

**THE PREVALENCE OF DEPRESSION AND BURDEN OF CARE  
AMONG FAMILY CARE GIVERS OF CANCER PATIENTS SEEN  
AT THE NAIROBI HOSPICE, NAIROBI, KENYA.**

**A DESERTATION SUBMITTED AS PART FULFILMENT FOR THE  
AWARD OF MASTERS OF SCIENCE IN CLINICAL  
PSYCHOLOGY**

**BY**

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## DECLARATION

I certify that this is my original work and it has not been presented for a degree in any other university

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## ACKNOWLEDGMENTS

I would like to thank:-

1. My supervisors, Professor David Ndeti and Dr Lincoln Khasakhala, for their encouragement, support, guidance and constructive criticism at all stages of this study.
2. My husband Mr. Peter Mungai and children Eunice, Monica, Julius and Joy for their moral support and encouragement and perseverance during this study period.

## **DEDICATION**

This work is dedicated to my children, Eunice, Monica, Julius and Joy.

## DEFINATION OF TERMS

1. **A family care giver:** applies to a person who cares for relatives and loved ones who are frail, elderly, or who have a physical or mental disability. (American society on aging.
2. **Care giver depression:** is a mood disturbance resulting from the stress of providing care that may be manifested as a feeling of loneliness, isolation, fearfulness, and being easily bothered.
3. **Caregiver's burden:** a multidimensional, biopsychosocial reaction resulting from an imbalance of care demands relative to caregiver's personal time, socio roles, physical and emotional states, financial resources, and formal care resources given the other multiple roles they fulfill

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## ABSTRACT

### Objectives

**General Objective:** To determine the prevalence of depression and burden of giving care among the care givers of terminally ill cancer patients

**Specific objectives:**

To determine the socio demographic variables of the study population

To determine the levels of depression among family care givers

To determine the burden of care among family care givers

To determine the association between the socio demographic variables and the levels of depression

To determine the association between the socio demographic variables and the burden of care.

**Study population:** Care givers of cancer patients registered at the Nairobi hospice and who meet the inclusion criteria over a period of one month

**Study design:** Cross sectional, Descriptive study

**Setting:** Nairobi hospice

**Methodology:** All family care givers visiting the Nairobi hospice for a period of one month were reviewed. Those who met the criteria completed the self administered socio demographic data form, Beck depression inventory and burden of care scales

**Main research variables:** The following variables in the care givers were sought: age, gender, education, relationship to the patient, employment status, patient cancer type, care givers burden and depression

**Results:** Care givers of cancer patients reported mild to moderate levels of depression. The younger the age of the care giver, the more the impact of depression. Cancer site, the level of dependency on the care giver and the distress symptoms experienced by the patients were causing a lot of distress to the care giver causing depression. The unemployed and those working part time were also severely affected by depression. The more educated care givers were less depressed and experienced less subjective burden. Heavy objective burden was reported in transport finances, treatment costs, children education, and care requirements materials and equipments. The feeling of subjective burden was evident in care givers who felt inadequate in providing the material requirements or being physically unavailable for their loved one. The social support

offered among the Kenyans of African origin was immense and this was shown by the low number of those affected by depression as compared to other studies done elsewhere.

**Conclusion:** Family care givers are at risk of developing depression and burden as a result of taking care of cancer patient. The care givers age, education, employment status, relationship with the patient, the period of care giving roles and social support may determine whether one gets depression or feels heavily burdened while giving care to a loved one.

## **CHAPTER 1.0**

### **INTRODUCTION.**

The diagnosis of terminal cancer has a profound effect on all the closest and most loving family members. The psychosocial crises it creates is severe, and quite unlike that of most other illness. Cancer is recognized by health professionals as a phenomenon experienced by the entire family, not just by the individual member diagnosed with the disease (1). The family is the principle source of biopsychosocial support for the sick. Spouses, children, parents and extended family members experience both mental and physiological health changes during a terminal illness in the family and in the bereavement period that follows. Continuing changes in health care have served to significantly increase demands on family caregivers. With an eye toward cost savings, patients are being discharged earlier from inpatient settings, treatments are now being given on an outpatient basis and sometimes even at home. In the light of these changes, family caregivers are assuming increasing responsibility for the care of their loved ones, often with little preparation. The knowledge obtained from this study will be important to improve the quality of care provided to the family caregivers of cancer patients.

#### **1.2 Background.**

The burden of providing care for patients with newly diagnosed cancer falls increasingly on the family and extends from diagnosis through treatment and death. The caregiver's response to the stressors engendered by caring for the patient with cancer might result in negative role perception. (2). Burden of care involves concrete events such as financial problems and personal activity limitations and also emotions related to fear or guilt and abandonment.

While the family was traditionally defined as an individual of blood relationship, a broad definition of family is most appropriate and best defined as those individuals considered family by the patient. Studies in oncology related to family care giving have generally found that approximately 70 percent of primary family care givers are spouses, 20 percent are children (of which daughters or daughters-in-law are most predominant), and 10 percent are friends or more distant relatives(3).

Care giving is a multifaceted role, ranging from simple activities such as providing transportation to the complexities of providing physical care and recognizing reportable symptoms. Also included in this process is being present to share patient's feelings of mortality and uncertainty. The concept of caregiver in this study will be used to refer to a member of the family who is involved in the provision of supervision or assistance to a relative suffering from cancer.

Care giver depression is a mood disturbance resulting from the stress of providing care that might be manifested by feelings of loneliness, isolation, fearfulness, and being easily bothered (4). Once a person has been diagnosed with a terminal illness like cancer, they require a lot of social and family support as they gradually go through the stages of dying. A 'good death' is said to be one in which a person is surrounded by loved ones and receives social support from the community instead of being isolated in a hospital bed alone, in pain, attached to a life support system.(4)

Hospice is a philosophy of care for the terminally ill people and their families that focus on palliation of symptoms and enhancing the quality of life during whatever time the patient has remaining. Hospice affirms life and neither hastens nor postpones death. The modern hospice begun in London, England, in 1967 when Dame Cecily Saunders started St Christopher's Hospice. Hospice programs must provide care using an interdisciplinary team. This team provides a variety of services including pain and symptom management, psychosocial and spiritual support, and bereavement services. All the components contribute to meeting the goal of comfort care for the patient and support for family members (5)

### **Statement of the problem.**

Family care givers of patients with cancer suffer ever increasing stress over the duration of their care giving experience as they take care of their loved ones with little or no training. The oncology nurses and other health care providers need to proactively anticipate the caregivers experience and begin assessment of psychological distress, and quality of life and provide interventions tailored to individual needs. The health care providers must also understand the burdens that are placed on family care givers if they are to assist caregivers in keeping patient's at home during their final months of life. Most family caregivers of patients with cancer tend to experience depression as they try to meet their needs and the patients needs simultaneously. Caregivers are usually working 'women with other families' responsibilities. Caring for a terminally ill patient is not only physically exhausting but also calls for a lot of emotional strength, spiritual, family and community social support. The personality of the care giver and that of the patient, their relationship and the site of the cancer determines the response and depressive symptoms experienced by the caregiver.

In Kenya, the Nairobi hospice opened its doors to the care of terminally ill patients in 1990. The main objective of the hospice movement is to provide care for the terminally ill in settings that are as close to everyday life as possible, and which emphasizes the need to reduce pain and suffering. The hospice also trains health workers in palliative care so that they can provide this service in other parts of the country and institutions where they are based. The other objective is to advocate the mainstreaming of palliative care in the curricula for training of doctors and health workers, and in the agenda of other health service providers.

If the care givers role is shifting to the family members it is important to look at the factors that contribute to distress, identify the people who are more likely to be victims and intervene early. This would go along way in ensuring that people do not fear death of one of their members as they prepare for their own eventual death. It would also instill confidence in the caregivers as fear is reduced and needs addressed but also reduce the burden of care and depression among the caregivers. More health workers need to be trained in palliative care and need to incorporate the care givers of terminally ill patients so that they can get adequate support and assistance.

#### **1.4 Justification of the study.**

In Kenya there is scarcity of data on family caregiver experiences of depression and burden when providing cancer care for a family member. The study was seeking to determine the prevalence of depression among family caregivers of cancer patients at the Nairobi hospice.

Regardless of the phase of cancer, care givers deal with obstacles that recur along the cancer continuum and the need for support occur throughout the disease trajectory. Identification of caregivers needs is the first step in planning interventions and therefore this study attempted to identify, categorize and asses the importance of needs expressed by caregivers and to determine how well these needs can be satisfied.



## CHAPTER 2.0

### 2. LITERATURE REVIEW

Caregiver depression is a mood disturbance resulting from the stress of providing care that might be manifested as feelings of loneliness, isolation, fearfulness, and being easily bothered. Caregiver depression is associated with burden of care which is considered a “multidimensional biopsychosocial reaction resulting from an imbalance of care demands relative to caregivers personal time, social roles, physical and emotional states, financial resources, and formal care resources given the other multiple roles they fulfill.” (6)

Family caregivers suffer tremendous stress as a result of providing increasingly intense care to the patients with advanced stage cancer. Caregivers report severe levels of depression that affect their daily functioning, quality of life, and ability to continue to provide care for their dying family members (7). The diagnosis with a potentially fatal disease in a family member can result in depression as a normal response to the loss and grief. Other factors may also severely exacerbate the normal response like chronic sleep deprivation (8). Numerous care givers responsibilities and responses to the patient’s condition, such as hyper vigilance and worry, may cause fatigue. Caregivers fatigue is significant when the care demands produce situations requiring constant, vigilant care and this lead to decreased quality of life for the caregiver. (9).

Care giving has a dramatic impact on the health and well-being of family caregivers. Between 40% and 70% of caregivers have been found to have clinically significant levels of depressive symptoms, and as many as 50% may meet criteria for a diagnosable depressive disorder at some point in their care giving careers. Caregivers have also been found to have an elevated risk of death compared with age- and sex-matched control subjects who are not providing care (10).

The studies of the adverse effects of care giving underscore the central role that families play in the care of people with a disease or disability. Although families have always cared for sick family members, both cultural and medical practice factors have made these responsibilities more difficult. (10) Notable changes in family life such as increased participation in the work place and decreased family size mean that there are fewer family members available to provide care. Those who are available may very likely have to work outside the home. In the area of medical care, decreasing length of hospital stays and decreased coverage for home health services result in families having to take on new tasks (e.g., providing intravenous medications, taking care of bladder catheters and managing home oxygen) that were previously performed by health care personnel. (10) Even in countries such as Sweden, that are generally known for providing services to people at home, families are being asked to provide more of the care. (10).

Issues of sexuality are often examples of divergent needs between patients and family care givers. Patients may have a continued or even stronger desire for sexual activity yet the partners may be reluctant to reciprocate due to either fear of physical harm, lack of stimulation due to physical changes or avoidance of intimacy with their loved ones given the prognosis. This may cause both the patient and the care giver to suffer stress and even depression. (3)

## **2.1 Burden of care**

Burden is the caregiver's response to the stressors engendered by caring for the patient with cancer that may result in negative role perception. It may be conceptualized as a multidimensional concept with objective and subjective components (11) Objective burden is defined as concrete events, happenings, and activities related to care giving, such as financial problems and personal activity limitations (11). Subjective burden is defined as affective response to the caregiver experience such as feelings and emotions related to fear, strain, or guilt (12). The emotional strain of care giving has been found to be more burdensome than activities related to providing care or disruptions in everyday

family life (13). Nijboer in 1998 reviewed the impact of care giving on caregivers and reported that cancer progression led to care tasks that caregivers perceived as either negative (burden) or positive. The caregiver's health was noted to be affected by these positive or negative effects. (14).

Approximately 25% of the United States population provides care to a family member or friend with a chronic or terminal illness. As the proportion of people living more than age 65 years increases, so will the number of chronically and terminally ill patients requiring care. Consequently, changes in demographics and health care delivery have heightened the burden of care giving for terminally ill patients. (15)

Lauren C. (2006), did a study in Ottawa of over 2,000 families caring for a family member with a serious illness, and found that nearly 20% of family caregivers quit work or made major life rearrangements to provide care, 31% of families lost most or all of their savings, and 29% of families reported loss of their main source of income. (15) For many family caregivers, care giving becomes a full time job. Given the magnitude of services provided and the sacrifices made by family caregivers, the adverse consequences of care giving have emerged as a serious public health concern. (15).

The burden of non-professional care giving for patients with terminal illness has been studied with regard to the physical, psychological, financial, social and employment effect it has on patients' families. Some studies have reported the use of all of the family's financial resources to pay for care and at times this has been compromised due to the reduction in the caregiver's income. There also tends to be a substantial reduction in social and leisure activities, and, when the caregiver is a parent, childcare is an added responsibility (16).

Grunfeld et al,(2006) in a longitudinal study on breast cancer patients and their principle caregivers in Canada found that caregivers experienced substantial psychological morbidity (anxiety and depression) at the onset of the patient's palliative illness and a substantial increase in caregiver burden and depression when the patient

reached a terminal stage of the illness (10) In addition to psychological morbidity, caregivers bore both economic and occupational burdens. Majority of caregivers experienced an adverse impact on their employment, particularly during the terminal period. In this study, 5% of caregivers had quit their job or declined advancement, and a large proportion lost work hours or used special leave or holidays to fulfill their care giving responsibilities. (10).

Cancer is responsible for 34% of all deaths in Italy. Therefore the effects on activities of daily living is becoming a public health problem where It has been estimated that about 90% of patients with cancer have a terminal care period, of which the average duration is about 3 months, during which time the disease does not respond to treatment and the goal of patient care shifts to maintaining the highest quality of life possible.(16) In Italy, the National Health Service provides free health assistance for all patients with cancer, independent of their insurance and economic status. Nevertheless, access to this assistance can be difficult; resulting in significant direct and indirect costs sustained by the patient and his/her family. Furthermore, some fundamental aspects of managing the last phase of life, such as accompanying the patient to medical appointments and assistance in activities of daily living, are not covered by the healthcare system, and are sustained entirely by the family. (16)

In an analysis study carried out for 1231 non-professional caregivers in Italy to assess the relevant changes in the family and difficulties in work and leisure activities. All 35% of the non-professional caregivers declared that the illness provoked major changes in the life of the family in the last 3 months of life of the patient, in 24% of the cases at least one relative quit, reduced or changed employment, 8% changed their personal or social life.(16)

## **2.2 Care giver challenges along the cancer continuum**

The psychosocial impact of cancer on the family can be presented within a framework of six phases of cancer: diagnosis, hospital, post hospital, adjuvant treatment, recurrence and terminal. During the initial phase of illness, caregivers are faced with many of the same feelings of anxiety, anger, and helplessness as the patient (17). At this

time caregivers have their first exposure to navigating the health care system. They may feel ignored or excluded by the medical personnel who attend to the patient. They may also have difficulty communicating their questions and information needs. Spouse caregivers may have trouble expressing concerns to their ill partners.(17)

Hospitalization is a period of acute stress for families. Caregivers find themselves in the position of helping patients to cope with the physical and emotional traumas of surgery, radiation and chemotherapy. In addition to visiting the patient and providing emotional support, caregivers are often forced to assume multiple roles vacated by the patient during hospitalization. These demands can result in feelings of overload and exhaustion. On leaving the hospital, the caregiver is faced with having to deal with the day to day challenge of living with cancer. Lewis (18) described the challenge as facing "the reality that cancer is a chronic illness is a part of the family's state of being and may require restructuring of the family environment". If a patient has physical limitations, the caregiver has the task of adapting his or her preexisting lifestyle to the patient's needs. Direct care giving tasks may take priority over the caregiver's usual activities. The economic realities of treatment become clear and may involve significant financial burden. (17)

During the treatment phase, patients and caregivers find themselves again interacting repeatedly with health care providers. Frequent visits for radiation treatments or chemotherapy pose time and transportation problems. The caregivers are faced with coordinating treatment visits for the patient while maintaining connection to their work. Recurrence creates emotional distress rivaling that created by the initial diagnosis. Caregivers can no longer deny the possibility of death, and hope erodes (17).

In the terminal stage the disease interferes with normal functioning and caregivers assume added responsibilities. During this phase they have the additional task of providing emotional support to the dying person. Isolation and loneliness peak for the caregiver during the terminal phase. Family members are faced with their own feelings of loss and separation and may experience acute anticipatory grief reactions. (19).

Regardless of the phase of cancer, caregivers deal with obstacles that recur along the cancer continuum. Anxiety, feelings of helplessness and loss, and the need for support occur throughout the disease trajectory. Caregivers often face emotional strain, uncertainty, fear, role changes, and financial issues throughout the course of illness (20). An increasing number of individuals are caring for patients with cancer throughout their illness. The oncology health care team can play a vital role in supporting caregivers as they make this difficult journey with their loved one.

### **2.3 Caregiver distress**

Family members of patients with cancer experience distress as a result of care giving roles, and these have been shown to continue over time and may be exacerbated by changes in the patient's condition. (21). The emotional impact of providing care is linked to the caregiver negotiations of care giving role because caregivers may be unfamiliar with the care they must provide and may not be aware of or able to use available resources. (22). Specifically, caregivers may experience distress from assuming the responsibility for communicating with health care professionals, managing symptoms, administering medications, performing complex medical or nursing treatments and handling patient's behavioral problems and emotional reactions (23).

### **2.4 Correlates of care giver distress.**

Consistently reported predictors for caregiver distress include caregiver gender, level of personal and social support, patient's functional status and patient symptom status. In general female caregivers and caregivers with lower levels of personal and social support experience higher levels of distress. Caregiver distress resulting from the

patient's functional status involves the caregiver's level of assistance with activities of daily living.(23)

Bandura in 1986 (24) Stated that caregiver burden is related to the degree of self-efficacy the caregiver feels over a particular situation and that it is the individual's perceived rather than actual capabilities that influence behavior. In accordance to Bandura, caregiver burden may come from a need to increase the caregiver's self-efficacy. If caregivers increase their skill level, they will feel more competent to handle the challenging demands of symptom management and care giving, therefore increasing self efficacy. Caregiver's optimism was also found to decrease the perception of burden. A positive appraisal of a situation led to a decreased feeling of burden and a potential exists for change in the level of burden over the disease trajectory (25).

## **2.5 Cultural Differences in Palliative Care**

In sub-Saharan cultures personhood is perceived in the context of 'familial self', characterized by togetherness and interdependence among members of a close-knit extended family. A sick person will be visited not only by his family and extended family but also by the entire village community. An adult African at his death bed would like to be surrounded by his children and grandchildren. Dying in isolation suggests poverty and implies lack of love by his family. Bereavement support is also provided by family members and relatives as long as it is needed. Because of his immense support, depression and burden of care are reduced remarkably. However the modernization process leads to the passing away of traditional practices and values.(3)

Among the Chinese patients with terminal cancer, Symbolic interactions among family members, which provide psychosocial support, are often expressed in delicate, subtle and sometimes paradoxical ways. Death remains a taboo subject. Breaking bad news to the patient and the family is often a delicate and complex process. Chinese patients and members of their families' often express their emotions in subtle and nonverbal ways and somatization is a common presentation of underlying depression. (3)

Siew Tzuh et al (2005) in a cross-sectional study conducted in Taiwan, found the Taiwanese family caregivers were at an extraordinary high risk of clinical depression of 75.9%. This was mainly attributed to the cultural groups that tend to somatize psychological problems.(26)

In Japan there is a strong negative image of death, a subject which has typically been taboo in the twentieth century. Doctors in Japan may reveal the diagnosis to the family members but not to the patient they are often uncertain about their own ability to help and support the patient after the disclosure. People in Japan particularly older people want to die at home. (3). In a study by Tatsuo Akechi et al (2006) in Japan, up to 63.8% of family care givers were referred for psychiatric consultation because of depression arising from taking care of their loved ones in Japanese families.(27)

This study will show the specific groups of caregivers who are at risk for negative outcomes and individualized interventions will improve the emotional health of caregivers of patients with cancer.



## CHAPTER 3.0

### 3. METHODOLOGY

#### 3.1 Research design

A Cross sectional, Descriptive, study.

#### 3.2 Hypothesis

##### Null hypotheses:

There is no burden or depression associated with family care giving to the cancer patients.

##### Alternate hypotheses:

There is a high level of depression and burden among family caregivers of cancer patients at the Nairobi hospice.

#### 3.3 Objectives of the study

##### 3.3:1 General objective were:

- 1 To determine the prevalence of depression and burden of giving care among the caregivers of terminally ill cancer patients.

### **3.3:2 Specific objectives were:**

- 2 To determine the socio-demographic variables of the study population
- 3 To determine the levels of depression among family care givers.
- 4 To determine the burden of care among family care givers.
- 5 To determine the association between the socio-demographic variables and the levels of depression.
- 6 To determine the association between the socio-demographic variables and the burden of care.

### **3.4 Study population**

Caregivers of cancer patients registered at the Nairobi hospice and who met the inclusion criteria over a period of one month between the month of October and November.

### **3.5 Study area**

The Nairobi hospice (Terminal care centre) is a charitable nonprofit registered organization that cares for, and supports, terminally ill patients, with full participation of families. It is an out patient facility, the first of its kind in East Africa. The hospice mission is to provide and promote quality and cost effective palliative care for the terminally ill. Among other objectives of the Nairobi hospice are to train health workers in palliative care. The care offered is holistic encompassing medical, psychological, emotional and spiritual among other, components whose sum total makes it so very special for the terminally ill patient, hence their motto is ‘ put life into their days, not just days into their life’’. The Nairobi hospice is situated a few meters from the casualty

department of Kenyatta National Hospital within Nairobi city. The land on which the hospice was built was provided by Kenyatta National Hospital Board of management. It was opened in 1990 and is being used to provide out patient and homecare services for the terminally ill.

The hospice depends on local and overseas donations for financial support and is looking after an average of 150-200 patients at any given time. The hospice patients are scattered all over Nairobi and the organization is capable of looking after patients within a radius of 20 kilometers.

### 3.6 Instruments

A total of three questionnaires were used.

1. A specially designed questionnaire was used to obtain information on the social-demographic characteristics of the family caregivers.
2. Beck Depression Inventory (**BDI**) The original BDI, first published in 1961 was created by Dr. Aaron T. Beck in 1961, (47) and later revised in 1971. The contents of BDI were obtained by consensus from clinical settings regarding symptoms of depressed patients (28). The revised BDI items are consistent with 6 of the nine DSM-III categories for the diagnosis of depression (29). These earlier versions consist of 21 questions about how the subject was feeling in the last week. Internal consistency is good, with a Cronbach's alpha co-efficient of around 0.85 (30). It is also positively correlated with the Hamilton Depression Scale (Brown et al., 1995) with a Pearson ratio of 0.71. The test was also found to have high one-week test-retest reliability with a Pearson value of 0.93 (31). The BDI is a self-administered self report which takes approximately 10 minutes to complete with demonstrated consistent properties over time and situation over and above what has already been said. Internal consistency for the BDI ranges from 0.73 to 0.92 with a mean of 0.86 (32). The BDI demonstrates high internal consistency, with alpha coefficients of 0.86 and

0.81 for psychiatric and non-psychiatric population, respectively (28). A meta-analysis of studies on the revised BDI's psychometric properties by Richter et al (1998) report advantages with the revised BDI's high content validity and validity in differentiating between depressed and non-depressed people. Beck, Steer and Garbin (1988) reported that the revised BDI has been found to include 3-7 factors, depending on the method of factor extraction. These include factors that reflect negative attitudes towards self, performance impairment and somatic disturbances, as well as a general factor of depression (33). Correlations with clinician ratings of depression using the revised BDI ranged from 0.62 to 0.66 (34). Clinical ratings for psychiatric patients are reported as being high to moderate ranging from 0.55 to 0.96 Mean = 0.72 (47). Groth-Marnat (1990) reported moderate correlations between the revised BDI and other scales measuring depression such as the Hamilton Psychiatric Rating Scale for depression (.073) and the Zung Self Reported Depression Scale (.76). However, some shortcomings of BDI on construct validity have been reported by Groth-Marnat (1990), who reported that controversy exists over whether the revised BDI is measuring state or trait variables. In 1996, the BDI was revised (28) to what is referred to as BDI-II and which is what was used in this study. The 1996 version of BDI was created to fall in line with the DSM-IV criteria for depression. Like the original BDI, the BDI-II contains 21 questions, each answer being scored on a scale value of 0-3.

#### Interpretation of the BDI

Add up the score for each of the 21 questions and obtain the total score. The highest score for each of the twenty one questions is 3, the highest possible total for the whole test is 63. The lowest possible score for the whole test is zero. Only one score per question.

3. Burden of illness questionnaire was used to measure subjective and objective burden experienced by the care giver as shown below:

a) Subjective burden

Impact of illness on work/employment, income/finance, household interaction, relationship with children and social life, each item was rated on likert scale 1-4 and indexed to broad categories, with higher scores indicating more problems. These indices are shown in table 1.

Table 1: The negative impact of patients' illness on the family

Area of relative affected	<i>Max scores</i>
Work/employment	12
Income/finance	20
Household interaction	16
Relationship with children	8
Social life	28

b) Objective burden

1. Finances and income
2. Household interactions
3. Children's education: this is adversely affected by financial problems, children's psychological conditions and children's absenteeism.
4. Stigmatization towards the family and patients

This has a yes or no answers, results are the calculated in percentages. (35)

### 3.8 Eligibility criteria

#### a) Inclusion

- The family caregiver above 18 years of age.
- Care givers who voluntarily agreed to participate.
- The caregivers who were family members to cancer patients
- Patient enrolled at the Nairobi hospice.

#### b) Exclusion

- 1 Those who did not consent into the study
- 2 Non family caregivers

### 3.9 Ethical consideration

This study was dealing with human subjects and as such care was taken to ensure that the participants emerged from the experience unharmed. The investigator sought informed consent from the participants after an explanation was given pertaining to the study. No risks was anticipated but psychological risks could not be ruled out as some people may experienced negative emotions when discussing imminent death of a loved one. The participants were assured of confidentiality of the information they were providing and use of names was avoided; a serialized coding system was used. There were no material benefits to the study participants. The participants were made aware that they can withdraw from the study if they felt uncomfortable to continue to participate without fear as there were no penalties or victimization because of doing so. The participants could contact the investigator incase of any issues they wanted to discuss and

telephone contact was be provided. Results of the study were disclosed to those who requested.

Before collection of data, approval was obtained from the department of Psychiatry; University of Nairobi and Kenyatta National Hospital Research and Ethic Committee. Permission was also sought from the Nairobi Hospice to carry out the research in their environment and for the assistance in terms of identifying the caregivers who met the set inclusion criteria.

### **3.10 Data collection**

The subjects completed the questionnaires in the quiet Nairobi hospice outpatient waiting area. The investigator provided the questionnaires, answered the participant's questions and retrieved the questionnaires on completion. For those participants who required help in filling up the questionnaire, the investigator read out the questions as they appear on the questionnaire without trying to interpret anything. If it was not clear the same was repeated and read again to the participants satisfaction. The participating care givers were assured of confidentiality of the information they provided and use of names were avoided, a serialized system was used. The contacts of the investigator was given incase they wanted to communicate anything of concern later. Because the subjects might experience increased caregiver burden as a result of answering many questions, primary care givers were informed that they could take a break at any time during the questionnaire completion that took approximately 45 minutes. The investigator thanked each and every participant for agreeing to be part of the research study.

At the completion of every data collection day, the completed questionnaires were put in a specially designed box and sealed. Only the principle investigator opened the ballot boxes.

## **Flow chart of data collection.**

- A. Selection of participants.
  
- B. Informed consent explanation and consent from caregivers to participate in the study
  
- C. Self administered questionnaires on socio-demographic data Beck's depression inventory, and burden of care, will be filled by the caregiver at the Nairobi hospice outpatient waiting area.
  
- D. Data analysis
  
- E. Results presentation
  
- F. Discussion presentation
  
- G. Completion of the dissertation



### 3.11 Data analysis

The statistical package for social sciences (SPSS) version 13 for widows was used to analyze the data by applying descriptive and inferential statistics. The results were presented in narratives, bar charts, tables, and pie charts

## 4.0 RESULTS

In this study a total of 111 care givers of the Nairobi hospice patients were interviewed between the month of October and November 2007. All the care givers were Kenyans of African origin.

Table 2: The Social Demographic Characteristics of care givers at the hospice.

		No.	%
Age Group	19-25	11	9.9
	26-33	18	16.2
	34-38	22	19.8
	39-46	19	17.1
	47-51	19	17.1
	52-60	16	14.4
	61-74	6	5.4
	Total	111	100.0
Gender	Male	49	44.1
	Female	62	55.9
	Total	111	100.0
Marital Status	Married	89	80.2
	Single	16	14.4
	Windowed	2	1.8
	Separated	4	3.6
	Divorced	0	.0
	Total	111	100.0
	Education Completed	Never	2
Primary school		34	31.2
Secondary school		41	37.6
College graduate		17	15.6
University graduate		15	13.8
Total		109	100.0
Religion	Catholic	42	37.8
	Muslim	2	1.8
	Protestant	67	60.4
	Total	111	100.0

Figure 1: A pie chart showing the caregiver's number of children

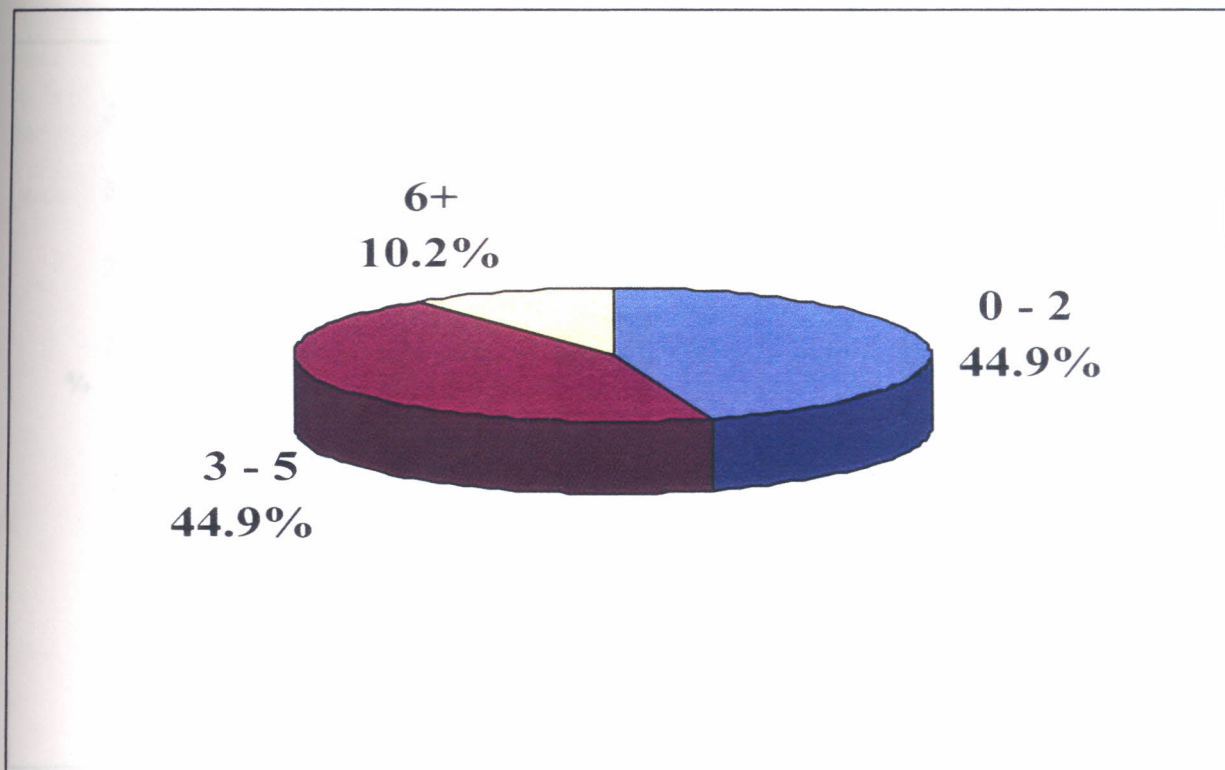


Figure2: A histogram showing the caregivers employment Status

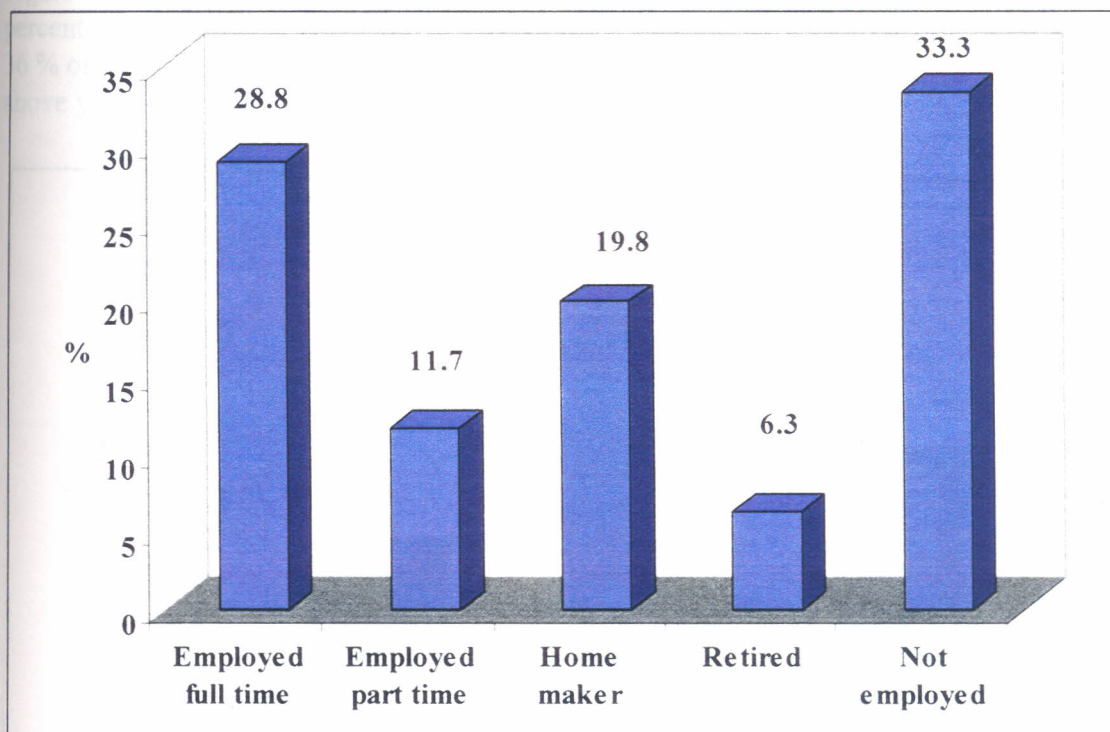


Figure 3: A histogram showing the caregivers years / months in care giving roles in percentages  
36 % of the care givers had served the clients for 7 months to 1 year, 32.5% for 2 and above years and 31.5% served for less than 6 months.

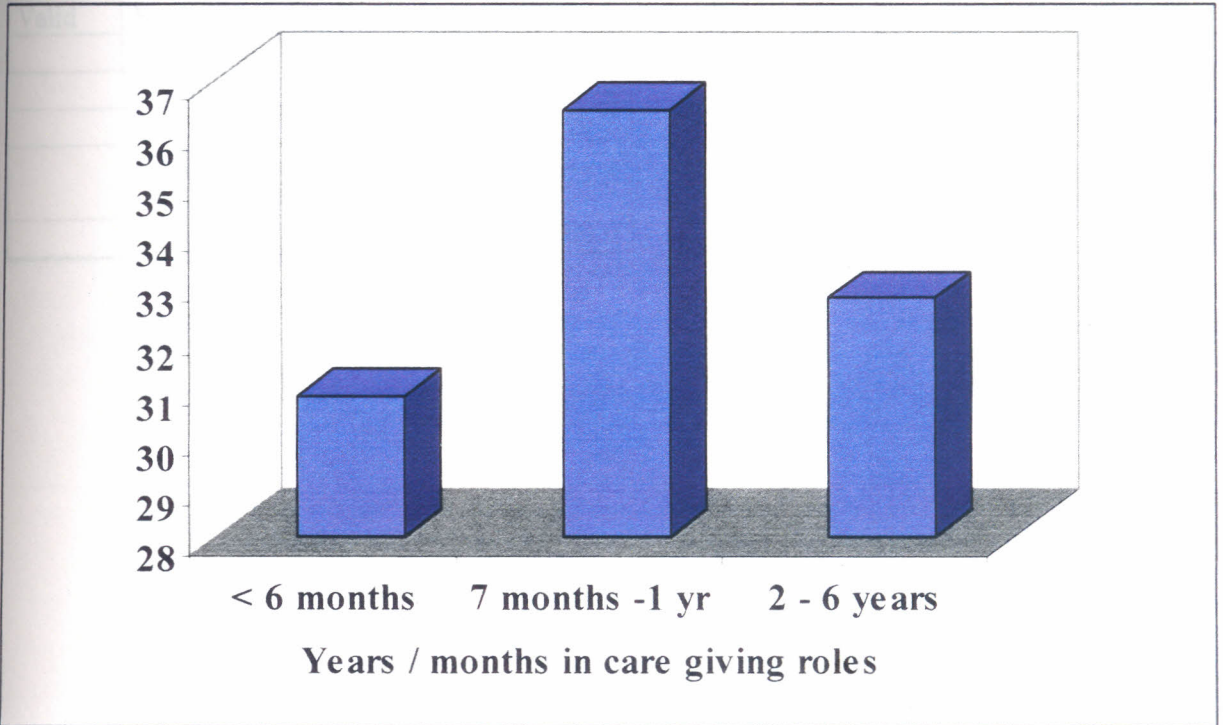


Table 3: Showing the care givers relation to the client

Relationship		Frequency	Percent
Valid	Parent	29	26.1
	Brother/Sister	11	9.9
	Children	28	25.2
	Spouse	18	16.2
	Others	25	22.5
	Total	111	100.0

Figure 4: A pie chart showing the clients living arrangements

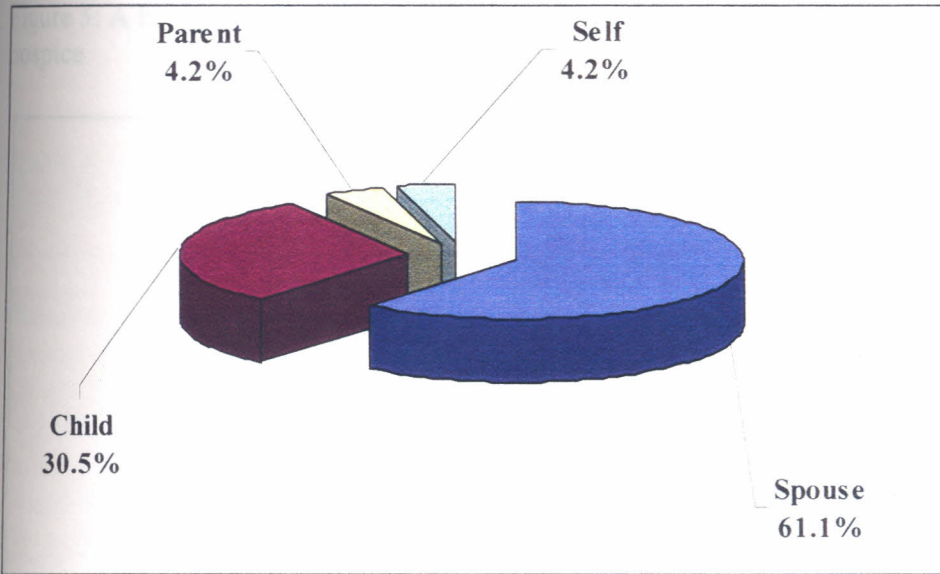


Figure 5: A histogram showing the interventions that the client had before referral to the hospice

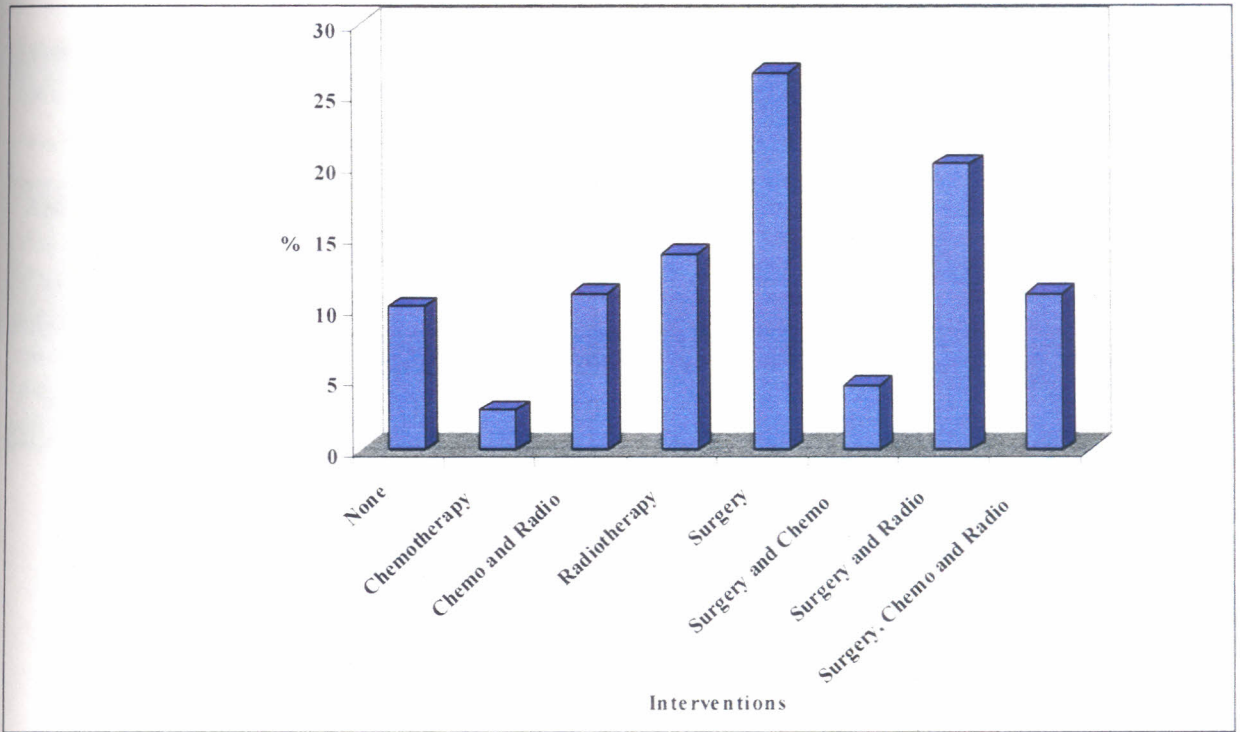




Table 3: Six  
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Table 4: Showing the client's cancer stage at diagnosis and at the time of referral  
 Early stage is stage i and ii, late stage is stage iii and iv

		No	%
Stage of cancer at diagnosis	Early	24	22.4
	Late	83	77.6
	Total	107	100.0
Patient's cancer stage at referral	Early	15	14.2
	Late	91	85.8
	Total	106	100.0

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Table 5: Showing the impact of cancer illness on the caregiver in relation to work, income, household interactions, care givers relationship with their children and caregivers social life

		No	%
Work/employment	Not Affected	13	17.3
	Mild	17	22.7
	Moderate	26	34.7
	Severe	19	25.3
	Total	75	100.0
Income/finance	Not Affected	0	.0
	Mild	11	9.9
	Moderate	28	25.2
	Severe	72	64.9
	Total	111	100.0
Household interaction	Not Affected	0	.0
	Mild	8	7.2
	Moderate	52	46.8
	Severe	51	45.9
	Total	111	100.0
Relationship with children	Not Affected	2	1.9
	Mild	42	40.0
	Moderate	29	27.6
	Severe	32	30.5
	Total	105	100.0
Social Life	Not Affected	49	44.1
	Mild	42	37.8
	Moderate	13	11.7
	Severe	7	6.3
	Total	111	100.0

Table 6: 5  
Assessed

Figure 6: A pie chart showing the depression levels of the care givers in percentages as assessed using the Beck's depression inventory

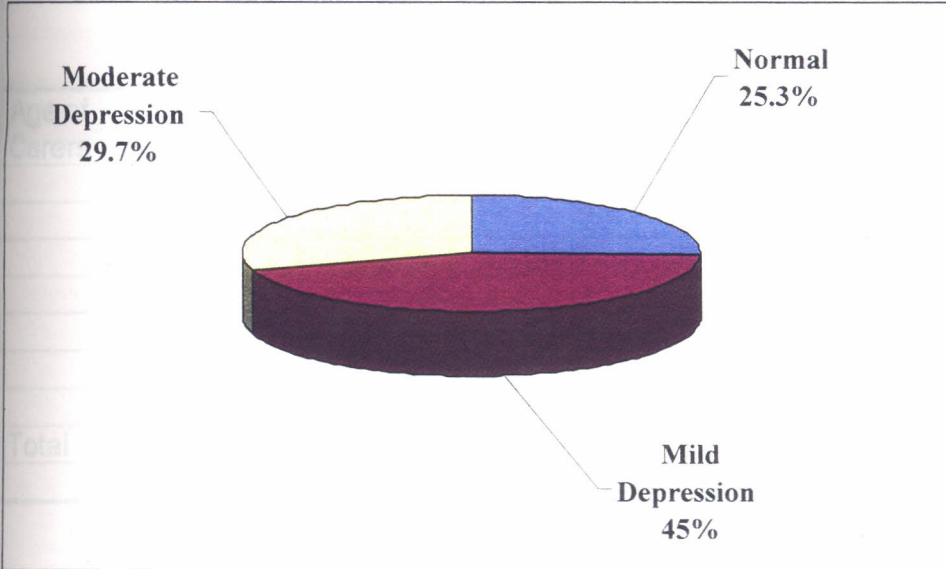


Table 6: Showing the correlation between the age of the caregiver and depression. The caregivers age affected the depression levels. The younger the care giver the more affected they became. (p=0.015)

		BDI Scores			Total
		Normal	Mild Depression	Moderate Depression	
Age of Carers	19-30	5	9	11	25
		20.0%	36.0%	44.0%	100.0%
	31-45	10	26	7	43
		23.3%	60.5%	16.3%	100.0%
	46-65	13	15	12	40
		32.5%	37.5%	30.0%	100.0%
	66+	0	0	3	3
		.0%	.0%	100.0%	100.0%
Total		28	50	33	111
		25.2%	45.0%	29.7%	100.0%

Table 7: Showing the correlation between the relationship of the caregiver to the patient and depression.

There was a statistical relationship between the relation of the care giver to the patient and depression ( $p=0.026$ )

		BDI Scores			Total
		Normal	Mild Depression	Moderate Depression	
Relation to the patient	Parent	9	11	9	29
		31.0%	37.9%	31.0%	100.0%
	Brother/Sister	2	2	7	11
		18.2%	18.2%	63.6%	100.0%
	Children	9	12	7	28
		32.1%	42.9%	25.0%	100.0%
	Spouse	2	8	8	18
		11.1%	44.4%	44.4%	100.0%
	Others	6	17	2	25
		24.0%	68.0%	8.0%	100.0%
Total		28	50	33	111
		25.2%	45.0%	29.7%	100.0%

Table 8

Table 8: Showing the education of the caregiver in relation to depression. The care givers with low education level were more depressed as a result of care giving roles( $P=0.016$ ).

		BDI Scores			Total
		Normal	Mild Depression	Moderate Depression	
Education Completed	Never	0	0	2	2
		.0%	.0%	100.0%	100.0%
	Primary school	4	16	14	34
		11.8%	47.1%	41.2%	100.0%
	Secondary school	9	21	11	41
		22.0%	51.2%	26.8%	100.0%
	College graduate	8	7	2	17
		47.1%	41.2%	11.8%	100.0%
	University graduate	7	6	2	15
		46.7%	40.0%	13.3%	100.0%
Total		28	50	31	109
		25.7%	45.9%	28.4%	100.0%

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Table 10

Table 9: Shows the correlation between care givers employment Status and depression

There was a strong statistical relationship between care givers employment status and depression. Unemployed care givers suffered more of moderate depression, retired had a small number and hence may not be compared ( $p=0.001$ )

		BDI Scores			Total
		Normal	Mild Depression	Moderate Depression	
Employment Status	Employed full time	14	14	4	32
		43.8%	43.8%	12.5%	100.0%
	Employed part time	4	8	1	13
Total		30.8%	61.5%	7.7%	100.0%
	Home maker	0	15	7	22
		.0%	68.2%	31.8%	100.0%
	Retired	1	2	4	7
		14.3%	28.6%	57.1%	100.0%
	Not employed	9	11	17	37
		24.3%	29.7%	45.9%	100.0%
Total		28	50	33	111
		25.2%	45.0%	29.7%	100.0%

Table 10: showing the age of the caregiver in relation to Work/employment. There was a strong statistical relationship between age of the care giver and work. The work of the younger care givers was more affected by the care giving roles (p=0.000)

		Work/employment				Total
		Not Affected	Mild	Moderate	Severe	
Age of Carers	19-30	5	0	0	5	10
		50.0%	.0%	.0%	50.0%	100.0%
	31-45	0	9	13	10	32
		.0%	28.1%	40.6%	31.3%	100.0%
	46-65	6	8	13	4	31
		19.4%	25.8%	41.9%	12.9%	100.0%
	66+	2	0	0	0	2
		100.0%	.0%	.0%	.0%	100.0%
Total		13	17	26	19	75
		17.3%	22.7%	34.7%	25.3%	100.0%

Table 11: The age of caregivers in relation to Income/finance. There is a strong statistical relationship between age of the care givers and income the ages between 46-65 were more severely affected (p=0.000)

		Income/finance			Total
		Mild	Moderate	Severe	
Age of Carers	19-30	0	11	14	25
		.0%	44.0%	56.0%	100.0%
	31-45	7	12	24	43
		16.3%	27.9%	55.8%	100.0%
	46-65	2	5	33	40
		5.0%	12.5%	82.5%	100.0%
	66+	2	0	1	3
		66.7%	.0%	33.3%	100.0%
Total		11	28	72	111
		9.9%	25.2%	64.9%	100.0%



Table 12: Age of caregivers in relation to household interaction  
 There was a strong statistical relationship between age and house hold interactions. The older the care giver the more the household interaction was affected (p=0.000)

		Household interaction			Total
		Mild	Moderate	Severe	
Age of Carers	19-30	6	13	6	25
		24.0%	52.0%	24.0%	100.0%
	31-45	2	25	16	43
		4.7%	58.1%	37.2%	100.0%
	46-65	0	12	28	40
		.0%	30.0%	70.0%	100.0%
	66+	0	2	1	3
		.0%	66.7%	33.3%	100.0%
Total		8	52	51	111
		7.2%	46.8%	45.9%	100.0%

Table 13: Age of the caregiver in relation to Social Life.  
 A statistical relationship exists between the age of the care givers and social life (p=0.001)

		Social Life				Total
		Not Affected	Mild	Moderate	Severe	
Age of Carers	19-30	10	12	3	0	25
		40.0%	48.0%	12.0%	.0%	100.0%
	31-45	12	19	8	4	43
		27.9%	44.2%	18.6%	9.3%	100.0%
	46-65	27	10	0	3	40
		67.5%	25.0%	.0%	7.5%	100.0%
	66+	0	1	2	0	3
		.0%	33.3%	66.7%	.0%	100.0%
Total		49	42	13	7	111
		44.1%	37.8%	11.7%	6.3%	100.0%

Table 14: Showing the care givers gender in relation to household interaction  
 There is a statistical relationship between gender and household interactions.  
 Males were more affected than females (p=0.040)

		Household interaction			Total
		Mild	Moderate	Severe	
Gender	Male	2	18	29	49
		4.1%	36.7%	59.2%	100.0%
	Female	6	34	22	62
		9.7%	54.8%	35.5%	100.0%
Total		8	52	51	111
		7.2%	46.8%	45.9%	100.0%

Table 15: Showing the education of the care giver in relation to Income/finance  
 A strong statistical relationship between education of the care giver and income.  
 The less the education level the more the income was affected (p=0.000)

		Income/finance			Total
		Mild	Moderate	Severe	
Education Completed	Never	0	0	2	2
		.0%	.0%	100.0%	100.0%
	Primary school	0	0	34	34
		.0%	.0%	100.0%	100.0%
	Secondary school	6	12	23	41
		14.6%	29.3%	56.1%	100.0%
	College graduate	2	6	9	17
		11.8%	35.3%	52.9%	100.0%
	University graduate	3	10	2	15
		20.0%	66.7%	13.3%	100.0%
Total		11	28	70	109
		10.1%	25.7%	64.2%	100.0%

Table 16: Education of the caregiver in relation to household interaction  
 There was a statistical relationship between education and household interaction  
 ( $p=0.001$ )

		Household interaction			Total
		Mild	Moderate	Severe	
Education Completed	Never	0	0	2	2
		.0%	.0%	100.0%	100.0%
	Primary school	2	9	23	34
		5.9%	26.5%	67.6%	100.0%
	Secondary school	2	27	12	41
		4.9%	65.9%	29.3%	100.0%
	College graduate	4	5	8	17
		23.5%	29.4%	47.1%	100.0%
	University graduate	0	11	4	15
		.0%	73.3%	26.7%	100.0%
Total		8	52	49	109
		7.3%	47.7%	45.0%	100.0%

Table 17: Education care giver in relation to children

There is a statistical relationship between care givers education and relation to children. College graduates were more affected ( $p=0.040$ )

		Relationship with children				Total
		Not Affected	Mild	Moderate	Severe	
Education Completed	Primary school	2	16	8	6	32
		6.3%	50.0%	25.0%	18.8%	100.0%
	Secondary school	0	10	14	15	39
		.0%	25.6%	35.9%	38.5%	100.0%
	College graduate	0	4	5	8	17
		.0%	23.5%	29.4%	47.1%	100.0%
	University graduate	0	10	2	3	15
		.0%	66.7%	13.3%	20.0%	100.0%
Total		2	40	29	32	103
		1.9%	38.8%	28.2%	31.1%	100.0%

Table 18:

Employment Status of the care giver in relation to Work/employment  
 A statistical relationship exists between employment of the care giver and work,  
 the ones working part time were more affected ( $p=0.028$ )

		Work/employment				Total
		Not Affected	Mild	Moderate	Severe	
Employment Status	Employed full time	4	4	2	2	12
		33.3%	33.3%	16.7%	16.7%	100.0%
	Employed part time	0	0	3	4	7
		.0%	.0%	42.9%	57.1%	100.0%
	Home maker	4	5	8	3	20
		20.0%	25.0%	40.0%	15.0%	100.0%
	Retired	3	2	0	0	5
		60.0%	40.0%	.0%	.0%	100.0%
	Not employed	2	6	13	10	31
		6.5%	19.4%	41.9%	32.3%	100.0%
Total		13	17	26	19	75
		17.3%	22.7%	34.7%	25.3%	100.0%

Table 19: Employment Status of the caregiver in relation to Income/finance  
 A strong statistical relationship exists between employment status and income.  
 The homemakers and unemployed were more affected ( $p=0.000$ )

		Income/finance			Total
		Mild	Moderate	Severe	
Employment Status	Employed full time	5	15	12	32
		15.6%	46.9%	37.5%	100.0%
	Employed part time	2	6	5	13
		15.4%	46.2%	38.5%	100.0%
	Home maker	0	2	20	22
		.0%	9.1%	90.9%	100.0%
	Retired	2	2	3	7
		28.6%	28.6%	42.9%	100.0%
	Not employed	2	3	32	37
		5.4%	8.1%	86.5%	100.0%
Total		11	28	72	111
		9.9%	25.2%	64.9%	100.0%

Table 20: Employment Status in relation to household interaction  
 A statistical relationship exists between employment status of the care giver in relation to house hold interactions. Unemployed were more affected (p=0.009)

		Household interaction			Total
		Mild	Moderate	Severe	
Employment Status	Employed full time	2	17	13	32
		6.3%	53.1%	40.6%	100.0%
	Employed part time	0	11	2	13
		.0%	84.6%	15.4%	100.0%
	Home maker	0	12	10	22
		.0%	54.5%	45.5%	100.0%
	Retired	0	3	4	7
		.0%	42.9%	57.1%	100.0%
	Not employed	6	9	22	37
		16.2%	24.3%	59.5%	100.0%
Total		8	52	51	111
		7.2%	46.8%	45.9%	100.0%

Table 21: Employment Status of the care giver in relation to Social Life  
 There is a statistical relationship between employment and social life. The home makers and unemployed were more affected ( $p=0.022$ )

		Social Life				Total
		Not Affected	Mild	Moderate	Severe	
Employment Status	Employed full time	13	15	4	0	32
		40.6%	46.9%	12.5%	.0%	100.0%
	Employed part time	9	0	4	0	13
		69.2%	.0%	30.8%	.0%	100.0%
	Home maker	10	7	2	3	22
		45.5%	31.8%	9.1%	13.6%	100.0%
	Retired	2	3	2	0	7
		28.6%	42.9%	28.6%	.0%	100.0%
	Not employed	15	17	1	4	37
		40.5%	45.9%	2.7%	10.8%	100.0%
Total		49	42	13	7	111
		44.1%	37.8%	11.7%	6.3%	100.0%



Table 22: Care givers period of care giving roles ( in months/years) in relation to Work/employment

There is a statistical relationship between period of caring and work. The care givers serving client for 2-6 years were more affected (p=0.000)

		Work/employment				Total
		Not Affected	Mild	Moderate	Severe	
Years / months in care giving roles	< 6 months	1	3	7	2	13
		7.7%	23.1%	53.8%	15.4%	100.0%
	2 - 6 years	6	3	3	15	27
		22.2%	11.1%	11.1%	55.6%	100.0%
	7 months -1 yr	4	11	16	2	33
		12.1%	33.3%	48.5%	6.1%	100.0%
Total		11	17	26	19	73
		15.1%	23.3%	35.6%	26.0%	100.0%

Table 23: Care givers period in care giving roles (in months/ years) in relation to Income/finance

There is a statistical relationship between period of care and income. The longer the period of care giving roles the more the care givers were affected

		Income/finance			Total
		Mild	Moderate	Severe	
Years / months in care giving roles	< 6 months	6	14	13	33
		18.2%	42.4%	39.4%	100.0%
	2 - 6 years	0	6	29	35
		.0%	17.1%	82.9%	100.0%
	7 months -1 yr	2	7	30	39
		5.1%	17.9%	76.9%	100.0%
		8	27	72	107
		7.5%	25.2%	67.3%	100.0%

Table 24: Relation of the caregiver to the client and how it affects the caregivers children.

There is a statistical relationship between relation of care giver to client and children. The spouse relation was more severely affected ( $p=0.015$ )

		Relationship with children				Total
		Not Affected	Mild	Moderate	Severe	
Relation to the patient	Parent	2	17	3	7	29
		6.9%	58.6%	10.3%	24.1%	100.0%
	Brother/Sister	0	2	5	0	7
		.0%	28.6%	71.4%	.0%	100.0%
	Children	0	13	5	10	28
		.0%	46.4%	17.9%	35.7%	100.0%
	Spouse	0	4	7	7	18
		.0%	22.2%	38.9%	38.9%	100.0%
	Others	0	6	9	8	23
		.0%	26.1%	39.1%	34.8%	100.0%
Total		2	42	29	32	105
		1.9%	40.0%	27.6%	30.5%	100.0%

Table 25: Relation of caregiver to the client and how it impacts on their Social Life.

There was a statistical relationship between the relationship of the care givers and social life ( $p=0.000$ )

		Social Life				Total
		Not Affected	Mild	Moderate	Severe	
Relation to the patient	Parent	16	8	4	1	29
		55.2%	27.6%	13.8%	3.4%	100.0%
	Brother/Sister	4	5	2	0	11
		36.4%	45.5%	18.2%	.0%	100.0%
	Children	10	12	4	2	28
		35.7%	42.9%	14.3%	7.1%	100.0%
	Spouse	7	11	0	0	18
		38.9%	61.1%	.0%	.0%	100.0%
	Others	12	6	3	4	25
		48.0%	24.0%	12.0%	16.0%	100.0%
Total		49	42	13	7	111
		44.1%	37.8%	11.7%	6.3%	100.0%

## DISCUSSION

The shift of health care to ambulatory care setting has resulted in a dramatic increase in the burden placed on a patient's family. Despite this, caregiver burden is greatly under identified by primary care physicians. Although research has not reached consensus on the effects of care giving on the care givers long term health, it has shown that informal care givers who report a burden are at a greater risk of adverse health outcomes (36). This prospective cohort descriptive study was carried out at the Nairobi hospice between the month of October and November 2007.

Cancer illness impacted negatively on the family especially where the patient or a spouse stopped working or worked part time due to the illness. This was experienced as severe subjective burden and had a strong correlation with the level of depression. Employment affected the relationship with the children who were still dependent and some had to drop out of school. Household interaction especially in a spousal relationship suffered severely as a result of work ( $p=0.009$ ). This was because of reduced income and the financial demands of caring for a cancer patient. The care givers experienced heavy objective burden because of the use of family resources on cost of transport to seek treatment, the treatment itself and buying or renting of equipments and materials for care giving to the patient. The social life of the family was less affected because of the immense social support received from other relatives, neighbors and the hospice team support ( home visits for bedridden patients, hospital visits for patients admitted patients). Group therapies at the hospice offered support to the caregiver. As the patient nears the end of their life they become more dependent on the care giver and the distress symptoms may become uncontrollable and the self-efficacy of the care giver goes down. This induces

feeling of inadequacy in controlling symptoms and in turn increases the level of powerlessness by the caregiver which significantly increases burden significantly (24). Even though there was no statistical relationship between religion and depression or burden it was observed that religious faith was a positive way of coping with the stress of caring and this reduced the predisposition to develop depression and feeling of burden (98% of the caregivers were Christians).

Household income was significantly affected by care giving especially where the caregivers were unemployed, retired, or working part time. A study done by Carey et al. (1991) showed that managing illness related finances was one of the top causes of burden (25). Results showed that most of the caregivers were poor and not able to afford special equipments, leave their jobs or hire someone else to carry out their obligations. This was similar to a study done by Wallace et al 1996 (37)

Forty five percent of care givers in this study reported mild depression and 29.7% reported moderate levels of depressive symptoms. This is consistent with the findings of Zarit done in 2004(10). Of the patients referred to the hospice, 85% were at a late stage after receiving several interventions like surgery, chemotherapy, radiotherapy or a combination of treatments. This causes a state of hopelessness for both patient and care giver as the patient is usually expected to die within six months.

An association emerged between levels of depression and age indicating that the younger the caregiver the more depressed they became as a result of care giving roles. Age was also significantly correlated with employment ( $p=0.000$ ). Fifty percent of young adult caregivers (19-30 years) suffered severe burden of work. This is the age at which most youth are pursuing their career, getting married and rarely do they think of death. The fact that they have to look after a dying person affects them psychologically. The middle aged adult (31-45 years) also suffered significant levels of burden of work. During this stage work is most crucial. The middle adult is also concerned with issues surrounding the children who may be leaving home and may also be faced with life's major changes like mid life crises. These multiple roles can cause depression and burden.

The income of this age group caused them significant financial burden (82.5%) compared to other age groups probably due to the multiple financial responsibilities. The household interaction, income and social life of the older adults (66 years and above) were moderately affected because most were already retired and their income was either constant or they had less responsibilities since their children were adults. During this stage of late adulthood, the care givers concern is for the whole life and has accepted death as the completion of life.

The majority of caregivers in this study were female (55.9%). This may be related to the cultural role of the female gender. Women traditionally have taken on care giving roles throughout the centuries in our society. This is consistent with findings of Mc Millan and Mahon in 1994 (38) and Sigel et al. In 1991 (39) all found a preponderance of female care givers. However gender had no statistical relationship with depression which contrasts a study by Kurtz et al that showed that being female in general predisposes individuals to higher levels of distress (7).

There was a significant statistical relationship between education of the care giver and depression ( $p=0.016$ ). Sixty seven percent of caregivers had achieved secondary school educations which translate to better jobs opportunities and therefore more income and less depression. Education also had a significant statistical relationship with the family income( $p=0.000$ ) with the more educated having less burden than those with no formal education at all who reported 100% severe financial burden impact on the family. However, financial burden remained a challenge to all despite the educational background. This also affected the household interaction and the way they related to their children. Interestingly a study done by Mc Millan in 1996 (40) found that higher care givers education levels were associated with decreased physical, emotional and social well being of caregivers. Perhaps the more educated care givers have other career demands or greater expectations about lifestyle freedom that affects their perception of the care giving roles. Care givers with secondary school and above education had more problems relating with their children than those with less education. This may be because most people in employment spent a lot of time outside the home, the nature of the jobs

may be very demanding causing physical and mental fatigue and reducing the contact time with their children. The less educated may have less demanding jobs and may spend time with their children.

Care givers employment status was also related to depression ( $p=0.001$ ). The unemployed and those who were not in formal employment suffered more depressive symptoms than their counterparts who were employed on fulltime basis. This contrasts a study by Given et al., 1994 suggesting that employment adds to overall level of psychological distress because of the way caregivers negotiate care giving and employment, including withdrawal or absence from work and or reduction in work productivity (21). Unemployment may cause depression and burden because of reduced income. The finding may also suggest that employment outside the home may act as a buffer to or as a respite from the care experiences for care givers. The caregivers who were working part time were more affected by the burden of work than their counterparts who were full time employed because withdrawal, absence and reduced productivity could have negative impacts on their jobs including losing the jobs. Care givers who were employed were less affected by the burden of income as compared to those with no income at all, hence, burden of income also correlates with the level of depression. The employment status of the care giver affected the interpersonal relationship of interaction in the house with the unemployed suffering more severely. Also the unemployed were more burdened by social life than their employed counterparts.

Retired family caregivers, presumably as a result of an absence of work related demands were less likely to be depressed and were less burdened. However the retired status may be involuntary since some caregivers had to leave desirable jobs to assume the care givers role or made major rearrangements to provide care (15)

The relationship between the care giver and the patient was statistically significant (0.026). The sibling relation suffered more moderate depression (63.6%) followed by spousal relationship with moderate depression (44.4%); Care givers who are the patients off springs were shown to be less depressed by their care giving roles and also less



burdened. A study by Siegel et al., 1991 showed non spouse care giving, usually by adult children to be associated with more unmet patient's needs (39).

In this study the longer the time in the care givers role and hospice care appeared as a predictor for increased burden related to work ( $p=0.000$ ) and income( $p=0.001$ ). This could be related to the time lost at work and use of family income in care giving costs. Most literature indicates that the longer the dying process is, the harder the experience is on the caregivers and this is consistent with the findings of a study by Bass & Bowman (1990) (41). The period of care had no correlation with depression which contrasts a study by Grunfeld in which depression is substantial at the onset of palliative illness and a substantial increase in care giver burden and depression when the patient reached a terminal stage of the illness.(10) This can be postulated that in our society the social support offered to a patient throughout the illness is significant and hence, reduced depression and burden among the caregivers.

Illness provoked major changes in the social life of the family with the care givers children suffering more as a result of the care giving roles some children dropped off from school, some spouses left the family because they could not cope with the illness and changes that came with it. The care givers who were daughters or sons of the patient have divided attention as they tried to balance out the care, between their child, their spouse, and their sick parent and their financial resources. Spouse care givers living with their partner formed 61.1% but the spouses indicated no changes in social life.

All the care givers in the study were Kenyans of African origin. Culturally Africans believed in brotherhood and as such a sick person is the responsibility of everyone in the village. The social life of the care givers was less affected as the family members were seen to be closely knit together and the sick person and family frequently visited by neighbors and extended relatives and also the entire village community. Because of this immense support (physical, socially, financially, spiritually and emotionally) depression and burden of care is reduced remarkably. (3)

## **Limitations**

This study was conducted at a single clinical site using a family care giver sample that was composed of Africans only, mostly from one ethnic group, most of whom were well educated, knew of the hospice services and could afford the hospice cost. Therefore caution must be used when generalizing from this sample to other cancer patient care giver population. The data was measured at one point in time giving only a snapshot of the family care giver experience. Preexisting depression and burden was not assessed and may have had an influence on the findings.

## CONCLUSION

The results of this study shows that family care givers of cancer patients are at risk of developing depression related to care giving roles or experience heavy burden and need assistance in delivering care to their loved ones. The health of the care giver may be affected negatively by the care giving roles. The quality of life may also be affected negatively. Economic inputs suffered the greatest impact followed by relationships and then social life which is consistent with the findings of a case study by Ndetei et al. (35) ;( burden and impacts of the mentally ill on their relatives in Kenya done at the Mathari hospital). Care givers who identify their patients as experiencing many cancer and treatment related symptoms are more likely to react to the care giving situation in ways that contribute to burden and depression. Both the clients and caregivers characteristics could contribute to depression and burden. The health care professionals may be able to predict and moderate care givers reactions by identifying care givers at risk and by helping care givers evaluate factors that may increase feelings of burden such as employment pressures. The study data indicate that specific groups of care givers are at risk for negative outcomes and that identification of groups at risk requires that health care professionals be aware of socio demographic characteristics of care givers. In the African society when a member is ill it becomes a community problem and everybody shares in whatever they are able to do to assist the affected party providing adequate social support. This greatly reduces the depression levels experienced by individuals and ~~also the burden in terms of shouldering~~ responsibilities together as a group. However, with urbanization this is changing and individuals have to experience the illness problem alone thereby increasing the levels of depression and burden.

## RECOMENDATIONS

1. Health care interventions need to be delivered proactively by enhancing caring relationships with care givers and acknowledging care givers as individuals and providing clear expectations of the family care giver role.
2. Health care providers should aim at key health care behavior that reduces psychological distress, as viewed by the family with cancer by the provision of accurate information in a timely fashion.
3. Interventions designed to improve the emotional health of the care givers of patients with cancer at the end of life should be targeted to at risk care givers.
4. Health care practitioners should also be aware that interventions aimed at decreasing symptoms severity could affect care givers burden and depression.
5. Since cancer care is increasingly being provided at home with family members taking the role of primary care givers more primary health workers should be trained in palliative care to assist this people in a home setting to enable them cope with the day to day activities with confidence thereby dealing with the impact of burden and depression and the experience of death and dying of a loved one at home.
6. Further research studying more than one hospice or geographic area also may be desirable for further generalizability.
7. Inpatient hospice facilities would go along way in alleviating suffering for those family care givers who cannot keep the patients at home for various reasons.

## **APPENDIX 1 a.**

### **Consent form and explanation.**

My name is Esther Mungai, a clinical psychology student at the University of Nairobi. I intend to write a dissertation on the prevalence of depression and burden of care among family care givers of cancer patients attending the Nairobi hospice for palliative care. The research study will examine the relationship between different variables in a family caregiver that makes him or her more prone to suffering depression and experience significant burden of care. The study is being performed as partial fulfillment of the requirements for a Masters degree in clinical psychology at the University of Nairobi. Your participation in this study will provide useful information on this topic. You qualify for participation if you are of age 18 years and above and you will be asked to complete three questionnaires to assess the level of depression, burden of care together with demographic questions. Participation in this study is strictly voluntary. There are no foreseeable risks with this research. The main potential benefit is in contributing to the scientific knowledge on this topic and future planning on caregiver's effective assistance by the health care workers to reduce or avoid depressive symptoms or burden of care. No costs or payments are associated with participating in this study, participants can call the number listed on this letter to ask questions or discuss their feelings with me. A more complete statement of the nature and purpose of the research will be available when the data collection is completed. You may withdraw from the study at any point without penalty. Participation is not associated with your class grade. All data from questionnaires and instruments are anonymous. Names of participants will not be connected to information and scores.

Thank you for your assistance.

Esther W Mungai

Msc. Clinical psychology

Department of psychiatry

University of Nairobi.

Tel. 0722409365

## APPENDIX 1b.

### Participants consent form.

I agree to participate in this research study and I understand that:

1. My participation is entirely voluntary. I may terminate my involvement at any time without penalty.
2. All my data are confidential. All research measures will be destroyed within five years after completion of the study.
3. All data are for research purposes only.
4. The nature of my participation includes completion of questionnaires provided.
5. If I have questions about the research, or if I would like to receive a copy of the aggregate findings of the study when it is complete, I can contact the researcher by calling (0722409365) or writing to the investigator using the address provided. (Esther Mungai, P.O Box 19786 Nairobi).

Signed \_\_\_\_\_ Date \_\_\_\_\_

(Participant)

Signed \_\_\_\_\_ Date \_\_\_\_\_

(Researcher)

Thank you for your assistance.

## APPENDIX 11:

### Sociodemographic data of the care giver

Date -----

Study No. -----

#### Personal data

1. Date of Birth: date/month/year-----

2. Gender:

Male-----

Female-----

3. Marital status:

Married

Single

Widowed

Separated

Divorced

4. Education completed

Primary school

Secondary school

College graduate

University graduate

6. Religion (specify)

7. Number of children( Specify)

8. Race

African

White

Asian

9. Employment status
  - Employed full time
  - Employed part time
  - Home maker
  - Retired
  - Not employed
  - Any other
10. Years / months in care giving roles-----
11. Relation to the patient (specify). -----

**Data Related to the patient**

1. Patient's age-----
2. Patient primary cancer site (specify) -----
3. Type/ name of cancer (specify)-----
4. Patient cancer stage
  - Early
  - Late
5. Patient lives with
  - Spouse
  - Child
  - Parent
  - Self
  - Any Other (Specify)
6. a) When was the patient diagnosed with cancer? -----
  - b) What stage was the cancer at the time of diagnosis?
    - Early-----
    - Late-----
7. For how long has the patient been enrolled at the hospice? -----



8. What interventions has the patient had? (Can choose more than one)

Surgery

Chemotherapy

Radiotherapy

None

## APPENDIX 111: a

### BDI (Beck's Depression Inventory)

On this questionnaire are groups of statements. Please read each of the statements carefully, then pick out the one statement in each group which best describes the way that you have been feeling the past week, including today.

Circle the number besides the statements in each group before making your choice.

1.

- 0 I do not feel sad
- 1 I feel sad
- 2 I am sad all the time and I cant snap of it
- 3 I am sad, unhappy that I cant stand it

2.

- 0 I am not particularly discouraged about the future
- 1 I feel discouraged about the future
- 2 I feel I have nothing to look forward to
- 3 I feel that the future is hopeless and that things cannot improve

3.

- 0 I do not feel like a failure
- 1 I feel like I have failed more than the average person
- 2 As I look back on my life, all I can see is a lot of failures
- 3 I feel I am a complete failure as a person

4.

- 0 I get much satisfaction out of things as I used to
- 1 I don't enjoy things the way I used to
- 2 I don't get real satisfaction out of anything anymore
- 3 I am dissatisfied or bored with everything

5.

- 0 I don't feel particularly guilty
- 1 *I feel guilty a good part of the time*
- 2 I feel guilty most of the time
- 3 I feel guilty all the time.

6.

- 0 I don't feel I am being punished.
- 1 I feel I may be punished
- 2 I expect to be punished
- 3 I feel I am being punished

7.

- 0 I don't feel disappointed in myself
- 1 I am disappointed in myself
- 2 I am disgusted with myself
- 3 I hate myself

8.

- 0 I don't feel I am any worse than anybody else.
- 1 I am critical of myself for my weaknesses or mistakes.
- 2 I blame myself all the time for my faults
- 3 I blame myself for everything bad that happens.

9.

- 0 I don't have thoughts of killing myself
- 1 I have thoughts of killing myself, but I would not carry them out
- 2 would like to kill myself
- 3 I would kill myself if I had the chance

10.

- 0 I don't cry any more than usual
- 1 I cry more now than i used to
- 2 I cry all the time
- 3 I used to be able to cry, but now I can't even though I want to

11.

- 0 I am no more irritated now than I ever was
- 1 I get annoyed or irritated more easily than I used to
- 2 I feel irritated all the time now
- 3 I don't get irritated at all by the things that used to irritate me.

12.

- 0 I have not lost interest in other people
- 1 I am less interested in other people than I used to be
- 2 I have lost most of my interest in other people
- 3 I have lost all of my interest in other people.

13.

- 0 I make decisions about as well as I ever could.
- 1 I put off making decisions more than I used to
- 2 I have greater difficulty in making decisions more than I used to
- 3 I can't make decisions at all anymore.

14.

- 0 I don't feel that I look any worse than I used to
- 1 I am worried that iam looking old or unattractive
- 2 I feel that there permanent changes in my appearances that make me look unattractive.
- 3 I believe that I look ugly.

15.

- 0 I can work about as well as before
- 1 It takes an extra effort to get started at doing something.
- 2 I have to push myself very hard to do anything.
- 3 I can't do any work at all

16.

- 0 I can sleep as well as usual.
- 1 I don't sleep as well as I used to.
- 2 I get tired form doing almost anything.
- 3 Iam too tired to do anything.

17.

- 0 I don't get more tired than usual
- 1 I get tired more easily than I used to.
- 2 I get tired from doing almost anything.
- 3 I am too tired to do anything

18.

- 0 My appetite is no worse than usual.
- 1 My appetite is not as good as it used to be.
- 2 My appetite is much worse now
- 3 I have no appetite at all anymore.

19.

- 0 I haven't lost much weight, if any, lately.
- 1 I have lost more than five pounds.
- 2 I have lost more than ten pounds
- 3 I have lost more than fifteen pounds.

20.

- 0 I am no more worried about my health than usual
- 1 I am very worried about my physical problems such as aches and pains; or upset stomach; or constipation
- 2 I am very worried about physical problems and it's hard to think of much else.
- 3 I am worried about my physical problems that I cannot think about anything else.

21.

- 0 I have not noticed any recent change in my interest in sex
- 1 I am less interested in sex than before.
- 2 I am less interested in sex now.
- 3 I have no interest in sex completely.

APPENDIX 111: b

Kiswahili BDI

Numbari-----

Tarehe-----

*Ya fuatayo ni mafungu ya sentensi. Tafadhali soma kila fungu kwa makini. Chagua kutoka katika kila fungu sentensi ambayo yaelezea vyema ulivyokuwa ukihisi JUMA LILILOPITA NA UNAVYOHISI LEO! Ashiria sentensi moja au zaidi ya moja uliyochagua katika kila fungu kwa kuweka alama ya mviringo juu ya nambari ya sentensi hiyo. Hakikisha umesoma sentensi zote katika kila fungu kabla ya kuchagua sentensi iliyo sambamba na unavyo hisi.*

SWAHILI

1

0 Sina huzuni

1 Nina huzuni.

2 Nina huzuni wakati wote na siwezi kujiondoa katika hali hii ya huzuni.

3 Nina huzuni sana mpaka siwezi kustahimili/kuvumilia.

2

0 Sijavunjika moyo hasa na siku za usoni.

1 Nahisi nimevunjika moyo na siku za usoni.

2 Nahisi sina ninalo tarajia siku za usoni.

3 Nahisi nimekata tamaa ya siku za usoni, na naona mambo hayawezi kuwa bora zaidi.

3

0 Sijihisi kama nimeanguka maishani.

1 Nahisi nimeanguka maishani zaidi ya mtu wa kawaida.

2 Nikiangalia maisha yangu yaliyopita naona nimeanguka sana.

3 Nahisi nimeanguka kabisa maishani.

4

0 Naridhika na mambo kama ilivyo kawaida yangu.

1 Si furahii mambo kama nilivyokuwa nikifurahia.

2 Sitosheki tena kikamilifu na jambo lolote.

3 Sitosheki wala sichangamshwi na chochote tena.

5

0 Sihisi hasa kama nina hatia fulani.

1 Nahisi nina hatia wakati mwingine.

2 Nahisi nina hatia wakati mwingi.

3 Nahisi nina hatia wakati wote.

6

0 Sihisi kama nina adhibiwa.

1 Nahisi kama naweza kuadhibiwa.

2 Natarajia kuadhibiwa.

3 *Nahisi nina adhibiwa.*

7

0 *Sihisi kama nimeikasirikia nafsi yangu.*

1 *Nimeikasirikia nafsi yangu.*

2 *Najidharau.*

3 *Najichukia.*

8

0 *Sihisi kama mimi ni mbaya zaidi ya mtu yeyote yule.*

1 *Najisuta (kujitoa makosa) sana katika makosa yangu ama udhaifu wangu*

2 *Najilaumu wakati wote kwa makosa yangu.*

3 *Najilaumu kwa ovu lolote linalo tendeka*

9.

0 *Sina wazo lolote la kujiuwa.*

1 *Nina wazo la kujiua,*

2 *lakini sitalitimiza wazo hilo.*

3 *Ningetaka kujiuwa. Nitajiuwa nikipata nafasi.*

10

0 *Silii siku hizi zaidi ya vile ilivyo kawaida yangu.*

1 *Nalia siku hizi zaidi ya ilivyokuwa kawaida yangu.*

2 *Nalia wakati wote siku hizi.*

3 *Nilikuwa nikiweza kulia, lakini sasa hata nikitaka kulia siwezi.*

11

0 *Sikasirishwi kwa urahisi siku hizi zaidi ya ilivyo kawaida yangu*

1 *Nakasirishwa kwa urahisi zaidi ya ilivyokuwa kawaida yangu.*

2 *Nahisi nimekasirishwa wakati wote siku hizi.*

3 *Sikasirishwi kamwe na mambo ambayo yalikuwa yakinikasirisha.*

12

0 *Sijapoteza hamu ya kujihusisha au kujumuika na watu.*

1 *Hamu yangu ya kujihusisha na watu imepungua zaidi ya ilivyokuwa.*

2 *Nimepoteza sana hamu yangu ya kujihusisha na watu.*

3 *Nimepoteza hamu yangu yote ya kujihusisha na watu.*

13

0 *Ninafanya uamuzi kuhusu jambo lolote kama kawaida.*

1 *Ninahairisha kufanya uamuzi zaidi ya vile nilivyokuwa nikifanya.*

2 *Nina uzito mkubwa wa kufanya uamuzi kuliko hapo awali.*

3 *Siwezi tena kufanya uamuzi wa jambo lolote lile.*

14

0 *Sihisi kuwa naonekana vibaya zaidi ya vile nilivyokuwa.*

1 *Nina wasi wasi kuwa naonekana sivutii.*

2 *Ninahisi kuwa kuna mabadiliko yasio ondoka kwenye umbo langu yanayofanya nisivutie.*

3 *Nina amini ya kuwa nina sura mbaya.*

15

0 *Naweza kufanya kazi kama vile ilivyokuwa hapo awali.*

1 *Nilazima nifanye bidii, ndipo nianze kufanya jambo lolote*

2 *Inabidi nijilazimishe sana ili niweze kufanya jambo lolote*

3 Siwezi kabisa kufanya kazi yoyote.

16

0 Ninalala kama kawaida yangu.

1 Silali vyema kama nilivyo kuwa nikilala hapo awali.

2 Naamka mapema kwa saa limoja au masaa mawili, ambayo sio kawaida yangu, halafu ni vigumu kupata usingizi tena.

3 Naamka mapema zaidi ya masaa mawili, ambayo sio kawaida yangu, halafu siwezi kupata usingizi tena.

17

0 Sichoki zaidi ya nilivyokuwa nikichoka hapo awali.

1 Nachoka kwa urahisi zaidi ya kawaida yangu.

2 Nachoshwa (Nachokeshwa), karibu na kila jambo ninalofanya.

3 Ninachoka sana hata siwezi kufanya lolote.

18

0 Hamu yangu ya chakula sio mbaya zaidi ya vile ilivyokuwa hapo awali.

1 Hamu yangu ya chakula sio nzuri kama vile ilivyokuwa hapo awali.

2 Hamu yangu ya chakula ni mbaya zaidi siku hizi.

3 Sina tena hamu ya chakula hata kidogo.

19

0 Sijapunguza uzito wa mwili wakuonekana hivi karibuni.

1 Nimepunguza uzito wa mwili zaidi ya kilo mbili.

2 Nimepunguza uzito wa mwili zaidi ya kilo tano.

3 Nimepunguza uzito wa mwili zaidi ya kilo saba.

Ninakula chakula kiasi kidogo kwa kusudio la, kujaribu kupunguza uzito wa mwili

Ndivyo \_\_\_\_\_ Sivyoy \_\_\_\_\_

20

0 Sina wasiwasi usio wa kawaida kuhusu hali yangu ya afya.

1 Nina wasiwasi kuhusu shida za mwili kama vile maumivu hapa na pale; au shida ya tumbo, au kufunga choo.

2 Nina wasiwasi sana kuhusu matatizo ya mwili mpaka inakuwa nivigumu kuwaza jambo lengi lolote.

3 Nina wasiwasi sana kuhusu matatizo yangu ya mwili mpaka siwezi kuwaza jambo lingine lolote.

21

0 Sijaona mabadiliko yoyote hivi karibuni kuhusu hamo yangu ya kufanya mapenzi.

1 Hamu yangu ya kufanya mapenzi imepungua zaidi ya vile ilivyokuwa.

2 Hamu yangu ya kufanya mapenzi imepungua sana siku hizi.

3 Nimepoteza kabisa hamu yangu ya kufanya mapenzi.

ASANTE SANA !!



## APPENDIX IV

### TIME SCHEDULE

- |                                 |                  |
|---------------------------------|------------------|
| a) Proposal Development         | March - May 2007 |
| b) Approval                     | May - June 2007  |
| c) Ethical committee            | July- 2007       |
| d) Data Collection              | August- 2007     |
| e) Data Analysis                | September- 2007  |
| f) Report Writing               | October- 2007    |
| g) Presentation                 | November- 2007   |
| h) Completion and bind the book |                  |

## APPENDIX V

### BURDEN OF ILLNESS

Specify the nature of relationship \_\_\_\_\_

#### **Impact of cancer illness on family**

##### **a. Work/Employment**

Tick the correct answer as applies to you

##### **Question 1.**

Has the Client lost her/his job due to illness?

Yes

No

##### **Question 2**

If yes, to what extent has it affected the family?

Mild

Moderate

severe

Extremely severe

##### **Question 3.**

Did any member of the family stop working due to the client's illness?

Yes

No

##### **Question 4**

If yes, to what extent has it affected the family?

Mild

Moderate

Severe

Extremely severe

##### **Question 5**

Is any member of the family working part time due to the client's illness?

Yes

No

##### **Question 6**

If yes, to what extent has it affected the family?

Mild

Moderate

Severe

Extremely severe

##### **Question 7**

Does any member of the family sometimes miss work due to the client's illness?

Yes

No

**Question 8**

If yes, has does it affect her/his work?-----

---

**b. Income/Finance**

Tick the correct answer as applies to you

**Question 9**

Has the client's treatment affected the family's income?

Yes

No

**Question 10**

If yes, to what extent has it affected the family's income?

Mild

Moderate

Severe

Extremely severe

**Question 11**

Has the family spent money on clients treatment?

Yes

No

**Question 12**

If yes, to what extent has it affected the family?

Mild

Moderate

Severe

Extremely severe

**Question 13**

Has the family borrowed money or organized fundraising to pay for bills incurred by the client?

Yes

No

**Question 14**

If yes, how often does it happen?

Mild

Moderate

Severe

Extremely severe

**Question 15**

Does the client need money for transport to attend clinic?

Yes

No

**Question 16**

If yes, to what extent is it a problem?

Not at all       A little       Moderate       very much

**Question 17**

Have you made extra arrangements for someone to look after your loved one?

Yes       No

**Question 18**

If yes, to what extent has it affected the family?

Mild       Moderate       Severe       Extremely severe

**Question 19**

Is the client receiving disability pension?

Yes       No

**c. Household interaction**

Tick the correct answer as it applies to you

**Question 20**

Does the client's illness cause tension within the family?

Yes       No

**Question 21**

Does the client's illness cause disagreements in the house?

Yes       No

**Question 22**

Has any member of the family moved out of the house due to the client's illness?

Yes (specify who.....)      No

**Question 23**

Has the client stopped helping with the household tasks due to illness?

Yes       No

**D Children**

Tick the appropriate answer as it applies to you

**I would like to find whether the patient's illness has affected the children in any way  
(if there are no children in the household, go to next section)**

**Question 24**

Is the client able to care for his/her children?

Yes  No

**Question 25**

If not, who takes care of the children? .....

**Question 26**

How does he/she relate to children?

Very poor  poor  good  very good

**Question 27**

Does the client look after the children as before?

Never  Rarely  Sometimes  Most of the times

**Question 28**

Is the education of the children affected because of the client's illness?

Yes (Specify.....) No

**e. Health**

**would like to find out whether the health of the family members has been affected  
by the patient's illness.**

**Question 29**

Have you suffered any illness related to taking care of your loved one?

Yes  No

**Question 30**

If yes, how serious was the illness?

Mild  Moderate  Severe  Extremely severe

**Question 31**

Has any other member of the family suffered any illness due to the client's illness?  
Yes (Specify who.....) NO

**Social life and leisure**

Tick the correct answer as it applies to you

**would like to find out whether the patient's illness has affected the social life and leisure activities of the family.**

**Question 32**

Has the frequency of visiting by relatives changed as a result of your loved one's illness?  
Not at all  slightly  moderately  very much

**Question 33**

Has the frequency of visiting by neighbors changed as the result of the client's illness?  
Not at all  slightly  moderately  very much

**Question 34**

Has the client's illness affected the relationship with the neighbors?  
Not at all  slightly  moderately  very much

**Question 35**

Does the family feel distressed over the loved one's illness?  
Not at all  slightly  moderately  very much

**Question 36**

Does the family feel unable to have visitors at home due to the client's illness?  
Not at all  slightly  moderately  very much

**Question 37**

Does the family feel unable to leave the client alone at home/  
Never  seldom  often  always

**Question 38**

Has any family member abandoned his/her holidays due to the client's illness?  
Never  rarely  sometimes  frequently



## APPENDIX VI

### THE BUDGET

1	Proposal preparation including internet, referencing	10,000
2	Transport and communication	25,000
3	Data processing and book binding	20,000
4	Miscellaneous	15,000
	Total Amount	<hr/> 70,000

The budget will be from my personal sources.



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