my teeth and I could not communicate well. I now do not have a salary..... it is now difficult for me to pay fees for my children and even to feed them as well as coming here for treatment. (44 year old mouth cancer respondent)*

> *I have been coming to the hospital since the beginning of the year. I just rest for a few days and come again. Thank god my work is flexible. I'm a lecture and I can influence the timetable. ....but there are those who cannot work yet need to pay for their treatment. (55 year old Kaposi Sarcoma respondent)*

Diverting labour time to seeking cancer treatment was another type of effect of cancer on labour participation as was revealed by this study. This can also be referred to as time cost. Time cost according to think tank represents the value of the time patients and their families spend on activities related to the patient's cancer screening and treatment. This is time that could be spent engaged in labour or doing other economically productive activities. Several people interviewed revealed that they had come to the hospital in company of some of their household member; husbands, wives,

children or relatives whom they lived with and that when they come to the hospital they spent there the whole meaning that day is counted as a day lost. This was well explained by the following two quotes from In-depth Interviews

> *I come here with my son. I could not come alone because I'm weak. My son did not go to work. I also cannot work in my tea farm as I am weak. (54 year old prostate cancer respondent)*

> *I was accompanied here by my wife, we left the home unattended. But I think tomorrow she will not come again, she must stay at home to attend to other activities. (43 year old thyroid cancer respondent)*

Thus seeking cancer care and treatment created time cost not only for the sick, but also for other household members thus reducing time spend on labour force participation. This is time cost that can be translated into lost money. This comes at a time when there is need for extra cash to meet medical bills and for survival.

4.3.2 Effects of cancer on participation in Farming

Agriculture is described as the backbone of Kenya's economy. As finding from this study indicate, out of the 85 patients who participated in the study 46 (54.1%) reported that they were engaged in farming activities. They were engaged in farming as the only source of livelihood or they were also engaged in other activities alongside farming. And out of 15 respondents who participated in In-depth Interviews, 11 (73.3%) reported that they were engaged in farming. Of those 11 who were doing farming 8 (72.7%) reported that cancer had affected their farming activities and only 3 (27.3%) reported that cancer had actually not affected their farming activities. Some of the explanations that they gave when asked how cancer had affected their farming activities were; that cancer had made the weak and they were unable to work on their farms, that they spent much time in the hospital and therefore there was no time for doing farm activities.

4.3.3 Effects of cancer on participation in business

Business was another core livelihood activity that people were found to be engaged in. out of the 85 respondents who participated in the study survey, 22 (25.9%) were

engaged in business activities. again, out of 15 respondents who participated in the In-depth Interviews, 5 (33,3%) reported that they were involved in doing business. According to the study findings, business was done as the only source of livelihood by some participants while other were combining it with employment and or farming. Cancer was found to affect patients' participation in business activities. Out of 22 people who reported to engage in business, 16 (72.7%) reported that cancer had affected their participation in business activities in the following ways; one that they take much of their time seeking cancer treatment leaving to time to participate in business activities, two, that due to suffering from cancer, they did not have energy anymore to engage in business activities, and third that they had used money from the business stock to pay for cancer treatment and they did not have extra money to put in the business.

The effects of cancer on labour participation in business were not only felt by the sick person. Other members of the household also felt this affects especially those who were providing care and accompanying the sick person to the hospital. Some household member had to close up their business as they accompany the sick to the hospital and stay there with the patients as they wait to be treated as revealed by the following two quotes from In-depth Interviews

> *... I came here with my daughter. She just closed her business. This is a loss to her work because customers will just come and go. She will not make any money and now that I was told that I will continue with radiotherapy for the next 1½ months, I don't know because she cannot be with me for this long. She must go back to her business... (50 year old breast cancer respondent)*

4.3.4 Effects of cancer on other Livelihood activities

From the finding in this study, other livelihood activities that people were engaged in included providing casual labour 3 out of 85 survey participants and 2 out of 15 In-depth interviews. Providing consultancy services was 2 out of 85 and again 1 out of 85 reported that their other source of livelihood was renting out residential houses. Those who used to earn their livelihood from providing casual labour reported to have been greatly affected by their suffering from

cancer. The following quote from In-depth interviews also agrees to the findings from the survey;

> *I'm a widow. I cannot provide casual labour on people's farms as I used to do. I cannot therefore get the money yet I need to take care of my grandchild. We need food and I need to come to the hospital. I had started treatment last year, but I stopped due to lack of money. After staying at home for almost a year, it got worse and now I have come back. (59 year old cervical cancer respondent)*

Suffering from cancer however does not negatively affect livelihood activities of all people. From the findings of this study, two participant, one suffering from cancer of the stomach and another one suffering from nasal cancer and earning their livelihoods from renting out residential houses reported than cancer had not affected their livelihood activities. This was also true with 1 participant who was suffering from thyroid cancer and earning a livelihood from providing Consultancy services. The respondent reported that cancer had not affected his livelihood.

These variations may be explained by the fact that different types of cancer affect people differently like in the case of thyroid cancer and Consultancy services there was no effect. However, information on the stage of cancer was not collected but it might contribute in explaining the variation of the effect. Also suffering from cancer can affect different livelihood activities in different ways. For example in the case of those who were providing casual labour, their livelihood activity was labour intensive and required a lot of physical involvement. In the case of cancer of the Stomach and Nasal cancer in relation to renting out residential houses, there was no requirement for physical involvement and therefore no effect was felt.

Suffering from cancer can cause changes in livelihood activities. People needed to raise money quickly in order to meet the increasing financial need. Some of patients interviewed revealed that some members in their households took on other activities in

order to raise more money including taking casual labour as seen in the following quote extracted from the In-depth Interviews.

> *My first-born boy was trained as a driver. He did not get work so he was working as a turn-boy. The work did not pay him well. When I got sick he left it. He started doing casual labour. He is the one who gave me money to come to the hospital today. (59 year old cervical cancer respondent)*

4.3.5 Financial constraint due to high cost of cancer treatment

The financial cost of treating cancer was high and was found to be of concern. The high cost was because of the various tests and treatment procedure that patients were supposed to undergo. All (5) of key informant interviewed reported that the high cost of treating cancer was of concern. The following quote from the key informant interviews attest to this.

> *It is quite expensive. Six courses of chemotherapy may be required and each costs about Ksh. 20, 000. Radiation therapy may be given in 25-30 sessions and each session cost about Ksh. 500. Surgery on the other hand may cost between Ksh. 20,000 to 30,000 depending on the location of the tumour and the type of surgery that is being performed. (35 year old doctor at the Cancer Treatment Centre)*

The study found out that 43% of the patients were on combined treatment. Treatment combination pushes the treatment cost further high because for example, combining surgery that cost Ksh. 20,000 and six courses of chemotherapy that cost Ksh.20, 000 which translate to Ksh. 120,000. It would be worse if a patient needs the third mode of treatment like radiation therapy which costs 500 for say 25 sessions.

Other than this treatment cost, there are additional cost for example transport to the health facility, accommodations and buying food. It was found out that a large percentage of the study participants had been referred to Kenyatta National Hospital from various counties and thus, they needed to travel and stay at a place close to the health facility as they undergo radiation therapy. This further increased the cost requirement for the patient and sometimes this made some of them to drop out of treatment or fail to initiation treatment because it was found to be costly. The following quote was extracted from Key Informant interviews.

You see, this disease does not wait but sometimes when you tell patients to be coming every day after initiating the treatment, they will say that they don't have transport to this place. When they come they don't have a place to stay if they don't have relatives willing to accommodate them in Nairobi. At the same time, they need food to eat. This makes some of them even opt out of treatment or ask for more time to look for money before they can initiate treatment. This always ends up with us loosing the patient. (44 year old Nurse at the cancer Treatment Centre)

Financial problems also came in as many patients could not continue with their daily routine activities and more so economic activities such as working on their farms, doing casual labour or continuing with business activities. This happened especially when the cancer patient was a household head and the spouse had to combine her participation in labour, taking care of the sick and being engaged in reproductive activities around the home, or if the patient heads a single parent household.

In a household, when the economic activities of one person are stalled, it becomes difficult for one's household to survive without the financial contribution that used to be made by that person. This coupled with the increased expenses of treatment, the problem was compounded and in some cases, affected households were forced to go into debt or sell their property to keep up with the demanding expenditures as seen in the following quote.

I was a carpenter and when I started to be sick in July 2010, I stopped. We now depend on my wife who is not employed but runs a small business and does farming. This money is not enough as we have children in primary school and I need to come for treatment. This made us to sale some of our furniture from our house (43 year old thyroid cancer respondent)

It was not only the affected person's economic activities that stalled, but also those of other family members who had to abandon most of their activities of labour force participation to spent time taking the patient to the hospital and giving them care. When the patient was admitted in hospital the problem became worse as household members had to spend a lot of time and money going to visit the patient daily. This negatively affected their participation in the labour force and other economic activities. This was aired by a 51 year old breast cancer patient who had been referred to the

Kenyatta National hospital for radiotherapy after receiving mastectomy and chemotherapy at the Texas cancer centre in Nairobi.

Other than spending time and money with cancer patients, the psychological aspect of not knowing what next made other household members to worry. This also contributed to their inability to perform in the labour force leading to financial problems as explained by the 51 year-old breast cancer woman.

> *... My husband is very worried; he always calls to find out how I'm doing especially when I have come to the hospital. Even when we are at home, I see him worried to the point that he cannot concentrate.*

4.3.6 Loss of livelihood assets through sale

Loss of labour was not the only immediate effect of morbidity caused by cancer; there were other expenses that were incurred during the illness and this happened at a time when income was also reduced. The cost of cancer treatment for example created a greater demand on the affected household's savings. This left the household with few resources or none at all that could be devoted to them.

Findings from this study indicate that, out of 85 respondents 62 (72.9%) reported that they had lost their assets through sale in order to generate money; the money was then used to pay for cancer treatment. Also out if 15 patients who participated in the In-depth interviews 13 (86.3%) reported that they had sold their assets to enable them pay for their cancer treatment. Among the assets sold included; plots, cattle, goats, houses land. The following two quotations, one from In-depth Interviews and another Key Informant Interviews affirm to the above findings.

> *I had bought a plot when I was doing tailoring and my business was doing well. But I had to sale that plot again because of treatment. I also sold my two cows and poultry and my sewing machine. (50 year old eye cancer patient)*

> *Some patients say that have sold land, cattle and other Valuable assets to finance cancer treatment. (47year old cancer health care provider)*

Selling of assets during times of distress meant that the returns were less and also this contributed to increased indebtedness. These finding are in corroboration with the

finding of a global study on the economic and social burden of malaria by Sachs and Malaney, (2002).

Whereas 62 (72.9%) reported that cancer had made them to sell their assets in order to pay for cancer treatment, 23 (27.1%) reported that they had not sold any of their livelihood assets. However, out of the 23 participant who had reported not to have sold any asset, 4 (17.4%) had not started cancer treatment while to others it was less than one year since their diagnosis others had therefore did not have much to comment on this issue. the following expression was a quote from one participant who reported that cancer and its treatment had never made him to sale his assets

4.3.7 Food insecurity due to reduced income

Food availability hinges on the availability of household assets. In times of need, assets such as livestock, land, trees and other household goods can be readily converted into cash through sell and the money used to buy food. Households usually accumulate assets as an insurance strategy. But chronic diseases like cancer can forces them to dispose of the same assets to meet the increased medical and consumption expenses. This acts to deny the affected individual and their households the food security during the hard times. It therefore impoverishes and makes them vulnerable to hunger. Findings from this study indicate out of 15 patients who participated in the study, 5 (33.3%) indicated that it was difficult for them to get enough to eat and this they attributed it to cancer. This can be captured in the sentiments expressed in the following quotation from In-depth Interviews.

> *I was a teacher; this is stopped when the disease became severe. I don't earn income. Our household income has reduced because don't earn. The little income that my husband earns is used for treatment. We have sold most of our assets and even sometime we find it difficult to eat.* (44 year old breast cancer from Nyandarua)

Findings from this study corroborate the findings from other studies that had earlier been done. For example, impoverishment of households, food insecurity and long-term vulnerability were also reported in Chand et al, (2004) in respect to the study of tuberculosis in India.

CHAPTER FIVE
STRATEGIES TO COPE WITH CANCER RELATED EFFECTS

5.0 Introduction

The previous chapter presented the findings and discussion on the effects of cancer on labour participation and livelihoods and this chapter presents the finding and discussion on the third specific study question on the coping strategies employed by patients in dealing with cancer related effects on their livelihoods. This is aimed at achieving objective number three of the specific objectives.

5.1 Coping strategies

Coping strategies can be defined as a set of action that aim to manage the cost of an event or (shock) a process that threatens the welfare of some or all of the household members. Ultimately, coping strategies seek to sustain the economic viability and sustainability of the household. In the case of this study, coping strategies describe how cancer patients and their households mobilize their resources to cope with illness. Coping strategies has become a term frequently used in development literature. Initially it was highlighted by works investigating household response to famine and the structural adjustment programmes (Moser, 1998).

The effects of cancer are neither limited to the patient nor the household where the patient live. Many more people are affected because the burden of cancer care may be shared among several households: the patient may move from one household to another like from rural to urban as they seek cancer treatment. Also households may make contributions in cash or kind towards cancer patient's support. Patients and affected households may employ several strategies to cope with labour loss and other effects of cancer on their livelihoods.

Households coped with illness differently. How they cope is largely influenced by the opportunities available to them and by their capabilities and asset stores (DFID, 2005).

It required drawing from all forms of assets available. This included income assets, physical assets (such as equipment, homes, land) human assets and social assets.

Over time this assets are reduced and if individual households are not able to replace them they become increasingly vulnerable and may be forced to rely on insecure or harmful strategies.

5.2 Coping with loss of labour participation

In this study, loss of labour or reduced labour participation was one of the reported effects of cancer. This effect was felt also in regard to participation in other livelihood activities. Loss of labour participation was caused cancer disabling the affected individual whereas reduced participation was caused diverting labour time to seeking cancer care and treatment. The study established that affected patients were using different strategies to cope with this reduced or labour loss.

From the findings, out of 85 patients who participated in the Survey Questionnaire 46 were found to be engaged in farming and out of these 31 (72.0%) reported that they had left their farming activities in the hands of their spouses. Others reported to have left farming activities in the hands of their children who had left school because of lack of school fees. They said that because all the money that they got was being used to paying for cancer care and treatment, they did not have extra money to use in paying for their children's schooling. This made the children to leave school and help with labour activities.

Another strategy that was used to cope with reduced or loss of labour participation was reducing of area under cultivation in order to reduce the requirement of labour others reported that they had reduced area under cultivation because they did not have much money to invest in the farm.

5.3 Coping with the effects of cancer on business

Cancer was found to affect business activities in three major ways; inability to continue engaging in business activities, diverting business time to seeking cancer care and treatment and diverting money meant for business stock to cancer care and treatment. To cope with these effects of cancer on business activities, out of 22 respondents who said that they were engaged in business 13 (59.1%) reported to have stopped engaging in business activities, 6 (27.3) reported that they had left business under the care of their children as they come for treatment while 4 reported that they had closed the business and will open it when they go back home.

5.4 Coping with the effects of cancer on other livelihood activities

From the study findings, the effect of cancer on other livelihood activities was varied. The variation was either because of the type of cancer and the nature of the livelihood activities that the patient was engaged in. Those who were engaged in physical activities like providing casual labour were adversely affected by the disease. These participants who made up of 3.5 per cent of all survey participants reported that they could not cope with the demand of casual labour and therefore they had to stop engaging in such activities.

5.5 Coping with increased financial needs

Financial constraints were experienced both by individual patients and the affected households. The increased financial needs were due the high cost of cancer treatment and the various forms of cancer treatment. This cost was much higher when patients were on combined treatment with two or more forms of treatment.

To cope with increased financial burden, a number of affected patients had sold some of their livelihood assets to help meet this increased financial need. From the study findings, out of 85 patients who participated in the survey 31(36.5%) reported that they had sold land, 24 (28.2%) reported that they had sold livestock; 10 (11.8%) reported that they had leased out their land, 4 (4.7%) reported that they had sold their plots. Other assets that 5 (5.8%) of respondents reported to have sold were motorbikes, Gas

cooker and Gas Cylinder, Pressure lump and furniture. Only 11 (12.9%) reported that they had not sold any livelihood asset. All these strategies were meant to help the affected individual cope with the increased financial needs both for treatment and for living. The following quote from the In-depth Interview affirm to these findings.

> *It is very bad. You know I started treatment sometimes back at Kisumu. I used all the money I had. When I was referred to Kenyatta National Hospital for radiotherapy, I had to sale my house and now I'm using the money for radiotherapy. (42 year old breast cancer patient)*

Other studies had included borrowing of money as one of the strategies that patient use to cope with the increased financial needs. However, findings from this study did not find borrowing to be a popular strategy used by affected patients. Out of the 85 patients who participated in the study, only 15 (17.6%) said that he had borrowed money. From In-depth Interviews one respondent explained that she borrowed money from Equity Bank to use for expanding her Business. However, the money was used in paying for cancer treatment and there was no money to repay the loan. She reported that when they asked and were about to auction all that she had, family and relatives contributed to help her repay back the loan.

5.6 Depending on social support

In times of depression, individuals may survive by calling on the extended family, friends, relatives and the wider community to support them. In this study, support from local institutions (family, neighbours, church and wider community were found to be instrumental and important during hard times both for individuals and households.. 0ut of the 85 patients who participated in the study, 74 (87.1%) reported to have at least used this strategy. the contribution from this was either in person or through a fund raiser.

However as it is revealed by a 44 year old breast cancer woman from Nyadarua, the option of getting help from friends relatives fade away over time as requests are made often and the same people are supposed to give their contribution in the case of

borrowed money, debts are not repaid. And in case such support is not obtained patients may not be able to continues with cancer treatment

> *I had earlier asked to the family members, relatives and friends for help. They managed to raise some money although it was not enough. .... I'm still looking up on the well wisher and if nothing happens, I might not continue with this treatment. However I do not have much hope because these are the same people who contributed for me last time.*

From the findings of this study, the most reported strategies used by patients, were receiving contributions from friends 37 (43.5%) and relatives and selling of their assets 31 (36.4%). Many of the participants in the survey reported to have used their savings except those who did not have any savings even before the onset of cancer and those who had just been diagnosed in the recent past and had not yet started treatment. These strategies were however not mutually exclusive as affected individuals used several of them as they tried to cope with the disease.

The string of responses to the cancer 'shock' for example; prolonged illness, reduced production, high treatment cost, shift to less demanding and remunerative enterprises, sale of livelihood assets and increased indebtedness resulted in deepening impoverishment of many afflicted individuals and their households. The following quote from In-depth interviews can capture these sentiments.

> *Cancer has made us poor. We were doing well before this disease came. But since it came we have been trying to treat it. The many treatments have depleted all our money and now we cannot afford to take care of ourselves. (44 year old breast cancer patient)*

Study findings showed that cancer can imposed increased financial needs to the affected individuals and their households over time. This was due to the high and various treatment cost compounded by that affected patients inability to participate in the labour force. The high cost of illness associated with cancer often went beyond the capacity of most affected households. The strategies that affected individual adopted to meet these increased costs were relatively risky and contributed livelihood insecurity.

For this study, the overwhelming impression created is that, the cost burden of cancer is extremely high for many households that are already resource constrained, forcing them to adopt risky coping strategies that reduce their livelihood asset portfolios, increase their vulnerability to other shocks and posing questions about their viability and sustainability.

This chapter presents the findings and discussion on the effects of cancer on livelihoods and coping strategies that affected individuals use to cope with cancer related effects. The following chapter gives a summary of the study's key findings, conclusion and recommendations.

CHAPTER SIX

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

6.0 Introduction

Chapter four presented the findings and discussions on the effects of cancer on labour participation, livelihoods and coping strategies. This chapter will present a summary of the study findings and draw conclusion from them. Further, it will give recommendations in line with these findings both for policy and direction for further research. The study aimed at examining the effects of cancer on labour force participation, livelihoods and coping strategies. The study was guided by the following three specific objectives: To examine the effects of cancer on patient's participation in the labour force, to examine the implications of cancer on the patient's livelihoods and to examine strategies that patient's use to cope with cancer related effects.

6.1 Summary of Study Findings

Findings from this study have shown that, cancer is increasingly affecting people within the actively productive age group causing adverse effect on labour participation. The negative effects of cancer on labour participation were not only felt by the cancer patients but also other members of the affected households.

Reduced labour participation was one of the most reported effects of the disease. The study findings showed that (83) 97.6 per cent of the survey participants could not participate in labour as the used to before they suffered from cancer. The study also found out that out of the 83 who reported that cancer had affected their labour participation (72) 86.7 per cent said that they lost their ability to participate in the labour force. Reduced or lack of participation in labour meant reduced or lack of income and this resulted in increased livelihood insecurity.

Absenteeism from work was another reported effect of cancer on labour participation. The findings also showed that for those who were employed, they were absent from

work as they were required to come for treatment and also to attend medical clinics on weekly basis after treatment for review.

The study found out that affected individuals and some of their family members were diverting labour time into seeking cancer care and treatment. Those patients who could not come to the hospital on their own had to be accompanied by either one or more members of their household to the hospital and this meant wasting of productive labour time. Other effects included: school absenteeism by children to accompany sick parents to the hospital and children leaving school to participate in labour to generate livelihoods.

On the effects of cancer on livelihoods, the study found out that people engage in different types of livelihood activities and suffering from cancer did not always have a negative effect on livelihood activities. The effect of cancer on livelihood depended on the type of cancer and whether the livelihood activity was physical.

Findings from this study show that farming was the mostly reported livelihood activity that participants were engaged in 54.9 per cent. This livelihood activity was engaged in as a sole livelihood activity or together with other activities. Almost all of the participants engaged in farming reported that because of cancer, they could not participate in farming activities as they used to. The explanation to this reduced or lack of participation was that cancer had affected their ability to work and that even if they could work there was no time at most of the time they are in the hospital waiting to be treated.

From the study findings, business activity was also livelihood activity that many participants were engaged in. Business was carried out as the sole livelihood activity or together with farming and or employment. Findings show that cancer affects business activity in three major ways, inability to participate in business, diverting business time to seeking cancer care and treatment and diverting money meant for business to paying for cancer treatment, this resulted in declining business engagement or ending of it.

Casual labour was another livelihood activity that people were found to engage in by 3.5 per cent of survey participants, Findings from this study revealed that cancer negatively affected the participation of patients in casual labour and resulted to livelihoods insecurity. However, other findings for this study indicate that cancer does not always negatively affect livelihoods of those affected. Cancer was found to have no effect on those patients who were earning their livelihoods from less physically demanding activities like renting out residential houses and doing Consultancy services.

Findings from this study also show that people suffering from cancer have increased financial needs. Cancer care and treatment has added financial burden to the patients and their households already reduced resources. The study showed that, patients incur increased financial cost as they sought treatment and care from hospitals. The costs included medical expense of paying for treatment, non medical expenses such as transport, accommodation and special and loss of productive labour time for both the patients and their care givers.

On strategies used to cope with reduced or loss of labour participation, the study found out that affected individuals were depending on the labour of other family members and children. However, sometimes the participation in labour of this other family members could be affected as they were sometimes required to help the patient to seek treatment from the hospital.

The study revealed that affected individuals and households were employing several coping strategies to deal with this increased financial burden. These strategies included: using their savings, using money meant for business or farming, selling some of livelihood assets asking for assistance from friends and relatives, use of personal, borrowing money from social networks and appealing to well-wishers to help them. Also some affected households had to stop the education of their children by using

money meant for fees to pay for treatment. Some of the livelihood assets that were sold included; livestock, plots and houses, and sometimes land;

All these coping strategies that the affected individuals and households were adopting impacted negatively on their livelihoods, caused food insecurity, and increased their vulnerability and eventually contributing to their impoverishment.

6.2 Linking back to theory

The relationship between disease and livelihoods provided the theoretical basis that was used in this study. The study findings were optimistic and did not wholly validate the framework. According to the Framework, those suffering from cancer will have their participation in the labour force and other livelihood activities affected. From the study findings, suffering from cancer was found to have effects on the participation in the labour force of those affected and some of their other household member who were required to provide support and accompany the patients to the hospital. However, cancer was found to have no effect on other livelihood activities that did not require physical involvement in doing them.

6.3 Conclusion

The study revealed that cancer can affect anybody with whichever socio-demographic characteristics. It can affect both the young and the older. It can affect people with whichever sex, educational level, marital status, household relationship, occupation and income level.

The study revealed that cancer affects labour force participation both of the patients and their other household members differently. Whereas a majority of the study participants reported to have been negatively affected by their suffering from cancer, others reported cancer had affected their lives but had not affected their livelihood. Among those whose labour participation had been affected, the effects were felt in their various livelihood activities they were engaged in like in employment, farming, business and other activities like providing casual.

The study revealed that among the effects of cancer on labour participation were; First it made the effected individual to be absent from the place of work because of either not feeling well or being away in hospital. Second cancer affected the physical ability of the affected individuals resulting into inability to work and earn an income. Third, it made the affected individuals and some of their other household member to divert labour time to seeking cancer care and treatment.

The study also revealed that these effects of cancer on labour participation had socio-economic implication on the affected individuals and their households. Notably, they furthered the process of impoverishment by disabling the affected individual, reducing household income and increasing financial needs.

The study revealed that due to the reduced ability to labour and reduced income, affected individuals and their households to adopt new coping strategies to meet the labour and financial needs. These strategies included using the labour of unaffected household member, compromising children's education and using them to provide labour.

The study revealed that due to the due to the increased financial needs created by high cost of cancer treatment, some patients adopted certain strategies that were helping them to cope with this situation. They included using savings, borrowing, selling their livelihood assets asking for help from family and friends and appealing to well-wishers to help them meet their financial needs.

From these findings, the study concludes that cancer affects labour participation and causes livelihood insecurity. It makes people unable to participate in labour, reduces their income and increases their financial needs. It forces the affected individual and their households to adopt certain coping strategies. The coping strategies that are adopted by affected people and their households to cope with the effects of the disease are usually not sustainable and lead to livelihood insecurity and increased vulnerability.

Cancer is therefore not only a health issue, it is also a socio-economic development issue because it affects labour participation, income, savings, other livelihood assets, social relations and roles, education as well as productivity and development of affected individuals and their households. In not an individual's but in fact a community development issue. It affects an individual, a household, family, relatives, the community where one leaves and the society at large.

It is therefore imperative that any development agenda that seek to improve the lives and livelihoods of a given community must in the first instance address the health issues affecting the people and undermining their livelihoods like cancer.

6.4 Recommendations

Cancer has become one of the many factors impoverishing affected households and yet it is not the only disease with which households have to deal with. However owing to the high occurrence rates and the current trends of it affecting the most productive age group, it warrants a special attention because it has major implications on the economy and the society at large. Based on the above findings, discussion and conclusion the study makes two types of recommendations, one for policy and the other for further research.

6.4.1 Policy recommendations

The government of Kenya has made enormous efforts towards improving cancer health care and cancer management. these new developments include; the president accenting to the cancer control bill so that it becomes a cancer control law, development of a cancer control strategy by both the Ministry of Health (MOH) and the Ministry of Public Health and Sanitation (MOPHS) and development of a cancer situational analysis in Kenya. However, these developments have been very slow and have not yet been put into full action. This makes many cancer patients to continue suffering as they seek cancer treatment and care at the Kenyatta National Hospital which is very far from

their homes and cannot accommodate them as they are treated as outpatients. Whereas this study acknowledges the mentioned developments, in light of its findings would like to make the following policy recommendations.

First, medical care can be improved by providing adequate information and service close to the community including; regular screening programmes for early detection, education on signs and symptoms, importance of regular medical check-ups, cheaper drugs for treatment, management and treatment services closer to the people.

Second, despite the high occurrence rates, cancer awareness is still extremely low in Kenya. Many people as revealed in the study do not yet know about early signs of cancer. There is need for intense public education programmes that teach about cancer.

Third, there is need to establish cancer diagnostic and treatment centres in all counties countrywide. As depicted in the study patients come from different counties to access holistic treatment in Nairobi County. Although some counties were not represented, this does not mean that cancer does not afflict people in those counties. This may be associated to low level of awareness or the means to travel to Nairobi for treatment. County cancer treatment centres should be one of the county government health development agenda. This will help to bring services closer to the people.

Fourth, cancer medical centres of excellence should be established on a public-private partnership with regulated cost of treatment and all centres should embrace the National Health Insurance Fund (NHIF) scheme. This will help to break the cost barrier for patients seeking treatment in private health facilities and it will help in pooling together knowledge and resources through shared initiative for the good of patients.

6.4.2 Direction for further research

In Kenya, cancer related research are very few and are mostly done by Kenya Medical Research Institute (KEMRI). This limited research has contributed to low levels of

understanding of the effects of cancer on both social and economic development it individual, household and national level. In relation to this inadequate research on cancer and low levels of understanding of the effects of cancer on socio-economic development, this study makes the following further research recommendations:

First, owing to the seemingly high cost of cancer treatment that is beyond the affordability of many households and the fact that cancer treatment is given in series, further research should be done to document the impact of treatment cost on patients' initiation and adherence to courses of treatment.

Secondly, since livelihoods of people from different parts of the country are not the same, a single study cannot effectively capture the impact of any epidemic disease. This study recommends that community level research should be done to identify those livelihood assets that are most likely to be affected in the local setting; For example using household survey and looking at effects of the disease on labour participation and livelihoods of men and women differently and taking into account the type of cancer.

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APPENDICES

Appendix i: Informed Consent Form

Name of the researcher: Maaka Hellen Nekesa

Name of the organization: Institute for Development Studies

Informed consent sheet for individuals participating in the research

Effects of chronic debilitating diseases on livelihoods and coping strategies: a case of working-age cancer patients at Kenyatta National Hospital.

Purpose of the research: My name is Maaka Hellen Nekesa. I'm a student at the institute for development studies, University of Nairobi. I'm currently doing a research on **the effect of chronic debilitating diseases on livelihoods and coping strategies: a case of working-age cancer patient at the Kenyatta National Hospital** – A requirement to complete Master of Arts degree in Development Studies. As you know cancer is an emerging health problem worldwide and in particular the Kenyan case is worrying. The research project aims at an understanding of how cancer affects patient's participation in the labour force, how these affect their livelihoods and the coping strategies that such patients employ in dealing with the disease.

To find answers to some of the questions, you are invited to take part in this research project. If you accept you will be required to take part in a survey/interview where you will be asked questions concerning

Procedure: Since I cannot ask everybody to participate in the study, I have chosen a few of you to be involved in the study. In this regard you will be asked some questions if you agree to be a participant in this study. The questions will be on your personal experience with cancer. The interview will take a few minutes.

Risks and Discomfort: There is a slight risk of sharing your personal information with the researcher. If you feel uncomfortable talking about certain issues you may decline to answer questions on the same. However, the researcher does not wish this to happen.

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Benefits: There will be no direct benefit to you as an individual. However your participation is likely to help in formulating health policies on cancer and employment. If this is the case then your participation will benefit many people.

Incentives: Despite this you will not receive any incentive to take part in the research.

Confidentiality: Please note that there will be no use of your name in the report that will be written; neither your name nor the name of any person you may happen to mention be made public for any reason. If the information from your interview will be used in the report, your identity will not.be revealed. The data that will be obtained will remain confidential.

Participation and withdrawal: Your participation in this study is voluntary. You can therefore choose to participate or not. If you volunteer to participate, your participation to the end will be highly appreciated however, you can still withdraw your participation even in the middle of the interview if you fill uncomfortable with the interview.

Do you have any question at this moment concerning what you have read?

Who to contact: If you have a question you may ask it now or later. If you wish to ask later you may reach the research on the following contact.

MAAKA HELLEN NEKESA,
UNIVERSITY OF NAIROBI,
INSTITUTE FOR DEVELOPMENT STUDIES,
P.O BOX 30197- 00101, NAIROBI
CELL PHONE: 0711135006

Please sign this consent form as a confirmation for your acceptance to participate in the study. (*Should be signed after fully explaining the content of the informed consent form)*

Consent form

I have read the information in the informed consent form, or it has been read to me. I have had an opportunity to ask questions. I have understood the content. I consent to voluntarily participate in the study.

....

Participant's Name signature date

Researcher's signature

The informant willingly consented to participate in this study

.....

.... Name of

researcher Signature Date

Appendix ii: Survey Questionnaire

Effects of chronic debilitating diseases on livelihoods and coping strategies: a case of working-age cancer patients at Kenyatta National Hospital.

Please note that the recruited participants should have signed the informed consent form (appendix I) after getting full explanation of the content in the form.

Interviewee's code ----------

Interview date ---------- interviewers initials ----------

1.	Home of origin (county)	
2.	Sex male=1, female=2	
3.	What is your Age ---------- years	
4.	Marital status Not married=1, married=2, divorced=3, separated=4, widowed=5	
5.	Relationship to a household. head=1, spouse=2, son=3, daughter=4	
6.	Level of education. primary=1, secondary=2, college=3, university=4	
7.	Occupation. government=1, private=2, business=3, unemployed=4, any other=5	
8.	If number seven (7) is any other, specify ----------	
9.	What is your average salary ----------	
10.	Other sources of income ----------	
11.	When were you diagnosed? ----------	
12.	Type of cancer breast=1 prostate=2 cervical=3, thyroid=4, stomach=5, ovarian=6, lung=7, blood=8, colorectal=9, any other=0	
13.	If number 12 is any other, specify ----------	
14.	Type of treatment undergoing, chemotherapy=1, radiotherapy=2, surgery=3, hormonal treatment=4	
15.	Has cancer affected your ability to carry out daily activities? Yes=1, No=2.	
16.	Explain how----------	
17.	Has cancer in any way affected your knowledge? Yes=1, No=2	
18.	Why would you say that----------	
19.	Has cancer in any way affected your skills? Yes=1, No=	
20.	Explain ----------	

21.	Has cancer affected your employment? Yes=1, No=2	
22.	Explain this ----------	
23.	Has your suffering from cancer affected the participation in labour of any member of your household? Yes=1, No=2	
24.	How is that----------	
25.	Has suffering from cancer affected your income? Yes=1, No=2	
26.	In which way----------	
27.	Has suffering from cancer affected your other sources of income? Yes=1, No=2	
28.	Has cancer treatment affected your savings? Yes=1, No=2	
29.	Why would you say that---------- ----------	
30.	Has cancer affected your family life? Yes=1, No=2	
31.	Has cancer affected the life and schooling of children in your household? Yes=1, No=2	
32.	In which ways /---------- ----------	
33.	Has cancer affected your social roles to the family and society? Yes=1, No=2	
34.	In which way ---------- ----------	
35.	Have you ever sold your assets to raise money for your treatment? Yes=1, No=2	
36.	If number 28 is yes, name some of the assets ---------- ----------	
37.	Have you ever asked for assistance to help meet treatment cost? Yes=1, No=2	
38.	From whom ---------- ----------	
39.	Have you ever borrowed money to help foot the treatment bill? Yes=1, No=2	
40.	Where did you borrow money from ---------- --------	

Appendix iii: In-depth Interview Guide

Effects of chronic debilitating diseases on livelihoods and coping strategies: a case of working-age cancer patients at Kenyatta National Hospital.

Please note that the participant must have signed an informed consent form appearing in appendix I, after receiving full information on the content in it.

Interviewee code ----------

Date of interview ---------- Interviewer initials ----------

1. **Biographic data**

Age of the respondent----------

Sex----------

Marital status----------

Level of education----------

Employment ----------

Home of origin (county) ----------

Type of cancer suffering from ----------

Self-reported effects of cancer on labour force participation

2. Could you please tell me about your health, health problem? What is the name you give to the disease you are suffering from?
3. In your opinion what do you think cause the disease? What are its signs and symptoms?
4. How did you come to learn that you had this condition? Did you know about the disease before you were diagnosed?
5. What are the problems caused by the disease as it relates to your participation in the labour force?
6. What effects has the disease had on work and productivity of other members in your family?

Implication on livelihoods

7. What impact if any does the disease has on children's schooling, nutrition, bonding and the time you spent with them?
8. What change has occurred in role play if any in your family as a result of your suffering from cancer?
9. Tell me about the state of your income since you were diagnosed with the disease? *(Probe)* the impact on earning, household income, savings, and other assets.

Coping strategies

10. Since the onset of the disease, did you have to sell your property, goods or even borrow money at any one point? Where was most of the money thus generated used?
11. What other strategies do you use to source money for your daily spending and for your treatment?
12. Do you fell socially isolated or stigmatized?

Any other thing

13. From the discussion we have had, do you think you have any other thing that you would want me to know about?

Appendix iv: Key Informant Interview Guide

Effects of chronic debilitating diseases on livelihoods and coping strategies: a case of working-age cancer patients at Kenyatta National Hospital.

The key informant must have signed the informed consent form that is appearing in appendix I after he/she has received full information on the content of the said form.

Interviewee code ----------

Date of interview ---------- Interviewer initials ----------

Position (title) of the key informant----------

Cancer effects on labour participation

1. How often do you attend to cancer patients? From the records, what are the most common types of cancer reported by patients in this facility? Generally in which stage do most patients present themselves?
2. What treatments do you provide to them and for how long? Are the treatment expensive and how successful are they?
3. What do you know about the impact of cancer on patient's overall health, ability to participate in the labour force, and socio-economic implications?

Implication on livelihoods

4. People who are employed either have skills in what they are employed to do or knowledge of their work. What is the impact of cancer on such knowledge and skill?
5. What does this imply on their other activities, earnings, household income, savings and assets?

Coping strategies

6. When people are diagnosed with cancer are there cases when they sell their property, goods or even borrow money for their treatment?
7. Is cost a concern that needs to be addressed as it regards to cancer treatment? If so could you please describe the concern?

8. What would you say to advise people to do in order to prevent, control or to manage cancer?

Any other

9. From the discussion we have had, do you think there is any other thing that you may want to share with me about cancer?

Appendix v

Table 6: socio-demographics of In-depth interview participants

n= 15	Sex	Age	M. Status	Livelihood	C. Type	Diagnosed
1.	Man	32	Married	Casual	Foot	2010
2.	Man	43	Married	Business	Thyroid	2010
3.	Man	54	Married	Farming/B	Prostate	2009
4.	Man	55	Married	Lecturer/F	Sarcoma	2011
5.	Man	44	Married	Teaching/F	Mouth	2011
6.	Man	41	Married	Unemployed/F	Lung	2011
7.	Woman	59	Widowed	Casual	Cervix	2010
8.	Woman	51	Married	C. service/F	Breast	2008
9.	Woman	44	Married	Unemployed/F	Breast	2010
10.	Woman	37	Married	Teaching/F	Breast	2008
11.	Woman	50	Married	Unemployed/F	Stomach	2011
12.	Woman	49	Divorced	Farming/B	Cervix	2011
13.	Woman	50	Single	Tailoring	Eye	2010
14.	Woman	52	Married	Farming/B	Ovary	2009
15.	Woman	52	Married	Farming/B	Cervix	2010