

**PREVALENCE OF DEPRESSION AMONG CAREGIVERS OF PATIENTS
RECEIVING PALLIATIVE CARE IN KENYATTA NATIONAL HOSPITAL**

**A DISSERTATION IN PART FULFILLMENT FOR THE AWARD OF THE
DEGREE OF MASTER OF SCIENCE IN CLINICAL PSYCHOLOGY.**

BY

ELIZABETH A. ADOL

ADM. NO: H56/62238/2010

DEPARTMENT OF PSYCHIATRY

SCHOOL OF MEDICINE

UNIVERSITY OF NAIROBI

2014.

DECLARATION

By Student;

I declare that this research proposal is my original work and has not been submitted for examination in any university.

Name Elizabeth Adhiambo Adol

Reg/No; H56/62238/2010

Signature.....

Date.....

Supervisors

This research proposal has been submitted for examination with our approval as University supervisors.

Supervisor’s name

Dr Anne Obondo

BA (Hons) Sociology (Delhi University, India), MSW (Bombay University, India), Dip. in psychiatric social work (University of Manchester, United Kingdom) Ph.D in Psychiatry (University of Nairobi, Kenya).

Signature

Date.....

Second supervisor’s name

Dr Pius Kigamwa

MB CHB, MMED(psych),C.C.P

Signature

Date.....

ACKNOWLEDGEMENT

I give thanks to the almighty God for bringing me this far.

I appreciate the moral support and warmth received from my husband, Dr P.A.Oduor, my children- Victor Oduor, James Adol and Danielle Chiwo.

Warmth and gratitude goes to my siblings, nephews, nieces and the entire Adols, who supported me financially, psychologically and socially, the friends, who are numerous, for their understanding and support in various ways.

I am most grateful to the staff of the department of psychiatry, University of Nairobi and especially to my able supervisors Dr Anne Obondo and Dr Pius Kigamwa for their guidance, time and wealth of knowledge during this academic journey.

The staff in mental department are appreciated for their guidance and cooperation during my practicum.

A lot of thanks go to information science expertise of Mr Ruto, (WARDI) Mr Mwangi (KNH), Edy Indalo and Cheserem Leonard (KNH) for their technical support, not forgetting the medical officer in charge of Palliative Care Unit (KNH), Dr Munyoro and her staff.

I appreciate the ethics and research committee members for their expertise, guidance and corrections into making an exemplary researcher out of me.

Lastly, I would like to acknowledge Kenyatta National Hospital Research and Program for both funding and training under Dr Kinuthia, Mr Mwenda and Mr Wahinya.

DEDICATION

I dedicate this dissertation to my late father, Fineas Adol, who died of cancer of the prostate, my siblings ,especially Agnes who died of cancer of the stomach, the entire Adol's, my husband and children, Victor, James and Danielle.

TABLE OF CONTENTS

DECLARATION.....	II
ACKNOWLEDGEMENT.....	III
DEDICATION.....	IV
TABLE OF CONTENTS	V
LIST OF FIGURES	VII
LIST OF TABLES	VIII
ABBREVIATIONS.....	IX
DEFINITION OF TERMS.....	X
CHAPTER ONE: INTRODUCTION	1
1.1 BACKGROUND INFORMATION	1
1.2 PROBLEM STATEMENT	2
1.3 OBJECTIVES	3
1.4 RESEARCH QUESTIONS	3
1.5 SCOPE OF THE STUDY.....	4
1.6 LIMITATIONS OF THE STUDY	4
1.7 JUSTIFICATION OF THE STUDY.....	4
CHAPTER TWO: LITERATURE REVIEW.....	5
2.1 THEORETICAL OVERVIEW	5
2.2 PATIENT AND CAREGIVER CHARACTERISTICS FOR DEPRESSION SYMPTOMATOLOGY	10
2.3 STUDIES DONE IN KENYA	14
2.4 CONCEPTUAL MODEL OF DEPRESSION	15
CHAPTER THREE : STUDY DESIGN AND METHODOLOGY	17
3.1 RESEARCH DESIGN	17
3.2 STUDY AREA.....	17
3.3 POPULATION.....	17
3.4 SAMPLE SIZE DETERMINATION:	17
3.5 SAMPLING PROCEDURE.....	18
3.6 INCLUSION CRITERIA	18
3.7 EXCLUSION CRITERIA.....	18
3.8 DATA COLLECTION TOOLS	19
3.9 DATA COLLECTION PROCEDURE.....	19
3.10 DATA MANAGEMENT AND ANALYSIS	19

3.11 ETHICAL CONSIDERATIONS.....	20
CHAPTER FOUR: RESULTS	22
4.1: Socio-demographic characteristics.....	22
4.2 Number of children under the caregivers’ care.....	23
4.3: Duration of care giving	24
4.4: Relationship with the patient.....	24
4.5: Income range of the caregiver.....	25
4.6 BDI SCORES OF THE RESPONDENTS.....	26
CHAPTER FIVE: DISCUSSION.....	40
5.1 Socio-demographic characteristics.....	40
5.1.1 Gender and depression	40
5.1.2 Age and depression	40
5.2 Care giver’s relationship with the patient and depression.....	42
5.3 Care giving duration range and depression	43
CHAPTER SIX	45
SUMMARY, CONCLUSION AND RECOMEMNDATION.....	45
6.1 INTRODUCTION.....	45
6.2 SUMMARY OF THE FINDINGS.....	45
6.3 CONCLUSION	45
6.4 RECOMMENDATIONS.....	46
BIBLIOGRAPHY	47
APPENDICES	57
APPENDIX 1: CONSENT AND EXPLANATION FORM	57
APPENDIX II: PARTICIPANTS CONSENT FORM	61
APPENDIX III: LETTER OF APPROVAL FROM ETHICS AND RESEARCH COMMITTEE	63
APPENDIX IV: BECKS DEPRESSION INVENTORY	64
APPENDIX V: SOCIODEMOGRAPHIC DATA OF CAREGIVER.....	70
APPENDIX VI: PROPOSED WORK PLAN- FLOW CHART	76
APPENDIX VII: BUDGET	77

LIST OF FIGURES

Figure 1: Conceptual Framework	16
Figure 2: Flow chart of methodology	21
Figure 3: Distribution of number of children under caregivers care	23
Figure 4: Duration of care giving.....	24
Figure 5: BDI scores of the respondents.....	26
Figure 6: Gender and Depression	28
Figure 9: Relationship with the patient.....	36
Figure 10: Income	38

LIST OF TABLES

Table 1: Socio-demographic characteristics of the sample.....	22
Table 2 : Care giver relationship with the patient.....	25
Table 3 : Distribution of care givers' income range per month.....	25
Table 4: Gender and depression.....	27
Table 5: Age and depression	29
Table 6: Cross tabulation between age and depression score	31
Table 7: Duration of care and depression	32
Table 8: Duration of care and depression	33
Table 9: Care giver's relationship and depression.....	35
Table 10: Care giver's relationship with patients and depression	36
Table 11: Income and depression	37
Table 12: Cross tabulation between care givers' income and depression score	38

ABBREVIATIONS

BDI	-	Becks depression inventory
DSMIV	-	Diagnostic Statistical manual fourth edition
ICD-10	-	International Classification of diseases
KNH	-	Kenyatta National Hospital
KNH/UON-ERC	-	Ethics and research committee, Kenyatta National Hospital and University of Nairobi
MOH	-	Ministry of Health
SPSS	-	Statistical package for social sciences
WHO	-	World health organization

DEFINITION OF TERMS

A family caregiver applies to a person who cares for relatives and loved ones who are frail, elderly or with physical or mental disability. This caregiver is different from a professional caregiver who is actually paid to do the job.

Caregiver distress is the stress arising as a result of care giving and can be manifested by anxiety, depression, helplessness, burden and fear. It is brought about by unending, unrelenting care of a person who is totally or partially reliant on care provided by another.

Caregiver Burden has been defined as a multi-dimensional response to the negative appraisal and perceived stress resulting from care of an ill individual. Caregiver burden threatens the physical, psychological, emotional and functional health of caregivers.

Palliative Care is a multidisciplinary approach aimed at managing physical, psychological and spiritual aspects associated with a life threatening illness to both the patient and the family.

Depression- is a mood disorder characterized by depressed mood, decreased interest/pleasure, appetite or weight changes, psychomotor agitation or retardation, sleep disturbances, fatigue, feelings of worthlessness or guilt, irritability or anger, self loathing, reckless behavior, unexplained aches and pains.

Psychotherapy; is a process of treating psychological disorders and mental distress. It is usually offered by trained psychotherapists who may include clinical psychologists, psychiatrist, counselors etc.

ABSTRACT

Background: Chronically ill and end of life patients are increasingly being cared for in the home by their families, friends, or neighbours. As care has shifted from the hospital to the home, the role of family caregiver has been transformed into a complex, multifaceted responsibility which may have consequences on the mental health of primary caregivers. Studies have shown that 40 to 70 percent of caregivers experience symptoms of depression (7). Identifying caregivers with depression is therefore necessary for various interventions to be considered.

The general objective was to determine the prevalence of depressive symptoms in caregivers of patients undergoing palliative care (most of whom are patients suffering from cancer) to determine their socio-demographic characteristics associated with depressive symptoms. The population comprised of caregivers of patients undergoing palliative care at the Kenyatta National Hospital. It was a cross-sectional study. Questionnaires were administered using Beck's Depression Inventory and a researcher designed socio-demographic characteristics questionnaire of the caregiver.

Data was analyzed using SPSS version 18 and statistical data analysis was carried out.

Results were presented using frequency tables, bar charts and pie charts.

The results showed that 62.7% of the caregivers presented with symptoms of depression. This is four times higher as compared to the general population. The severity of the depressive symptoms ranged from mild to severe with the majority experiencing symptoms of severe depression. Spousal caregivers had the highest prevalence of depressive symptoms followed by those who were taking care of their children.

Recommendation includes having healthcare providers do routine screening for depression in family caregivers and not just on patients alone. Respite care also provides a temporary relief to the caregiver and should be instituted in the care of the terminally ill. There should be advocacy for policy change for flexible employment arrangement for family caregivers who may need time off from work.

CHAPTER ONE: INTRODUCTION

1.1 BACKGROUND INFORMATION

Chronically ill and end of life patients are increasingly being cared for in the home by family, friends, or neighbours (1). The caregivers are referred to as informal or voluntary caregivers. With cancer rapidly developing into a continuous care problem because of increasing incidence rates, longer survival times, and reduction of stays in acute care settings and shifting of treatment toward ambulatory care, increased responsibilities have been transferred to family members for both the physical and emotional care of patients with cancer (2).

Recent treatment, economic and policy changes have resulted in a shift from inpatient to outpatient care for many serious illnesses, including cancer, placing an increased care giving responsibility on family and friends of the ill patients (3). As care has shifted from the hospital to the home, the role of the family caregiver has been transformed into a complex, multifaceted responsibility that many are ill prepared to assume (4). While the duration of cancer illness may be shorter than that of other chronic illnesses like dementia, caregivers of cancer patients provide more hours of care per week (5).

Care giving may not cause depression, nor will everyone who provides care experience the negative feelings that go with depression. But in an effort to provide the best possible care for a family member or friend, caregivers often sacrifice their own physical and emotional needs and the emotional and physical experiences involved with providing care can strain even the most capable person. Everyone has negative feelings that come and go over time, but when these feelings become more intense and leave caregivers totally drained of energy, crying frequently or easily angered by their loved ones or other people, it may well be a warning

sign of depression. Concerns about depression arise when the sadness and crying do not go away or when those negative feelings are unrelenting (6).

Studies show that 40 to 70 percent of caregivers experience symptoms of depression (7). Many caregivers do not take time to eat well, exercise or see their own doctor. Some studies show that caregivers have a higher rate of high blood pressure and heart disease as opposed to non caregivers of the same age (8). Identifying caregivers with depression is therefore necessary not only for the physical and emotional health of the caregiver but also for the sake of the quality of care of the patient. When the care giver is unwell, the quality of care will be compromised. Many chronically ill patients are now commonly managed at home and home based care is recommended due to friendly environment as well as cost reduction measure in healthcare.

1.2 Problem statement

Based on the reports from Ministry Of Health 1999-2005, the prevalence of terminal illness is on the increase. There are more cases of cancer being reported in Kenya now but studies to determine the reasons for the increase in prevalence and incidence have not been conducted. (9). Although a great deal of research has been performed on correlates of distress for caregivers who are at various points in the care trajectory, little work has been done to assess the depression of the care givers providing end-of-life care to the patients with cancer. Given the manner that distress echoes throughout both the family and community in the setting of cancer, the care giving experiences of the partner or significant other of the patient with cancer is of great interest. What is not fully understood is the emotional and psychological impact of taking on the role of family-based caregiver in the cancer setting (10). Research on care giving to cancer patients is sparse and there has been little research specifically addressing the experiences of caregivers who are caring for terminally ill patients (11).

The study attempts to contribute to the gap that exists in the literature specifically on the experiences of primary caregivers by highlighting the experiences and challenges leading to

depression faced by these family caregivers' care to patients with terminal illness. It attempts to understand the impact of the care-giving role and explores caregiver characteristics associated with caregiver depressive symptoms in the palliative care unit at the Kenyatta National Hospital.

1.3 Objectives

1.3.1 Broad Objective of the study

To study the prevalence of depressive symptoms among caregivers of patients undergoing palliative care.

1.3.2 Specific Objectives of the study

- i. To determine the prevalence of depressive symptoms in care givers of patients undergoing palliative care.
- ii. To determine the levels and severity of depression.
- iii. To determine the socio – demographic characteristics of the caregivers of patients undergoing palliative care.
- iv. To determine the caregiver characteristics associated with depressive symptoms among caregiver of patients undergoing palliative care.
- v. Based on the findings of the study suggest intervention/strategies to address issues related to depression among care givers of patients undergoing palliative care.

1.4 Research questions

- i. Are there depressive symptoms among care givers of patients undergoing palliative care?
- ii. What are the levels of depression among the caregivers?
- iii. What are the socio –demographic characteristics of caregivers of patients undergoing palliative care?
- iv. What are the treatment options and/or strategies for management of depressive symptoms?

1.5 Scope of the study

The study was carried out at Kenyatta National Hospital (KNH) in the palliative care unit. The sample was collected from population of care givers of all ages in this clinic. The study took a period of one month.

1.6 Limitations of the study

This study was limited by the following factors

- Limited finance to carry out research on a bigger sample.
- Some questionnaires were not filled satisfactorily.
- Some questionnaires were not completed by the sampled population.
- Other psychosocial factors may have been associated with care-giving of the patients in palliative care however; the scope of the study was just limited to the prevalence of depressive symptoms among the caregivers.

1.7 Justification of the study

There is little data on caregiver depression for cancer patients. This study was to determine prevalence of depressive symptoms in caregivers of cancer patients receiving palliative care at the palliative care unit at the Kenyatta National Hospital. Previously attention had been given to the patient but in this study, the researcher was able to determine prevalence and levels of depression in caregivers. It will assist healthcare providers in managing caregivers as well as the patients. Study will help other scholars in the field of knowledge and serve as a basis for further research.

CHAPTER TWO: LITERATURE REVIEW

2.1 Theoretical overview

2.1.1 Introduction

This study was based on the Framework of a Good Death model (12). This model usually includes four components: i) fixed characteristics of the patient (age, ethnicity); ii) modifiable dimensions of the patient's experience (symptoms, social support); iii) potential interventions provided to patients, families, friends, healthcare providers, and others, and iv) outcomes.

The validity and stability of the model was assessed over time. It reported good construct validity of the tested portion of the model, with eight variables accounting for 46% of the variance in the patient's end of life experience (Cronbach's α 0.63 to 0.85). The model was adapted to clarify the flow of the model from left to right, including caregivers' measurable outcomes (13).

The major factors from the literature associated with caregiver depression symptoms were used to construct a model from the McMillan's modified Emanuel and Emanuel Model of a Peaceful Death to predict hospice cancer caregivers' depressive symptoms. Caregivers' and patients' fixed physical and psychosocial factors combine with caregivers' and patients' modifiable physical and psychosocial factors in predicting caregiver depressive symptoms. The patients' cancer diagnosis and the caregivers' gender, ethnicity, age, health status, previous history of depressive symptoms, and a relationship to patient are immutable at the start of the care giving experience. Modifiable factors which may vary to influence caregivers' depressive symptoms either positively or negatively are: patients' symptom distress, functional status, depressive symptoms, and quality of life and the caregivers' perception of social support, mastery of patient care, burden, coping skills, attitude and sense of coherence (12).

2.1.2 Palliative care

Palliative care is specialized medical care for people with serious illnesses. It is focused on providing patients with relief from the symptoms, pain, adverse reactions and stress of a serious illness whatever the prognosis. The goal is to improve quality of life for both the patient and the family as they are the central system for care. Palliative care is provided by a team of doctors, nurses, and other specialists who work together with a patient's other doctors

to provide an extra layer of support to the patients. It is appropriate at any age and at any stage of a serious illness and can be provided along with curative treatment (15).

A World Health Organization describes palliative care as "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual(16)." More generally, however, the term "palliative care" may refer to any care that alleviates symptoms, whether or not there is hope of a cure by other means; thus, palliative treatments may be used to alleviate various side effects of curative treatments, such as relieving the nausea associated with chemotherapy.

The term "palliative care" is increasingly used with regard to diseases other than cancer such as chronic, progressive pulmonary disorders, renal disease, chronic heart failure, HIV/AIDS, and progressive neurological conditions. In addition, the rapidly growing field of pediatric palliative care has clearly shown the need for services geared specifically for children with serious illness (17).

In general Palliative care:

- provides relief from pain, shortness of breath, nausea, and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor to postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible;
- offers a support system to help the family cope;
- uses a team approach to address the needs of patients and their families;
- will enhance quality of life;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy. While palliative care may seem to offer a broad range of services, the goals of palliative treatment are concrete: relief from suffering, treatment of pain and other distressing symptoms, psychological and spiritual care, a support system to help the individual live as

actively as possible, and a support system to sustain and rehabilitate the individual's family (18).

2.1.3 Family members as primary caregivers

There is no dispute that a life threatening illness such as cancer echoes through the entire family; not least because the family is the primary unit for both social support and health care (19). In a quantitative study, it was mentioned that regardless of patient or family preferences, current health care trends, including shortened hospital length of stay, increased amounts of care being provided on an outpatient basis and limited availability of palliative care beds contributed to the shift of care to the home setting. To make this possible, usually a family member had to assume the role of primary care provider (20).

Often the role of care giving fell to a family member (21; 22). In their longitudinal study of breast cancer patients and their principal caregivers (23), over half the caregivers were male (55%) and the patients' spouse or partner (52%). Spouses, in particular, occupied a central position during the cancer experience. They have been frequently identified as the key person who gave emotional support and provided physical assistance to the woman with breast cancer (24). Furthermore, spouses often took on additional roles when their wives were ill in order to maintain the day-to-day functioning of family life. Spouses were important not only because of the tangible support that they provide for their wives, but also because their adjustment to the illness affected the adjustment of their wives (25).

The family was a major factor in the individual's health process and played a prime role in the course and management of an illness (26; 27, 28). Patients and their caregivers were now commonly based in their homes with complicated medical therapies to be administered. These changes placed great demands on caregivers' and patients' 'informal' support structure. The caregiver role could dramatically impact on a family member and a family (29).

A study on focus groups on care giving for women with advanced breast cancer, found that most married patients' husbands assumed the role of principal caregiver. Spouse caregivers viewed care giving as part of their marriage partnership. Working spouse caregivers had to juggle employment, family responsibilities (such as child care) and care giving. Non-spousal

caregivers took on the role of principal caregiver as an extension of an existing role as daughter, sister, niece and friend (30).

In a quantitative study on family caregiver quality of life, it showed that the adult child, most often the daughter, usually was the caregiver if the spouse was not. The care giving experience was very different depending on the caregiver's relationship to the patient. The adult child may have had to care for children and job responsibilities in addition to caring for an ill parent (31).

The role of family caregivers has shifted from one of custodial care to a complex, multifaceted role that included symptom management, monitoring for changes in hallmark symptoms, equipment care, patient transport and advocacy, and management of activities/responsibilities the patient has foregone because of illness. Due to advances in treatment, the cancer care trajectory has increased from days and weeks to months and years meaning the period of survival is longer (32).

2.1.4 Emotional experiences of primary caregivers

As cancer progressed, care tasks were generated, which could be perceived by the caregiver as either negative (i.e. burdensome) or positive. These care giving experiences may have led to negative as well as positive effects on the caregiver's health (11). It was well recognized that care giving could adversely affect the psychological adjustment of the family caregiver as well as increase caregiver burden (22). 'Caregiver burden' was generally used to refer to the physical, psychological, social and /or financial reactions that could be experienced in giving care (33).

There is an abundance of literature demonstrating the emotional, physical and financial distress experienced by primary home caregivers, as well as their frequent social isolation (34). Another longitudinal study 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 (35). Their finding that caregiver's psychological morbidity was equal to or greater than the patient's was consistent with other research in the field (22; 36).

Their findings also indicated that although patient's physical and emotional factors predict caregiver distress, perceived burden was the strongest predictor of caregiver anxiety and depression. Family caregivers reported distress from uncertainty about the course of the disease as well as feelings about their inability to provide care and also to manage the patient's symptoms such as depression and anxiety (33).

Another study also found that caregiver's level of anxiety particularly in palliative care, were extremely high (37). A study found that caregivers found the anxiety of the patient a more difficult challenge to meet than some of the physical care requirements, and it heightened their own anxiety (38). One prospective longitudinal study found that caregivers aged 45 to 54 reported the highest levels of depressive symptoms and caregivers aged 35 to 44 reported the strongest sense of abandonment (39). Caregivers who were the adult children of patients with cancer and those who were employed reported high levels of depressive symptoms. Feeling abandoned was more prevalent in female, non spouse, and adult children caregivers.

One of the conclusions made in one study concerning the views of families regarding palliative care was that the needs of the caregiver may exceed those of the patient (37). The results of yet another study conducted, supported earlier work showing that spouses were as distressed as patients. The study provided additional evidence for cancer as a problem not of the individual but of the couple. In light of the significant emotional impact that cancer could have on spouses, some investigators have questioned who the real patient was during the cancer experience - the woman or her partner (19).

The findings of a study on family members of patients suffering from cancer indicated that recurrent breast cancer seemed to take a sizeable emotional toll on family members (40). Family members were expected to be the primary providers of physical and emotional support to the patient, yet they perceived little support from others, either professional or personal, in carrying out this essential role. Often, the family caregiver was the one most responsible for managing the side effects of treatment and symptoms of disease at home as the patient's condition deteriorated. The distress that they experienced not only may have affected their ability to care for the patient, but also may have impacted their ability to provide emotional support, to support activities of daily living, and to assist with other physical aspects of care (41). In one quantitative study on lifestyle interference and emotional distress in family caregivers of advanced cancer, patients found that caregivers experienced

increased emotional distress, regardless of the amount of care provided, when limited in their ability to participate in valued activities and interests (42).

Care giving for a loved one with advanced breast cancer was described as emotionally difficult. Personal variables such as anxiety and depression affected the caregiver's perception and reactions to caring. Husbands' and wives' coping styles, for example, facilitated coping for some couples, but for other couples, it caused emotional distress and an increased sense of burden. A study indicated that husbands of women with recurrent breast cancer appeared to be especially vulnerable to the impact of the illness because of more role adjustment problems, higher levels of uncertainty and more hopelessness they experienced (43).

As the illness progressed, some study showed that caregivers experienced more depression, a greater adverse impact on their own health and daily lives and spent more time helping patients cope with daily living activities (44). Studies of family members caring for persons with advanced cancer have shown that most caregivers experienced stress in the care giving role and significant stress in observing the patient suffering. Additional stress could be experienced by having to 'stand by' and observe the disease progress while being unable to alter or manage the illness (45).

Pain was experienced by many cancer patients, either acutely or chronically. Knowing that a loved one was in pain, and trying to help were very difficult experiences for family members (46). The findings in a qualitative study showed that the significant others experienced deep often unrelieved suffering and considered themselves prisoners of a situation of uncertainty and powerlessness when standing by the woman (47). The significant others considered the suffering of the woman as the primary thing and their own suffering 'at second place'.

Caregivers experienced multiple challenges, including declining health of the patient and psychological distress over social and cultural issues surrounding death and dying. Caregivers to individuals with advanced cancer were often required to provide increasing amounts of care as the patient's health deteriorated, and had to also prepare for their imminent death (48).

2.2 Patient and Caregiver characteristics for depression symptomatology

Various factors contributing to caregiver depression may be related to both the caregiver and the patient.

2.2.1 Patient Behavioral Problems and Depressive symptoms

Behavioral problems, memory problems, and depression of Alzheimer's disease (AD) patients have been associated with caregiver depression symptoms and fatigue (49; 50; 51). Caregiver sleep disturbance, resulting from AD patient behavior problems, has also been correlated to increased caregiver depressive symptoms (52). Depressive symptoms in patients have been correlated with symptoms of depression in caregivers (53; 54; 55). When patients met criteria for any psychiatric diagnosis, their caregivers were 7.9 times as likely to meet the criteria for any psychiatric diagnosis and vice versa (56).

2.2.2 Patient Functional Status

Caregivers of terminally ill patients with high care needs, including transportation, nursing, homemaking and personal care, have higher depressive symptoms (57). Spousal caregivers' increased negative appraisal of cancer or dementia patients' ability to self-care has also been found predictive of caregiver depressive symptoms (58). Caregivers with no previous symptoms of depression are more likely to have depressive symptoms as the patient's need for assistance with activities of daily living (ADL) increased (59).

Dementia caregivers provide more help with Activities of Daily Living (ADL) and Instrumental Activities of Daily Living than cancer caregivers. Dementia caregivers are more likely to provide care in a nursing home than the cancer caregivers, however both hospice caregiver groups provide more than double the number of hours of care than caregivers of ambulatory dementia patients. While dementia caregivers provide care for many more months, cancer caregivers provide many more hours of care giving a week (5). Cancer patient ADL dependency, the extent to which a patient cannot perform essential activities of daily living, is correlated not only with increased patient depressive symptoms, but also with caregiver depressive symptoms (73). Caregivers of terminally ill patients, including cancer, with high care needs including transportation, nursing, homemaking and personal care, had high depressive symptoms (57). Cancer caregivers' increased negative appraisal of the patients' ability to self-care is a predictor of caregiver depressive symptoms (73).

2.2.3 Caregiver Health Status, Gender and Relationship to Patient

A caregiver's health status has been associated with caregiver depressive symptoms, with caregivers reporting care giving strain more likely to have lower levels of perceived health,

greater depressive symptoms, less rest, lower likelihood to rest when ill, less time to engage in exercise, and higher incidence of congestive heart disease (CHD) than non-caregivers (60; 61). The elevated incidence of metabolic syndrome significantly explained CHD prevalence in male and female caregivers (61). In contrast, caregivers who report better health have lower levels of depressive symptoms (58).

There are gender differences in depression symptoms with female caregivers, including spousal caregivers, having significantly higher levels of depressive symptoms than male caregivers (62; 63; 58; 64). Women have been reported to have higher rates of depressive symptoms, more likely to be socially isolated and have almost twice the rate of probable major depression (65; 66; 67; 68). Male caregivers may also have higher rates of depressive symptoms with male gender being the most significant correlate of depressive symptoms (69). Male spousal caregivers of AD patients have had depressive symptoms scores significant for a diagnosis of depression (70).

2.2.4 Caregiver History of Depression

Individuals who have had a history of depression may be more likely to experience depressive symptoms when assuming the role of caregiver. Caregivers of Alzheimer's disease (AD) patients with a past depressive - anxiety disorder had a higher rate of symptoms of depression than those without a past history of those disorders (71). AD patient caregivers with a prior history of depressive symptoms have also been found to have fewer depressive symptoms while care giving (59). However, ADL dependency resulted in more depressive symptoms in caregivers without a prior history of depression and in caregivers with a history of mild depressive symptoms, supporting early studies of the effect of ADL dependency on the psychological health of caregivers discussed earlier (72; 73; 58; 59)

2.2.5 Caregiver Attitude, Health, Sense of Coherence, Coping, and Neuroticism

Negative caregiver mood has been related to poor health and depression symptoms (74; 75). Caregivers with higher optimism were found to have significantly lower levels of depressive symptoms while those with higher pessimism had significantly higher levels of depressive symptoms and poor physical health, with a faster decline in health (75). The higher levels of depressive symptoms and poor physical health also confirm other studies linking depression symptoms with poor health (76; 77; 61). Caregivers who evaluated care giving as less stressful and had greater perceived benefits of care giving had less depressive symptoms (58).

A caregiver's general attitude about life and ability to cope with stress has been measured using the Sense of Coherence scale (78). Male caregivers with significantly higher sense of coherence scores had lower levels of depressive symptoms (64). Coping styles may influence depressive symptoms, with approach coping associated with lower levels of depressive symptoms and avoidance coping with higher levels of depressive symptoms (79). Emotion-focused coping strategies were found to mediate anxiety levels in AD caregivers but not depressive symptoms (80). A psycho-educational skill intervention reduced caregiver burden from patient symptoms and care giving tasks, and increased overall quality of life. However, the study did not assess depression specifically (81). Caregiver neuroticism, the tendency to focus on the negative aspect of care giving, has also been associated with higher levels of depressive symptoms in a study of dementia spousal caregivers (82; 83).

2.2.6 Caregiver Mastery and Burden

Caregivers' perception of their competency in providing patient care is referred to as mastery (84). Caregivers with high mastery have lower levels of depressive symptoms, with lower scores on mastery predictive of higher levels of depressive symptoms over time (85). Increased mastery has been directly associated with lower depressive symptoms (86).

Caregiver burden includes factors such as feelings of stress of tasks, meeting responsibilities and finances, as well as a perceived decline in health (87; 88). Caregiver burden is highly correlated with caregiver depressive symptoms, with caregiver depression symptoms predictive of caregiver burden (89; 90). Younger caregivers are more burdened than older caregivers (91; 92; 93). However, it is not possible to compare caregiver burden in non caregivers to determine the clinical significance of burden (94).

2.2.7 Caregiver Social Support

Caregivers of patients with AD and other dementias with lower social support had increased depressive symptoms while those with higher levels of support had fewer symptoms (92; 95; 58; 96). Greater satisfaction with social support was also associated with higher life satisfaction (73). Cancer caregivers reporting a low level of social support have more depressive symptoms over time than those who reported a high amount of social support (85). Other studies have also confirmed that a lack of perceived social support contributes to caregiver depressive symptoms (92; 101).

2.2.8 Caregiver Ethnicity

Several studies have reported differing rates of caregiver depressive symptoms in various race and ethnic groups. Caucasians caregivers have been found to have more depressive symptoms than African Americans caregivers (96). Coping and social network resources may have been responsible for the fewer depressive symptoms in African American caregivers (96). However, there is no appreciable difference between Caucasian and Hispanic/Latina caregivers as regards symptoms of caregiver depression (97). Anglo American, African American and Japanese American dementia caregivers have reported depressive symptom rates of 66%, 57% and 78% respectively. Mexican Americans had an 89% reported depressive symptom rate clinically significant for a diagnosis of depression, of which 51% was probable major depression (65). While these rates are different, they indicate depressive symptom rates are high for all caregiver ethnicities.

2.2.9 Caregiver Age

Younger age has been associated with higher depression symptom levels in dementia caregivers (98; 99). Middle-aged caregivers may be caring for a parent while raising their own children with additional family and employment responsibilities (98; 100; 99). Dementia caregivers older than 65 years have also been found to have depressive symptom levels high enough to be classified as clinically depressed (63). However, caregiver age has not been found predictive of caregiver depressive symptoms (89).

2.3 Studies done in Kenya

A study done at the Nairobi Hospice revealed that cancer impacted negatively on family especially where the caregiver stopped working to take care of the patient. According to this study, group therapy offered support to the family (103). Another study on cancer patient care and found that cancer management is a continuous process involving oscillation between the hospital and home. The hospital becomes very unpleasant to both the patient and the caregiver as the patient approaches end of life stage of illness (104). Exploration of the risk of depression in caregivers of children with intellectual disability was done in Nairobi. In this study, 79% were at risk of developing clinical depression (105).

2.3.1 Treatment

Depression is highly treatable with most people experiencing relief of symptoms and the ability to return to their daily routines. Identifying hospice caregivers of cancer patients experiencing symptoms of depression is also important to provide for screening and early intervention. Early treatment is more effective and increases the probability of preventing

recurrence (101; 102). Depression deserves to be treated with the same attention afforded any other illness, such as diabetes or high blood pressure.

2.3.2 Treatment Options

Upon review of the physical and mental evaluation, a course of treatment will be recommended. Primary treatment options are psychotherapy (also referred to as mental health therapy) and antidepressant medication. Complementary and alternative therapies may also be used e.g. extracts from the leaves and flowers of St John's wort (a herb) is treatment for depression commonly prescribed for mild depression. It is proposed that the mechanism of action of St. John's wort is due to the inhibition of reuptake of certain neurotransmitters. Exercise has been found to reduce the effects of depression. Walking three times a week for 30 to 45 minutes has been linked to reducing or alleviating symptoms of depression. Support group is also a way of managing caregiver burden and depression. The caregiver learns to hold on and share universality of distressing experience. Other management strategies have been identified as: learning more about cancer as a disease, time and self management, creating time for friends and exercise, having fun, asking for resources and support through other bodies.

2.4 Conceptual Model of Depression

There is a relationship between loss, grief and depression. Grieving turns into depression when the bereaved felt ambivalent about the lost object (i.e. person) and cannot tolerate the negative side of this ambivalence. Childhood loss, especially loss of a parent has had a positive association with adult depression; in addition, depression is more likely to have its onset after a loss, separation or even disappointment (109).

A patient or a care giver may react to the impending death of self or a loved one by; denial, anger, bargaining, depression and acceptance. Sometimes a care giver may not be able to express his/her anger on the patient. As a result, the caregiver may undergo the physiological and psychological processes, symptoms of which may indicate depression. According to cognitive theory which is related to hypotheses derived from rational emotive therapy, negative thinking causes depression (14). If everything a person does seems to work out, the mood remains positive. If something happens to contradict an all or nothing assumption, it proves globally disruptive to self confidence and the negative side of the patient's thinking dominates. When a patient feels helpless as a result of not having been able to influence the outcome of a complex and a difficult situation, he/she stops trying to do anything to deal with later, simpler stresses. When this lack of effort results in subsequent failure then the patient

comes to believe that he/she cannot change the negative environment. Systematic errors in thinking also lead to catastrophic thinking and transition of single negative events to global negative expectations of self, the environment and the future (the cognitive triad).

Figure 1: Conceptual Framework

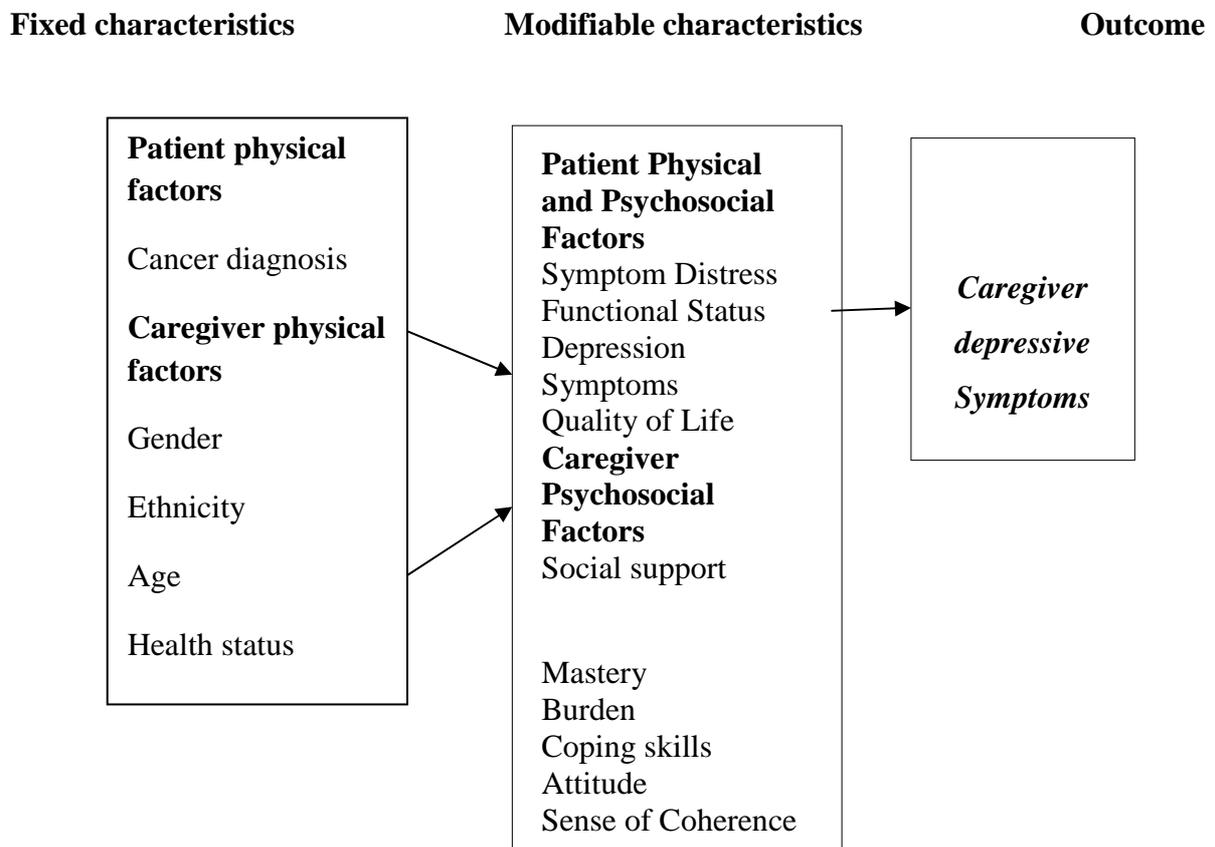


Figure 1. McMillan’s Modified Emanuel and Emanuel (1998) Model for a Peaceful Death. The major factors associated with caregiver depressive symptoms, available from baseline assessment data from the original study, were used to construct a model for the current study to predict hospice cancer caregiver depressive symptoms (Figure 1). The available physical and psychosocial patient factors were cancer diagnosis, symptom distress, functional status, depressive symptoms and quality of life. The available caregiver physical and psychosocial factors were gender, ethnicity, age, health status, relationship to the patient and social support.

CHAPTER THREE : STUDY DESIGN AND METHODOLOGY

This chapter presents the research design, study area, population of the study, sample design and sampling size, selection criteria, data collection procedure, ethical consideration and data analysis procedure.

3.1 Research design

This was a cross-sectional study. This was better suited in examining the experiences of caregivers of patients receiving palliative care at the Palliative Care Unit at KNH.

3.2 Study area

The study was carried out in Kenyatta National Hospital, Nairobi County, Kenya. Kenyatta National Hospital is Kenya's tertiary referral hospital. The distance from the city centre to the hospital is about 7 km. It is situated along Hospital road. It has a capacity of 1800 beds and caters for over 2000 patients daily. Majority of the patients have life threatening illnesses.

Palliative care unit was started on 1st March, 2007. It is located in the consultants' clinic, no 28. The clinic runs daily from Monday to Friday (8am-5pm). It is managed by one medical officer and five nursing officers. They offer services like; Pain and symptom relief, patient and family counseling, education and research, bereavement counseling and nursing care. It takes care of both in-patients and out-patients. Currently, an average of 160 patients is attended to per month. Out of these, an average of 30% of the patients gets counseling services.

3.3 Population

The population of the study comprised of Care givers of patients who were undergoing palliative care at the Kenyatta National Hospital during the month of May-June, 2014. The population constituted both men and women offering care giving services to patients attending Palliative care Unit at KNH during the time of the study.

3.4 Sample size determination:

The sample size of caregivers was determined using Krejcie & Morgan formula represented below;

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

Where n = Sample Size

N = the total population

I = constant

E = limit of sampling error = 0.05

This can be computed as shown below:

$$n = \frac{160}{1 + 160(0.05)^2}$$

$$n = \frac{160}{1.4}$$

$$= 114$$

n Approx = 114

From the above formula 114 caregivers were selected to participate in the study. However, after cleaning and coding, a total number of 110 respondents were analysed.

3.5 Sampling procedure

The study used purposive sampling. The reason for choosing this method is because purposive sampling only focuses on particular characteristics of a population that are of interest which will enable the researcher to answer research questions. This study only focused on the caregivers and not on all the population in the clinic. All those willing caregivers who met the criteria were interviewed during the stipulated period of the study. All were included until the 114th participant.

3.6 Inclusion criteria

Care givers who were willing to participate in the study were included in the study. Those who could not express themselves in either Kiswahili or English were assisted by the researcher to understand and to fill in the information. They must have consented to participate in the study. Participants were also required to participate voluntarily in the study.

3.7 Exclusion criteria

Those who had just accompanied the patient to hospital but did not give primary care were not included in the study. Those who met the inclusion criteria but were not willing to participate were not included in the study.

3.8 Data collection tools

In this study, both Becks Depression Inventory (BDI) and socio-demographic survey tools were used. BDI was used to capture the experience of the caregiver to determine the level of depression. The BDI contains 21 questions, with each answer scored on a scale value of 0 to 3. The cutoffs used are: minimal depression (0-13); mild depression (14-19); moderate depression (20-28); and severe depression (29-63). The 21-item survey is self-administered and is scored on a scale of 0-3 in a list of four statements arranged in increasing severity about a particular symptom of depression, bringing the BDI into better alignment with DSM–IV criteria. The scale higher total scores indicate more severe depressive symptoms. The socio-demographic survey tool was used to capture the caregivers' socio – demographic characteristics (e.g. age, gender, ethnicity, marital status, level of education and income) that may be associated with depressive symptoms.

3.9 Data collection procedure

The medical officer in charge was informed of the impending study in order for the researcher to access the facility. The researcher introduced herself to the patients' caregivers and the details of the study were explained in a semi private room at the clinic or in the ward. This is because some of the patients attended in this clinic are in-patients. This occurred mainly every working day (Monday to Friday). There were instances when the researcher carried out the interviews over the weekend or after 5pm. This applied to cases where the caregiver could only be accessed during such times. The participants who met the inclusion criteria were briefed on the nature of the study by the researcher. Those who were willing to participate were given the consent form and the two questionnaires to fill in succession. For those who did not understand the languages, the researcher would read the questions as they appeared in the questionnaire and responses were recorded by the researcher as answered. Any questions from the participants were answered appropriately. There were two questionnaires namely: socio-demographic and the Becks depression Inventory checklist. Each questionnaire had code numbers. Those whose scores depicted depression were referred for further management. The ones in the wards were referred to the ward counselors.

3.10 Data management and analysis

The questionnaires were collected and kept under lock and key in the researcher's office away from the site of research. Cleaning and coding was then done before entry into the computer for analysis. The data was kept for three months after completion of analysis. This would facilitate any reference or correction as may be deemed necessary by the ethics and

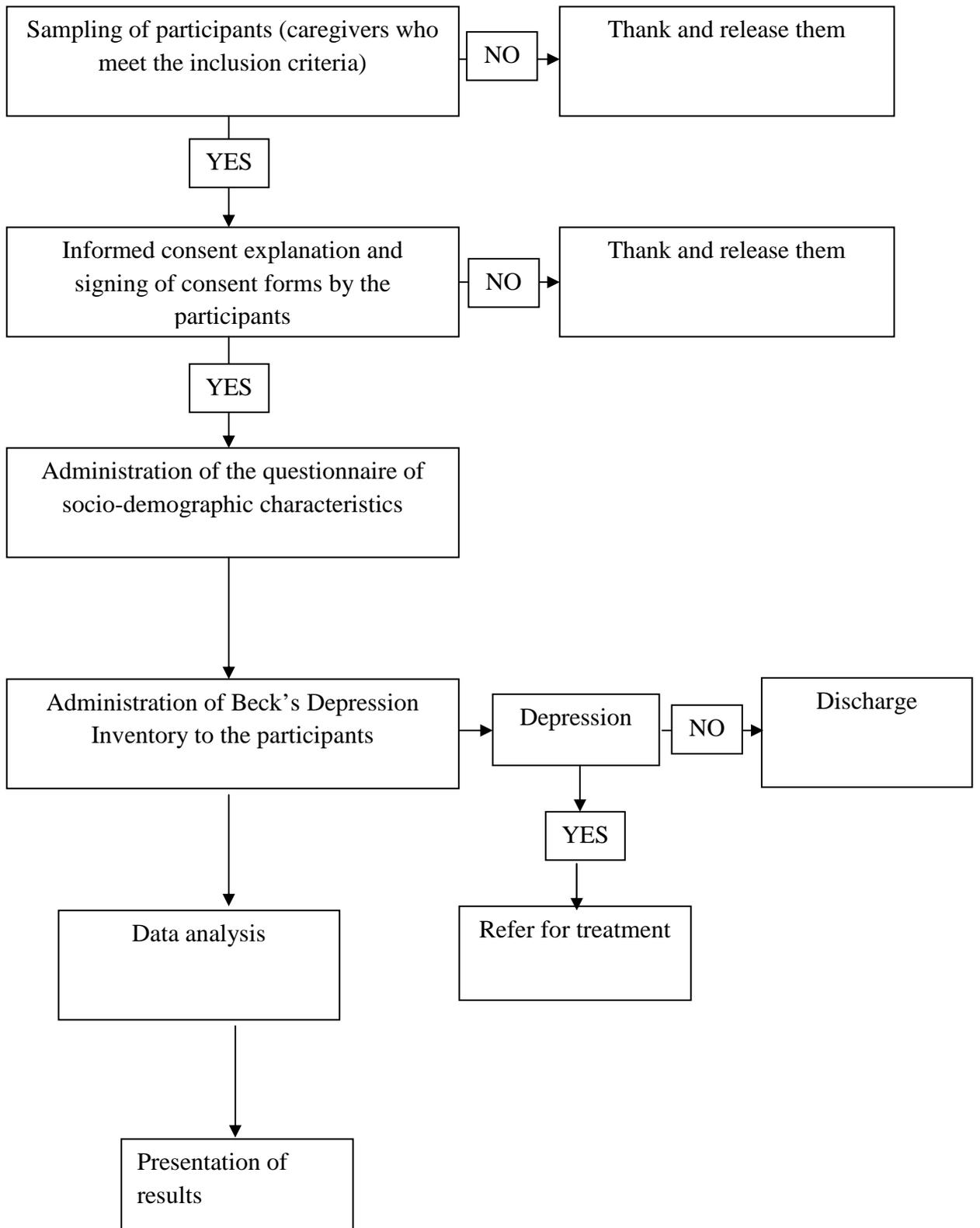
research committee. The data was then entered into the computer and analyzed using Statistical package for social sciences (SPSS) version 18. Using descriptive statistics, socio-demographics and scores from BDI were presented. Socio-demographic data was analyzed to give care givers' characteristics such as age, education, income, marital status in relation to level of depression. BDI was analyzed to give the scores to show the levels of depression of the care givers. The results were presented in tables, graphs, percentages and bar/pie charts.

3.11 Ethical considerations

The proposal was presented to Ethics and Research Committee of Kenyatta National Hospital/University of Nairobi for approval. A letter obtained from the ethics committee was given to the medical officer in charge of the palliative care unit at the hospital before the research was undertaken. Informed consent was obtained from the research participants after briefing them on what the research entailed. The informed consent form was issued by the researcher and any clarifications were made as required. This was administered after screening out those who met the inclusion criteria. Confidentiality was ensured by using codes and not names to identify the participants. The exercise took place in semi private rooms. The list with the real names and the codes of participants was kept separately from the completed questionnaires. This was also kept under lock and key. There were no expected risks from the study since it did not involve invasive procedures but those who experienced emotional distress received counseling after the session. No one was discriminated against on the basis of tribe, age, gender or race. No compensation was given to the subjects of the study. Participants were free to withdraw from the study at will.

The data was kept under lock and key for purposes of confidentiality, to protect the participants' personal information from accessibility to others other than the researcher. The only persons who had access to the results were the researcher and the data analyst. At the end of the research, the data analyst had access to the research data during data analysis. The benefit of the study included identification of symptoms of depression and offering intervention e.g. on the spot counseling and referral for further management.

Figure 2: Flow chart of methodology



CHAPTER FOUR: RESULTS

4.1: Socio-demographic characteristics

This study had a total of 110 respondents. There were more female caregivers 59 (53%) than males 51(47%) with majority of them in the age range of 40-50 years (43.6%) and mean age of 43.6, median, 44.1 and a standard deviation of 10.6 Majority (78.2%), were married, 17(15.5%) were single, separated were 5(4.5%), while 1.8% (2) were divorced. None of the respondents were cohabiting at the time. Most (43.6%) had secondary education and only 8.2% had no formal education. 21.8% received primary education while 26.4% acquired tertiary education. Most (43%) were self-employed, 22.7% were employed, 26.4% were unemployed and 8.2% had retired. Majority (88.2%) were Christians while (11.8%) were Muslims. Table 1 presents the summary of socio-demographic characteristics of the respondents.

Table 1: Socio-demographic characteristics of the sample

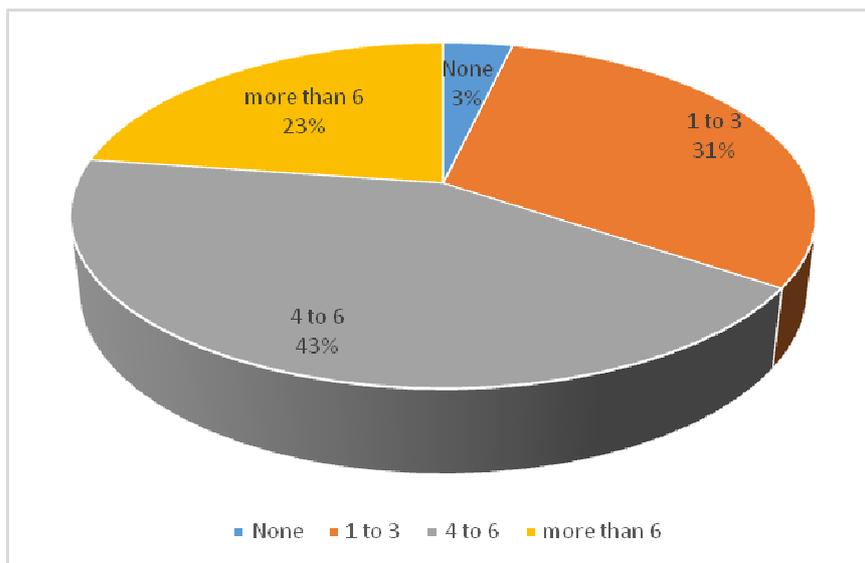
Characteristic	Frequency	Percentage
Gender		
Male	51	46.4
Female	59	53.6
Age category		
18-28 years	12	10.9
29-39 years	21	19.1
40-50 years	48	43.6
51-60 years	27	24.5
61 and above years	2	1.8
Marital status		
Single	17	15.5
Married	86	78.2
Separated	5	4.5
Divorced	2	1.8
Level of education		
None	9	8.2
Primary	24	21.8
Secondary	48	43.6
Tertiary	29	26.4
Occupation		
Employed	25	22.7

self-employed	47	42.7
Retiree	9	8.2
not employed	29	26.4
Religion		
Muslim	13	11.8
Christian	97	88.2

4.2 Number of children under the caregivers' care

From figure 4.1 below, 42.7% of the care givers had 4-6 children, 30.9% had 1-3 children, 22.7% had more than six children and 3.6% had no children under their care.

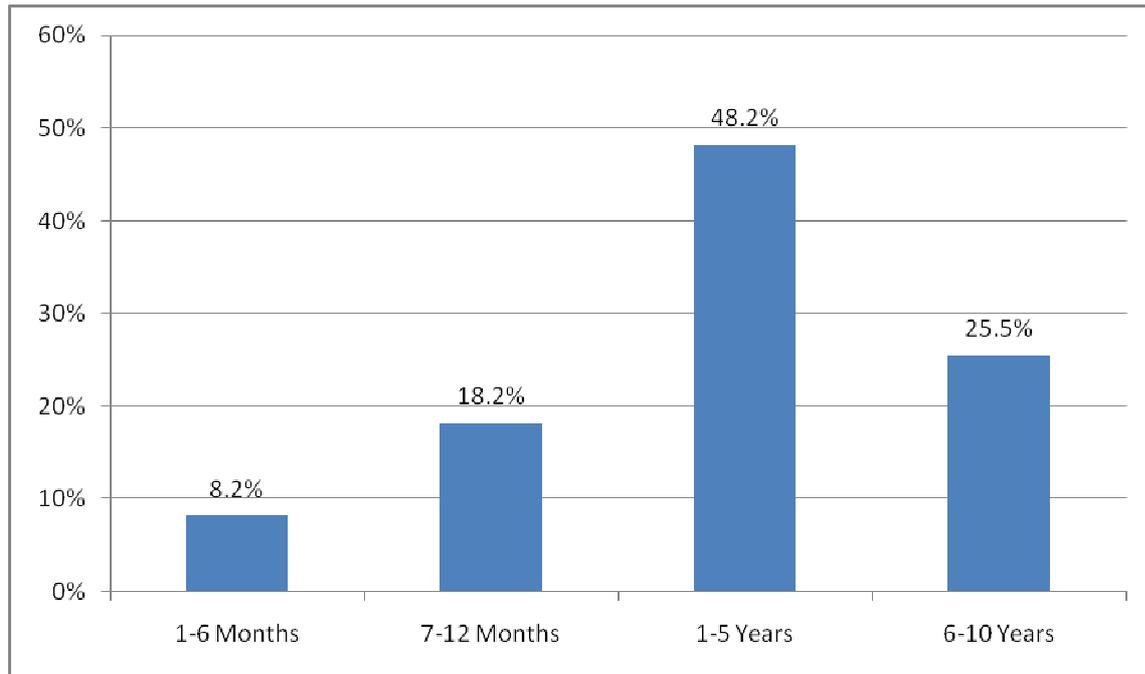
Figure 3: Distribution of number of children under caregivers care



4.3: Duration of care giving

Figure 4: Duration of care giving

From figure 2 below, 53(48.2%) care givers had been caring for the patients over a period of 1-5 years, 28(25.5%) respondents had been caring over a period of 6-10 years and 20 (18.2%) respondents had been caring for a period of 7-12 months.



4.4: Relationship with the patient

Table 2 below shows that majority of the care givers were parents of the patient with 46%, wife to the patient were 23%, husbands to the patient were 25%, others which included nephew, friend, uncle, brother and sisters were 14% while In-laws were 2%.

Table 2 : Care giver relationship with the patient

Relationship	Frequency	Percent
Child	46	41.8
In-law	2	1.8
Wife	23	20.9
Husband	25	22.7
Others	14	12.7

4.5: Income range of the caregiver

Income range of the care givers was also analyzed and the results are as shown in table 3 below.

Table 3 : Distribution of care givers' income range per month

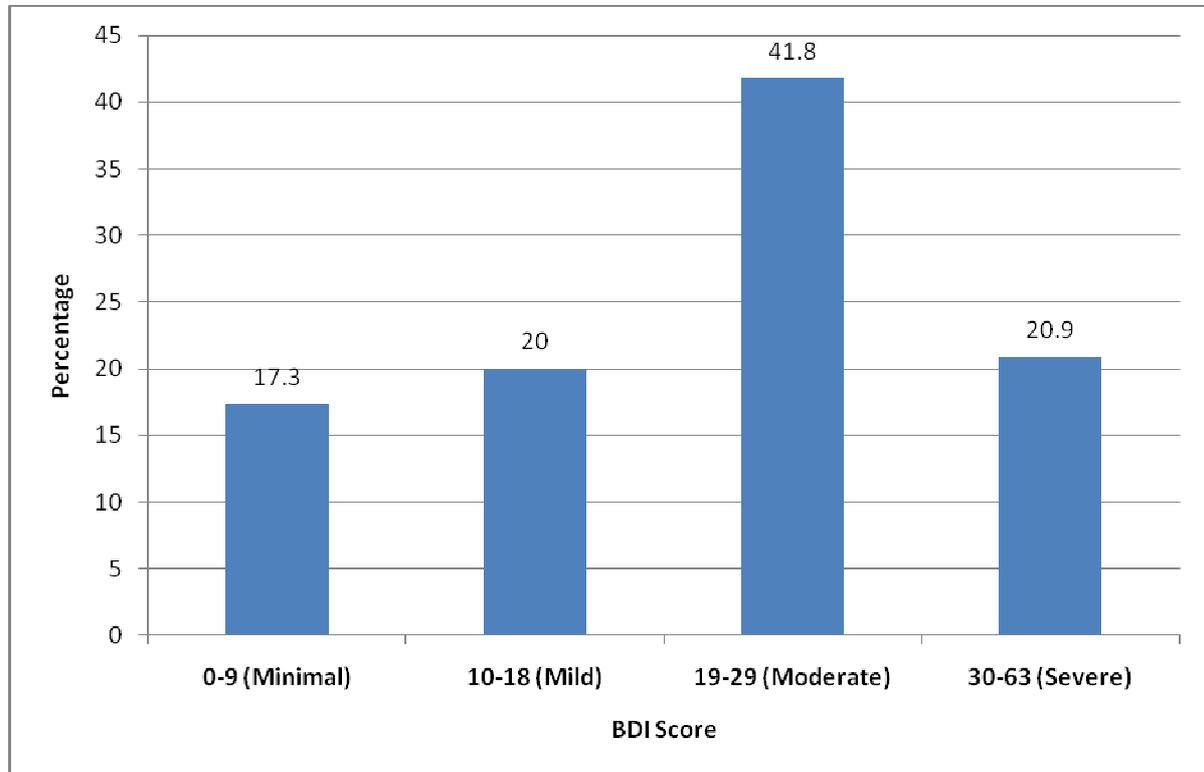
Income in Ksh	Frequency	Percent
Less than 10000	37	33.6
10001-20000	5	4.5
20001-30000	21	19.1
30001 and above	47	42.7

From the above table, majority of the care givers earned Ksh 30,001 and above as represented by 47%, those who earned less than Ksh 10,000 were 37%, those who earn between 20001 and 30000 were 21% while those who earn between 10001 and 20000 were 5%.

4.6 BDI scores of the respondents

The BDI scores of the respondents were analyzed and the findings are presented in figure 3.

Figure 5: BDI scores of the respondents



From the above figure 3 above, it is evident that most of the care givers had a moderate level of depression (42%), severe were 21%, mild were 20% and minimal were 17%.

Association of BDI scores and socio-demographic characteristics

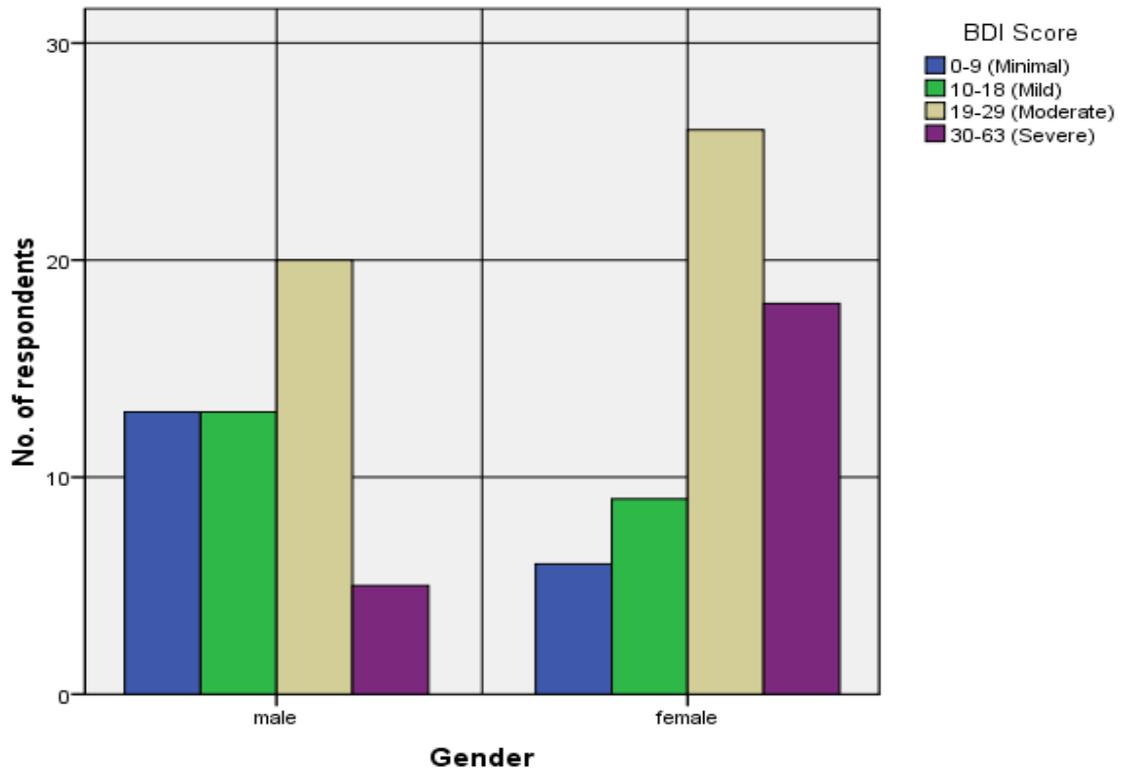
Table 4: Gender and depression

Cross tabulation

		BDI Score				Total
		0-9 (Minimal)	10-18 (Mild)	19-29 (Moderate)	30-63 (Severe)	
Gender Male	Count	13	13	20	5	51
	% of Total	11.8%	11.8%	18.2%	4.5%	46.4%
female	Count	6	9	26	18	59
	% of Total	5.5%	8.2%	23.6%	16.4%	53.6%
Total	Count	19	22	46	23	110
	% of Total	17.3%	20.0%	41.8%	20.9%	100.0%

The females are more likely to experience moderate and severe levels of depression at 26 (23.6%) and 18 (16.4%) as compared to the male at 20 (18.2%) and 5 (4.5%) respectively.

Figure 6: Gender and Depression



Chi-Square Tests

	Value	Df	Asymp. Sig. (2-sided)
Pearson Chi-Square	10.913 ^a	3	.012
Likelihood Ratio	11.374	3	.010
N of Valid Cases	110		

a. 0 cells (.0%) have expected count less than 5. The minimum expected count is 8.81.

For the Gender variable, the chi-square obtained is 10.913. With 3 degree of freedom and a significance level of .012, which falls well below the .05 alpha level, the difference between

the observed and expected values is significant. Thus there is a statistically significant association between gender and depression.

$$\chi^2(3) = 10.913, p \geq 0.012$$

Table 5: Age and depression

Cross tabulation

		BDI Score				Total
		0-9 (Minimal)	10-18 (Mild)	19-29 (Moderate)	30-63 (Severe)	
Age 18-28 years	Count	3	0	9	0	12
	% within BDI Score	15.8%	.0%	19.6%	.0%	10.9%
29-39 years	Count	0	4	11	6	21
	% within BDI Score	.0%	18.2%	23.9%	26.1%	19.1%
40-50 years	Count	11	15	12	10	48
	% within BDI Score	57.9%	68.2%	26.1%	43.5%	43.6%
51-60 years	Count	5	3	12	7	27
	% within BDI Score	26.3%	13.6%	26.1%	30.4%	24.5%
61 and above years	Count	0	0	2	0	2
	% within BDI Score	.0%	.0%	4.3%	.0%	1.8%
Total	Count	19	22	46	23	110

Cross tabulation

		BDI Score				Total
		0-9 (Minimal)	10-18 (Mild)	19-29 (Moderate)	30-63 (Severe)	
Age 18-28 years	Count	3	0	9	0	12
	% within BDI Score	15.8%	.0%	19.6%	.0%	10.9%
29-39 years	Count	0	4	11	6	21
	% within BDI Score	.0%	18.2%	23.9%	26.1%	19.1%
40-50 years	Count	11	15	12	10	48
	% within BDI Score	57.9%	68.2%	26.1%	43.5%	43.6%
51-60 years	Count	5	3	12	7	27
	% within BDI Score	26.3%	13.6%	26.1%	30.4%	24.5%
61 and above years	Count	0	0	2	0	2
	% within BDI Score	.0%	.0%	4.3%	.0%	1.8%
Total	Count	19	22	46	23	110
	% within BDI Score	100.0%	100.0%	100.0%	100.0%	100.0%

The respondents between the age of 40-50 years are more likely to experience higher levels of depression as compared to other age groups i.e. the age group between the age of 40-50 years 10 (43.5%) had severe depression as compared to 51-60 years at 7 (30.4%) and 29-39 years at 6 (26.1%).

Figure 7: Age

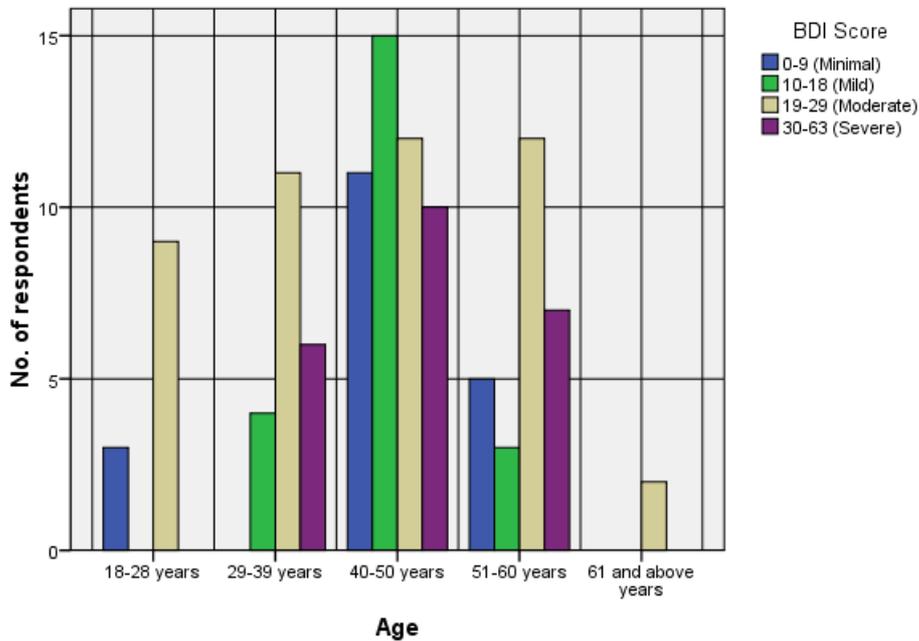


Table 6: Cross tabulation between age and depression score

Chi-Square Tests

	Value	Df	Asymp. Sig. (2-sided)
Pearson Chi-Square	24.683 ^a	12	.016
Likelihood Ratio	33.363	12	.001
N of Valid Cases	110		

11 cells (55.0%) have expected count less than 5. The minimum expected count is .35.

For the Age variable the chi-square obtained is 24.68. With 12 degree of freedom and a significance level of .016, which falls well below the .05 alpha level. The difference between

the observed and expected values is significant. Thus there is a statistically significant association between the age group and level of depression.

$$\chi^2(12) = 24.683, p \geq 0.016$$

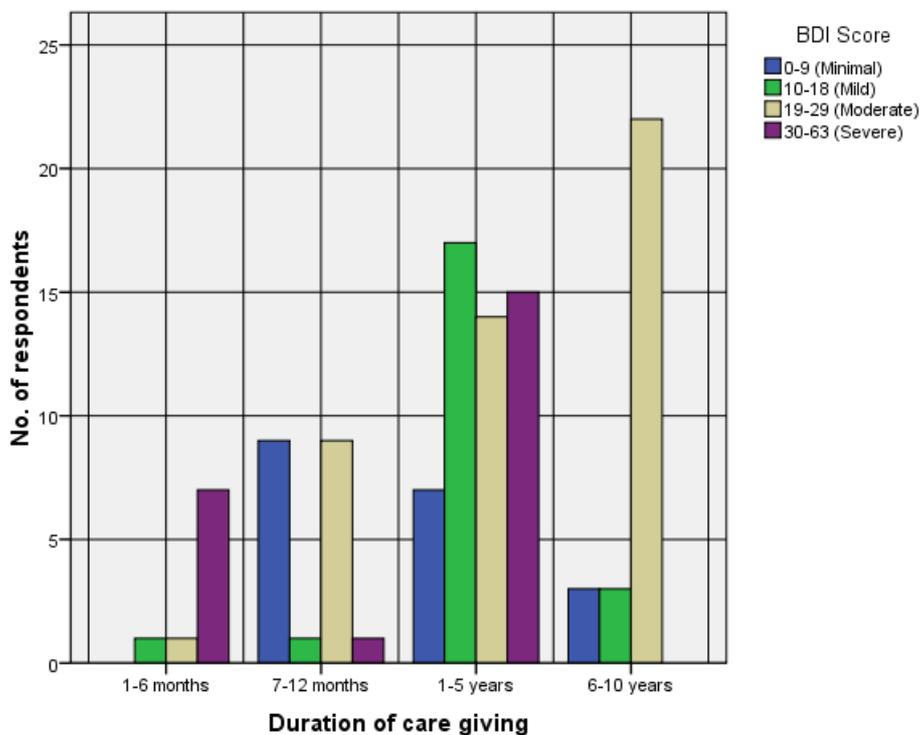
Table 7: Duration of care and depression

Cross tabulation

		BDI Score				Total
		0-9 (Minimal)	10-18 (Mild)	19-29 (Moderate)	30-63 (Severe)	
Duration of care giving	1-6 months	Count 0	Count 1	Count 1	Count 7	Count 9
		% within 0%	% within 4.5%	% within 2.2%	% within 30.4%	% within 8.2%
		BDI Score				
7-12 months		Count 9	Count 1	Count 9	Count 1	Count 20
		% within 47.4%	% within 4.5%	% within 19.6%	% within 4.3%	% within 18.2%
		BDI Score				
1-5 years		Count 7	Count 17	Count 14	Count 15	Count 53
		% within 36.8%	% within 77.3%	% within 30.4%	% within 65.2%	% within 48.2%
		BDI Score				
6-10 years		Count 3	Count 3	Count 22	Count 0	Count 28
		% within 15.8%	% within 13.6%	% within 47.8%	% within .0%	% within 25.5%
		BDI Score				
Total		Count 19	Count 22	Count 46	Count 23	Count 110
		% within 100.0%	% within 100.0%	% within 100.0%	% within 100.0%	% within 100.0%
		BDI Score				

The respondent with 6-10 years duration of care were more likely to suffer from moderate level of depression 22 (47.8%) and those with a duration of care between 1-5 years were more likely to have a severe levels of depression at 15 (65.2%).

Figure 8: Duration of Care



Chi-Square Tests

Table 8: Duration of care and depression

	Value	Df	Asymp. Sig. (2-sided)
Pearson Chi-Square	57.048 ^a	9	.000
Likelihood Ratio	57.149	9	.000
N of Valid Cases	110		

Chi-Square Tests

Table 8: Duration of care and depression

	Value	Df	Asymp. Sig. (2-sided)
Pearson Chi-Square	57.048 ^a	9	.000
Likelihood Ratio	57.149	9	.000

a. 8 cells (50.0%) have expected count less than 5. The minimum expected count is 1.55.

For the duration of care variable the chi-square obtained is 57.05. With 9 degree of freedom and a significance level of .000, which falls well below the .05 alpha level, the difference between the observed and expected values is significant. Thus there is a statistically significant association between duration of care level of depression recorded.

$$\chi^2(9) = 57.048, p \geq 0.000$$

Table 9: Care giver's relationship and depression

Cross tabulation

			BDI Score				Total
			0-9 (Minimal)	10-18 (Mild)	19-29 (Moderate)	30-63 (Severe)	
Relationship with the patient	child	Count	8	9	20	9	46
		% within BDI Score	42.1%	40.9%	43.5%	39.1%	41.8%
	in-law	Count	0	0	2	0	2
		% within BDI Score	.0%	.0%	4.3%	.0%	1.8%
	wife	Count	5	9	9	0	23
	% within BDI Score	26.3%	40.9%	19.6%	.0%	20.9%	
	husband	Count	0	4	8	13	25
		% within BDI Score	.0%	18.2%	17.4%	56.5%	22.7%
	others	Count	6	0	7	1	14
		% within BDI Score	31.6%	.0%	15.2%	4.3%	12.7%
Total		Count	19	22	46	23	110
		% within BDI Score	100.0%	100.0%	100.0%	100.0%	100.0%

Wives were more likely to suffer from severe depression while their husbands were sick i.e. severe depression levels at 13 (56.5%) as compared to those who were taking care of their children who had a moderate depression level of 20 (43.5%) and husbands with mild depression levels at 9 (40.9%).

Figure 9: Relationship with the patient

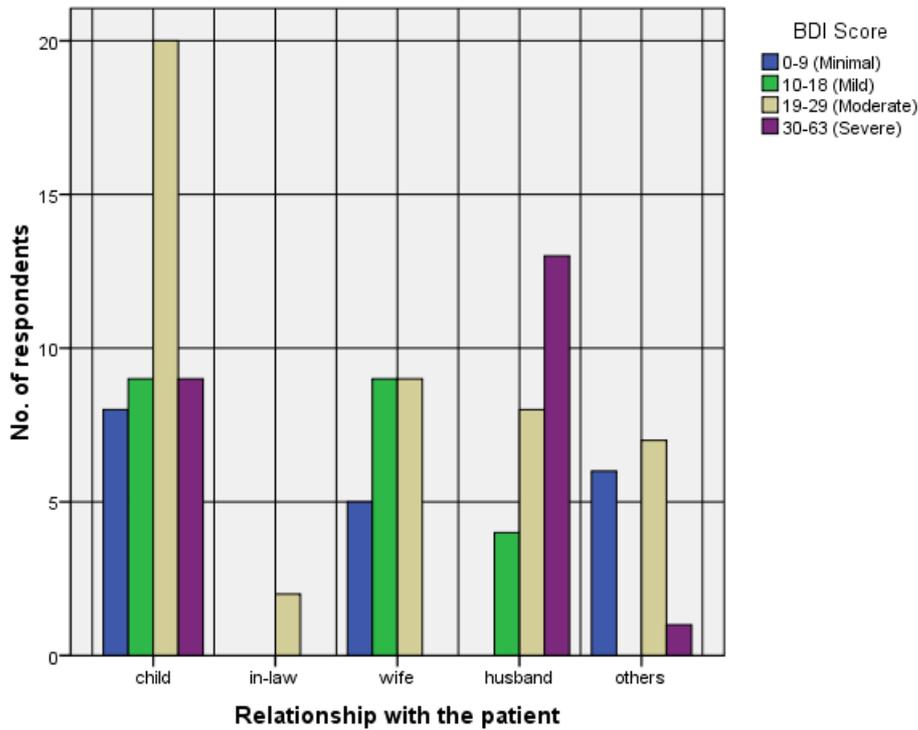


Table 10: Care giver's relationship with patients and depression

Chi-Square Tests

	Value	Df	Asymp. Sig. (2-sided)
Pearson Chi-Square	38.431 ^a	12	.000
Likelihood Ratio	45.627	12	.000
N of Valid Cases	110		

a. 11 cells (55.0%) have expected count less than 5. The minimum expected count is .35.

For the care giver's relationship with patient variable the chi-square obtained is 38.431. With 12 degree of freedom and a significance level of .000, which falls well below the .05 alpha level, the difference between the observed and expected values is significant. Thus there is a

statistically significant association between care giver relationship and level of depression recorded.

$$\chi^2(12) = 38.431, p \geq 0.000$$

Table 11: Income and depression

Crosstab

		BDI Score				Total
		0-9 (Minimal)	10-18 (Mild)	19-29 (Moderate)	30-63 (Severe)	
Income less than 10000	Count	11	5	11	10	37
	% within BDI Score	57.9%	22.7%	23.9%	43.5%	33.6%
10001-20000	Count	0	3	0	2	5
	% within BDI Score	0.0%	13.6%	0.0%	8.7%	4.5%
20001-30000	Count	0	5	8	8	21
	% within BDI Score	0.0%	22.7%	17.4%	34.8%	19.1%
30001 and above	Count	8	9	27	3	47
	% within BDI Score	42.1%	40.9%	58.7%	13.0%	42.7%
Total	Count	19	22	46	23	110
	% within BDI Score	100.0%	100.0%	100.0%	100.0%	100.0%

The respondents with the lowest income suffered from severe depression 10 (43.5%) as compared to their counterparts. The income earners with income above KSh. 30,001 were more likely to suffer higher levels of depression.

Figure 10: Income

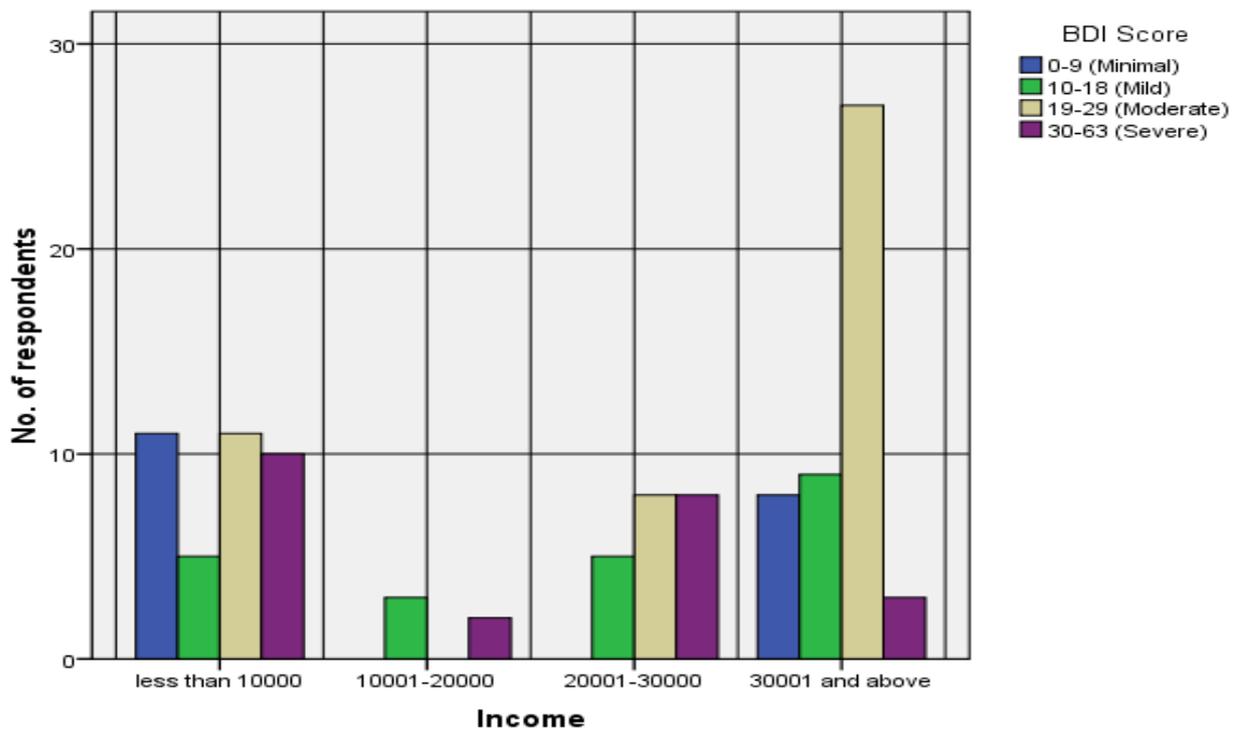


Table 12: Cross tabulation between care givers' income and depression score

Chi-Square Tests

	Value	Df	Asymp. Sig. (2-sided)
Pearson Chi-Square	28.207 ^a	9	.001
Likelihood Ratio	33.699	9	.000
N of Valid Cases	110		

a. 7 cells (43.8%) have expected count less than 5. The minimum expected count is .86.

For the income variable the chi-square obtained is 28.21. With 9 degree of freedom and a significance level of .001, which falls well below the .05 alpha level, the difference between the observed and expected values is significant. Thus there is a statistically significant association between income and level of depression.

$$\chi^2(9) = 28.207, p \geq 0.001$$

CHAPTER FIVE: DISCUSSION

As many as 62.7% of the respondents had symptoms of moderate to severe depression. This is higher than prevalence in the general population which is 6-15%.

5.1 Socio-demographic characteristics

5.1.1 Gender and depression

It is evident from the current study that more females had symptoms of depression. About 84% had moderate to severe levels of depression ($p=0.002$). Caregivers of their children had 63% with moderate to severe levels of depression. These comprised mainly of women. In the current study most of the caregivers of children were mothers however, studies have shown that there are gender differences in depressive symptoms with female caregivers, including spousal caregivers, having significantly higher levels of depressive symptoms than male caregivers (62; 63; 58; 64). Women have been reported to have higher rates of depressive symptoms, more likely to be socially isolated and have almost twice the rate of probable major depression (65; 66; 67; 68). Male caregivers may also have higher rates of depressive symptoms with male gender being the most significant correlate of depressive symptoms (69). Male spousal caregivers of AD patients had depressive symptoms scores significant for a diagnosis of depression (70). This high rate of depression in women can be attributed to societal expectations of women as nurturers and caregivers. This points at gender differences in socialization where little girls are socialized by their parents and teachers to be nurturing and sensitive to others' opinion while boys are encouraged to develop a sense of mastery and independence over their lives. . Women also lack socio-economic support and are prone to stress as opposed to men. Care giving in the long run has been found to disrupt economic position of the woman by interrupting income. In this study most of the respondents were self employed. This means that their input is directly proportional to the outcome of their various businesses. Women suffer many disadvantages in the society. They have been found to endure high levels of stress and adversities in life e g widowhood, losing a child, among others. Women are also known to react with distress and burden not to mention maternal depression (107).

5.1.2 Age and depression

In this study, there was a statistically significant relationship between the age of the caregiver and clinical depression in that the higher the age the higher the prevalence of depressive symptoms ($p=0.016$). The majority with symptoms of depression had age range of 40-50

years. This marks the period of middle adulthood when the children of the caregivers need much attention as relates to their stages in development. According to one of the studies, it was purported that caregiver age is not predictive of caregiver depressive symptoms (89) which is clearly in contrast to the current study. This also marks the period when the caregiver has responsibility of caring for their children, establishing a career and any stressor debilitates the health of the caregiver especially the female caregiver. Other studies have shown that in later years, there are so many confounders causing depression even without one being a caregiver. E.g. medications like anti-hypertensives (beta blockers), calcium channel blockers, corticosteroids, hormones, anti-Parkinson's agent etc. So biological risk factors may interact with psychosocial factors to cause or worsen depressive symptoms.

Contrary findings from other studies show that younger age has been associated with higher depression symptoms in dementia caregivers (98; 99). Middle aged caregivers are said to be having additional responsibilities of caring for their own children with additional responsibilities of employment (98; 99; 100).

5.1.3 Marital status

Out of the respondents, 78% of the respondents were married. Wives constituted 22.7% while husbands were 20.9 (n=86). The spouse has been identified as the primary caregiver who provides both emotional and physical support. Marriage union has been described as sacred and there are societal expectations when a spouse is ill. In other studies, in their focus groups on care giving for women with advanced breast cancer, it was found that most married patients' husbands assumed the role of principal caregiver (43). In their longitudinal study of breast cancer patients and their principal caregivers (23), over half the caregivers were male (55%) and the patients' spouse or partner constituted 52%. Spouses, in particular, occupied a central position during care giving of cancer patients. They had been frequently identified as the key persons who gave emotional support and provided physical assistance to their wives with breast cancer (24). Furthermore, spouses often took on additional roles when their wives were ill in order to maintain the daily functioning of family life. Spouses were important not only because of the tangible support that they provided for their wives, but also because their adjustment to the illness affected the adjustment of their wives (25).

Spouse caregivers were said to view care giving as part of their marriage partnership. This is similar in the current study where most caregivers are married as shown above. Working

spouse caregivers have to juggle employment, family responsibilities (such as child care) as well as care giving (30).

Married caregivers are likely to suffer depression because a spouse might be forced to work part time or leave employment due to illness. This causes a multiplier effect where the family income is reduced such that financial obligations cannot be met. Children might drop out of school with further repercussions. Cost of medical equipments and care of the patient may aggravate the situation further. Providing care for a loved one with advanced breast cancer was emotionally difficult. A study indicated that husbands of women with recurrent breast cancer appeared to be especially vulnerable to the impact of the illness because of more role adjustment problems, higher levels of uncertainty and more hopelessness they experienced (43).

5.2 Care giver's relationship with the patient and depression

It was evident in this study that most caregivers were family members. There was a very significant relationship (statistically) between the relationship with the patient and depression ($p= 0.000$). In this study, majority of the population are family members. They constitute spouses (43.6%) and parents (41.8%). Others constituted 12.7% and this group still had part of family other than spouse and parent. These could be children or siblings to the patients. Another quantitative study on family caregiver quality of life showed that the adult child, most often the daughter, usually was the caregiver if the spouse was not. The care giving experience was very different depending on the caregiver's relationship to the patient. The adult child may have had to care for children and job responsibilities in addition to caring for an ill parent. The role of family caregivers has shifted from one of custodial care to a complex, multifaceted role that included symptom management, monitoring for changes in hallmark symptoms, equipment care, patient transport and advocacy, and management of activities/responsibilities the patient has foregone because of illness (31).

In this study, the adult child may have been captured in the 'others'- further showing an association between the relationship and depression.

Another study found that the family was a major factor in the individual's health process and played a prime role in the course and management of an illness (26; 27, 28). Patients and their caregivers were now commonly based in their homes with complicated medical therapies to be administered. These changes placed greater demands on caregivers' and

patients' 'informal' support structure. The caregiver role could dramatically impact on a family member and a family as a whole (29). A study reported that women react to care giving with a greater tendency to become distressed and to feel burdened by care giving. Female by nature are nurturers and get emotionally drawn into their activities. They also put unreasonable burdens on themselves while sacrificing their own physical and emotional needs in a bid to provide the best for the child. This subjective care giving burden may be associated with maternal depression (107).

In this study, most mothers experienced depressive symptoms. Those who were taking care of their children were mostly mothers in the paediatric wards (41.8%). It was well recognized that care giving could adversely affect the psychological adjustment of the family caregiver as well as increase caregiver burden (22). 'Caregiver burden' was generally used to refer to the physical, psychological, social and /or financial reactions that could be experienced in giving care (33).

5.3 Care giving duration range and depression

Due to advances in treatment, the cancer care trajectory has increased from days and weeks to months and years –meaning the period of survival is longer (32). This is evident when one looks at the duration of care of the caregivers. The caregivers who have been taking care of their loved ones for as long as 6-10 years had 78.6% moderate to severe levels of depression. This study shows that the longer the duration of care, the higher the prevalence of depression. This was statistically significant ($p=0.000$)

As the illness progresses, caregivers experience more depression, a greater adverse impact on their own health and daily lives and spend more time helping patients cope with daily living activities. Studies of family members caring for persons with advanced cancer showed that most experienced stress in the care giving role and significant stress is in observing the patient suffering (44). Additional stress could be experienced by having to 'stand by' and observe the disease progress while being unable to alter or manage the illness (45).

As the times goes by, there is increasing deterioration in the condition of the patient. The patients' functional status demands more care and attention. Nursing, transportation, accrued bills, depression levels in the patient increase and all these factors interplay to give rise to depression in the caregiver. The patients' characteristics merge with the caregivers' characteristics to give rise in the depressive symptoms in the caregivers (57).

Some studies show that depression is more prevalent at the beginning of care.

5.4 Income and depression

His study showed a statistically significant relationship between income and depression ($p=0.001$). The caregivers with low income suffer higher levels of depression. Managing illness in resource limited settings can be stressful due to the high cost of living, cost of medication and transportation to the medical facilities for procedures e g radiotherapy. In patient care is further very expensive for one who earns less than ksh10.000 per month. Managing illness related finances has been found to be one of the top causes of burden(108).

The race was basically Africans as the hospital in a National referred hospital. The majority were Christians and the pattern gives a national outlook. In Kenya, the population is 80% Christian while in our study, Christians constituted 88%. This is very similar.

According to the results, 43% were also caring for 4-6 children while 23% were caring for more than six children and 31% had 1-3 other children under their care. This shows that burden of care giving coupled with the responsibility of caring for other children may enhance the others depression. Balancing finances with the stress that come with caregiving can be appreciated.

Most of the caregivers acquired secondary level of education (43.6%). This shows that few went to formal colleges and it concurs with the employment status in that most of them are self employed. The earnings from self employment is directly proportional to the input. Care giving therefore usurps the time that the caregiver could dedicate to their work, resulting in reduced income. Reduced income has been associated with high levels of depression.

This finding is close to a study where informal caregivers who were at risk for depression was almost three times higher than in the general populations of similar age (77).

The lifetime risk of suffering from major depression is 10-25% for women and 5-12% for men with an average age of onset of 25 years old. Another study in Kenya reported a prevalence rate of 79% of clinical depression among caregivers (105).

A similar study was conducted in caregivers of children with mental disorders in the same hospital and the prevalence of depression was 56.2% (106)

CHAPTER SIX

SUMMARY, CONCLUSION AND RECOMEMNDATION

6.1 Introduction

This chapter presented the summary of key data findings, conclusions drawn from the findings highlighted and recommendations that were made. The conclusions and recommendations drawn were in quest of addressing research objectives of determining prevalence of depression among care givers of patients receiving palliative care in Kenyatta National Hospital.

6.2 Summary of the findings

From the study, it is evident that socio-demographic characteristics of the care givers could contribute to depressive symptoms. This is shown by the larger number of female respondents having more depressive symptoms than male.

It is also clear that the duration of care giving affects care givers level of depression. From the study, the longer the period of care giving, the more the depressive symptoms.

Caregiver relationship to the patient also contributed to depression levels. From the study it was noted that care givers of children and the wives had more depressive symptoms than the rest of the categories. This may be attributed to the close attachment of the care givers to patient. In most cases mothers would care for their children and their husbands which could add into the societal gender roles of the woman. Care giving role was shouldered by close family members.

Age of the care givers has also been noted to increase the depression levels. From the study the older care givers were found to have more depression symptoms than the younger care givers. It is clear from the study that those who are 30 years and above were more and they had high depression levels.

6.3 Conclusion

There is a high prevalence of depressive symptoms in caregivers of patients undergoing palliative care at the Kenyatta National Hospital as compared to the general population. The severity of the depressive symptoms ranged from mild to severe with the majority experiencing symptoms of severe depression. There are various caregiver variables associated with depressive symptoms in the caregivers. Spousal caregivers have the highest

prevalence of depressive symptoms. Various interventions are required to help address issues related to depression among care givers of patients receiving palliative care.

6.4 Recommendations

1. From the findings of this study it is important that healthcare providers should not concentrate only on the patients but also on the caregivers of patients receiving palliative care because they undergo a lot of stress which contribute to their depression. The providers need to deliberately examine the caregivers for symptoms of depression and provide effective management. This not only improves care of the provider but it also improves the care of the patient.
2. Health care providers require further training to be able to identify and manage symptoms of depression in the caregivers just as much as it is done to the patients and to do routine assessment of caregivers and to assess those who may be at risk.
3. Advocacy for policy change for flexible employment arrangement for caregivers who need to take time off from work to offer care-giving services to their loved ones with terminal illness.
4. Multidisciplinary research leading to evidence based practice approaches to home based palliative care e.g. respite care should be encouraged. This gives a temporary relief to the family care-giver and the latter should be encouraged to equip themselves with stress inoculation techniques to restore their health.

BIBLIOGRAPHY

1. O'Donnell, M., Raina, P., Schwellnus, H., Rosenbaum, P., King, G., Brehaut, J., et al. (2004). Caregiving process and caregiver burden: Conceptual models to guide research and practice. *BMC Paediatrics*, 4 (1).
2. Given, B., Wyatt, G., Given, C., Sherwood, P., Gift, A., DeVoss, D., & Rahbar, M. (2004). Burden and depression among caregivers of patients with cancer at the end of life. *Oncology Nursing Forum*, 31, 1105-1117.
3. Given, B.A., Given, C.W., & Kozachik, S. (2001). Family support in advanced cancer. *CA: A Cancer Journal for Clinicians*, 51, 213-231.
4. Glajchen, M. (2004). The Emerging Role and Needs of Family Caregivers in Cancer Care. *The Journal of Supportive Oncology*, 2, 145-155.
5. Haley, W. E., Lamonde, L. A., Han, B., Narramore, S., & Schonwetter, R. (2001). Family caregiving in hospice: Effects on psychological and health functioning among spousal caregivers of hospice patients with lung cancer or dementia. *The Hospice Journal*, 15(4), 1-18.
6. Rivera, Henry R., "Predictors of cancer caregiver depression symptomatology" (2009). *Graduate School Theses and Dissertations*. <http://scholarcommons.usf.edu/etd/2166>
7. Aoun, S.M., Kristjanson, L.J., Currow, D.C., & Hudson, P.L.(2005). Caregiving for the terminally ill: at what cost? *Palliative Medicine*, 19, 551-555.
8. Chen, M., & Hu, C. (2002). The generalizability of caregiver strain index in family caregivers of cancer patients. *International Journal of Nursing Studies*, 39, 823-829.
9. Alice Musibi, KEMRI and KNH, (2008). Solid tumours – breast, colon and lymphomas – Management outcomes, new therapeutic interventions and epidemiology in our own populations
10. Lethborg, C. E., & Kissane, D. W. (2003). “It Doesn’t End on the Last Day of Treatment”: A psycho-educational intervention for women after adjuvant treatment for early stage breast cancer. *Journal of Psychosocial Oncology*, 21, 25-41.
11. Nijboer C, Triemstra M, Tempelaar R, et al (1998). Measuring both negative and positive reaction to giving care to cancer patients: psychometric qualities of the Caregiver Reaction Assessment. *Social Science and Medicine* 1999;48: 1259–1269.
12. Bemporad (1988) Compound caregiving: When lifelong caregivers undertake additional caregiving roles. *Rehabilitation Psychology*, 55(4), 409-417.

13. Kubler Ross 1996 *The MetLife study of working caregivers and employer healthcare costs: New insights and innovations for reducing health care costs for employers* (National Alliance for Caregiving, University of Pittsburgh Institute on Aging). New York, NY: MetLife Mature Market Institute.
14. Beck et al (1985) Mortality associated with caregiving, general stress, and caregiving-related stress in elderly women: Results of caregiver-study of osteoporotic fractures. *JAGS*, 58(5), 937-943. doi: 10.1111/j.1532-5415.2010.02808.
15. Seymour JE, Clark D, Winslow M (2004). Morphine use in cancer pain: from 'last resort' to 'gold standard'. Poster presentation at the Third Research Forum of the European Association of Palliative Care. *Palliative Medicine* ;18(4):378
16. WHO definition of palliative care. (2006). *World Health Organization*. Retrieved December 2, 2006 from <http://www.who.int/cancer/palliative/definition/en/>.
17. Strang P, Strang S, Hultborn R, Arnér S (2004). "Existential pain—an entity, a provocation, or a challenge?" *J Pain Symptom Manage* 27 (3): 241–50.
18. Walsh, S. M., martin, S. C., & Schmidt, L.A. (2004). Testing the efficacy of a creative-arts intervention with family caregivers of patients with cancer. *Journal of Nursing Scholarship*, 36(3), 214–219
19. Baider L, Kaufman B, Peretz T, Manor O, Ever-Hadani P, Kaplan De-Nour A. 1996. Mutuality of fate: adaptation and psychological distress in cancer patients and their partners. In *Cancer in the Family*, Baider L, Cooper CL, Kaplan De-Nour A (eds). Wiley: Chichester; 173 – 186.
20. Cameron, J., Shin, J., Williams, D., & Stewart, D. (2004). A brief problem-solving intervention for family caregivers to individuals with advanced cancer. *Journal of Psychosomatic Research*, 57, 137-143.
21. Houts, P. S., Nezu, A. M., C. M., & Bucher, J. A. (1996). The prepared family caregiver: a problem-solving approach to family caregiver education. *Patient Education and Counseling*, 27, 63-73.
22. Weitzner MA, McMillan SC, Jacobsen PB (1999). Family caregiver quality of life: differences between curative and palliative cancer treatment settings. *J Pain Symptom Manage* 1999;17(6):418–428.
23. Grunfeld, E., Coyle, D., Whelan, T., Clinch, J., Reyno, L., Earle, C. C., Willan, A., Viola, R., Coristine, M., Janz, T., & Glossop, R. (2004). Family caregiver burden: Results of a longitudinal study of breast cancer patients and their principal caregivers. *Canadian Medical Association Journal*, 170, 1795 – 1801.

24. Northouse, L.L. (1988). Social support in patients' and husbands' adjustment to breast cancer. *Nursing Research*, 37(2), 91-95.
25. Northouse, L. L., & Peters-Golden, H. (1995). Cancer and the family: Strategies to assist spouses. *Seminars in Oncology Nursing*, 9(2), 74-82.
26. Wright, L.M., & Leahey, M. (2005b). The three most common errors in family nursing: How to avoid or sidestep. *Journal of Family Nursing*, 11(2), 90-101.
27. Weihs, K., Fisher, L., & Baird, M. (2002). Families, health, and behavior. *Families, Systems & Health*, 20(1), 7-46.
28. Duhamel, F., & Dupuis, F. (2005, June). *Where does the "one question question" lead us in family nursing?* Paper presented at the 7th International Family Nursing Conference, Victoria, British Columbia, Canada.
29. Deeken J.F., Taylor K.L., Mangan P., Yabroff K.R. & Ingham J.M. (2003) Care for the caregivers: a review of self-report instruments developed to measure the burden, needs and quality of life of informal caregivers. *Journal of Pain and Symptom Management* 26, 922–953.
30. Coristine M, Crooks D, Grunfeld E, Stonebridge C, Christie A. Caregiving for women with advanced breast cancer. *Psycho-Oncology*. 12(7):709–719, 2003
en.wikipedia.org/wiki/Social_support
31. Weitzner, M. A., McMillan, S. C., Jacobsen, P. B. 1999. Family Caregiver Quality of Life: Differences Between Curative and Palliative Cancer Treatment Settings. *Journal of Pain and Symptom Management* 17, 418-428.
32. Given, B.A., Given, C.W., & Kozachik, S. (2001). Family support in advanced cancer. *CA: A Cancer Journal for Clinicians*, 51, 213-231.
33. Hinds, C. (1985). The needs of families who care for patients with cancer at home: are we meeting them? *Journal of Advanced Nursing*, 10, 575-581.
34. Ferrario, S. R., Cardillo, V., Vicario, F., Balzarini, E., & Zotti, A. M. (2004). Advanced cancer at home: caregiving and bereavement. *Palliative Medicine*, 18, 129-136
35. Grunfeld, E., Coyle, D., Whelan, T., Clinch, J., Reyno, L., Earle, C. C., Willan, A., Viola, R., Coristine, M., Janz, T., & Glossop, R. (2004). Family caregiver burden: Results of a longitudinal study of breast cancer patients and their principal caregivers. *Canadian Medical Association Journal*, 170, 1795 – 1801.

36. Chappell, N.L., & Penning, M. (1996). Behavioural problems and distress among caregivers of people with dementia. *Ageing and Society*, 16, 57-73.
37. Higginson, I. J., Gao, W., Wei, G. 2008. Caregiver assessment of patients with advanced cancer: concordance with patients, effect of burden and positivity. *Health and Quality of Life Outcomes* 6, (1).
38. Coristine M, Crooks D, Grunfeld E, Stonebridge C, Christie A. Caregiving for women with advanced breast cancer. *Psycho-Oncology*. 12(7):709–719, 2003
en.wikipedia.org/wiki/Social_support
39. Given, B., Wyatt, G., Given, C., Sherwood, P., Gift, A., DeVoss, D., & Rahbar, M. (2004). Burden and depression among caregivers of patients with cancer at the end of life. *Oncology Nursing Forum*, 31, 1105 – 1115.
40. Northouse LL, Mood D, Kershaw T, Schafenacker A, Mellon S, Walker J, Galvin E, Decker V (2002) Quality of Life of Women with Recurrent Breast Cancer and Their Family Members, *Journal of Clinical Oncology*, 20, 19, 4050-64.
41. Laizner, A.M., Yost, L.M., Barg, F.K., & McCorkle, R. (1993). Needs of family caregivers of persons with cancer: A review. *Seminars in Oncology Nursing*, 9, 114–120.
42. Cameron, J., Shin, J., Williams, D., & Stewart, D. (2004). A brief problem-solving intervention for family caregivers to individuals with advanced cancer. *Journal of Psychosomatic Research*, 57, 137-143.
43. Northouse, L.L., Dorris, G., & Charron-Moore, C. (1995). Factors affecting couples' adjustment to recurrent breast cancer. *Social Science and Medicine*, 41, 69-76.
44. Kurtz, M., Kurtz, J., Given, C., & Given, B. (1995). Relationship of caregiver reactions and depression to cancer patients' symptoms, functional states, and depression—A longitudinal view. *Social Science and Medicine*, 40, 837-846.
45. Stetz, K.M. (1987). Caregiving demands during advanced cancer: the spouse's needs. *Cancer Nursing*, 10, 260-268.
46. Gotay, C.G. (1996). Cultural variation in family adjustment to cancer. In L. Baider, C. Cooper, & A.K. De-Nour (Eds.), *Cancer and the family* (pp. 31-52). England: John Wiley & Sons.
47. Lindholm, L., Rehnsfeldt, A., Arman, M., & Hamrin, E. (2002). Significant other's experience of suffering when living with women with breast cancer. *Scandinavian Journal of Caring Sciences*, 3, 248– 255

48. Cameron, J., Shin, J., Williams, D., & Stewart, D. (2004). A brief problem-solving intervention for family caregivers to individuals with advanced cancer. *Journal of Psychosomatic Research*, 57, 137-143.
49. Clark, P. C. (2002). Effects of individual and family hardiness on caregiver depression and fatigue. *Research in Nursing and Health*, 25(1), 37-48.
50. Teri L. (1997). Behavior and caregiver burden: Behavioral problems in patients with Alzheimer disease and its association with caregiver distress. *Alzheimer Disease & Associated Disorders*. 11(Suppl. 4), 35–38.
51. Victoroff, J., Mack, W. J., & Nielson, K. A. (1998). Psychiatric complications of dementia: Impact on caregivers. *Dementia and Geriatric Cognitive Disorders*, 9(1), 50-55.
52. Creese, J., Bedard, M., Brazil, K., & Chambers, L. (2008). Sleep disturbances in spousal caregivers of individuals with Alzheimer's disease. *International Psychogeriatrics*, 20(1), 149-161.
53. Bambauer, K., Zhang, B., Maciejewski, P. K., Sahay, N., Pirl, W. F., Block, S. D., et al. (2006). Mutuality and specificity of mental disorders in advanced cancer patients and caregivers. *Social Psychiatry & Psychiatric Epidemiology*, 41(10), 819- 824.
54. Fleming, D. A., Sheppard, V. B., Mangan, P. A., Taylor, K. L., Tallarico, M., Adams, I., et al. (2006). Caregiving at the end of life: Perceptions of health care quality and quality of life among patients and caregivers. *Journal of Pain Symptom Management*, 31(5), 407-420.
55. Land, H., Hudson, S. M., & Stiefel, B. (2003). Stress and depression among HIV-positive and HIV-negative gay and bisexual AIDS caregivers. *AIDS and Behavior*, 7(1), 41-53.
56. Bambauer, K., Zhang, B., Maciejewski, P. K., Sahay, N., Pirl, W. F., Block, S. D., et al. (2006). Mutuality and specificity of mental disorders in advanced cancer patients and caregivers. *Social Psychiatry & Psychiatric Epidemiology*, 41(10), 819- 824.
57. Emanuel, E. J., Fairclough, D. L., Slutsman, J., & Emanuel, L. L. (2000). Understanding economic and other burdens of terminal illness: The experience of patients and their caregivers. *Annals of Internal Medicine*, 132, (6), 451-459.
58. Haley, W. E., LaMonde, L. A., Han, B., Burton, A. M., & Schonwetter, R. (2003). Predictors of depression and life satisfaction among spousal caregivers in hospice: Application of a stress process model. *Journal of Palliative Medicine*, 6(2), 215-224.

59. Neundorfer, M. M., McClendon, M. J., Smyth, K. A., Strauss, M. E., & McCallum, T. J. (2006). Does depression prior to caregiving increase vulnerability to depressive symptoms among caregivers of persons with Alzheimer's disease? *Aging & Mental Health, 10*(6), 606-615.
60. Schulz, R., Newsom, J., Mittelmark, M., Burton, L., Hirsch, C., & Jackson, S. (1997). Health effects of caregiving: The caregiver health effects study: An ancillary study of the cardiovascular health study. *Annals of Behavioral Medicine, 19*, 110-116.
61. Vitaliano, P. P., Scanlan, J. M., Zhang, J., Savage, M. V., Hirsch, I. B., & Siegler, I. C. (2002). A path model of chronic stress, the metabolic syndrome, and coronary heart disease. *Psychosomatic Medicine, 64*(3), 418-435.
62. Beeson, R. A. (2003). Loneliness and depression in spousal caregivers of those with Alzheimer's disease versus non-caregiving spouses. *Archives of Psychiatric Nursing, 17*(3), 135-143.
63. Covinsky, K. E., Newcomer, R., Fox, P., Wood, J., Sands, L., Dane, K., et al. (2003). Patient and caregiver characteristics associated with depression in caregivers of patients with dementia. *The Journal of General Internal Medicine, 18* (12), 1006-1014.
64. Thompson, R. L., Lewis, S. L., Murphy, M. R., Hale, J. M., Blackwell, P. H., Acton, G. J., et al. (2004). Are there sex differences in emotional and biological responses in spousal caregivers of patients with Alzheimer's disease? *Biological Research for Nursing, 5*, (4), 319-330.
65. Adams, Aranda, Kemp, & Takagi, 2002. Ethnic and gender differences in distress among Anglo American, African American, Japanese American and Mexican American spousal caregivers of persons with dementia. *Journal of Clinical Geropsychology, 8*(4), 279-301.
66. Cossette, S., Levesque, L., & Laurin, L. (1995). Informal and formal support for caregivers of a demented relative: do gender and kinship make a difference? *Research in Nursing & Health, 18*(5), 437-451.
67. Gallicchio, L., Siddiqi, N., Langenberg, P., & Baumgarten, M. (2002). Gender differences in burden and depression among informal caregivers of demented elders in the community. *International Journal of Geriatric Psychiatry, 17*(2), 154-163.
68. Mui, A. C. (1995). Caring for frail elderly parents: a comparison of adult sons and daughters. *Gerontologist, 35*(1), 86-93.

69. Siegel, K., Karus, D. G., Raveis, V. H., Christ, G. H., & Mesagno, F. P. (1996). Depressive distress among the spouses of terminally ill cancer patients. *Cancer Practice, 41*(1), 25-30.
70. Shanks-McElroy, H. A., & Strobino, J. (2001). Male caregivers of spouses with Alzheimer's disease: Risk factors and health status. *American Journal of Alzheimer's Disease and Other Dementias, 16*(3), 167-175.
71. Russo, J., Vitaliano, P. P., Brewer, D. D., Keaton, W., & Becker, J. (1995). Psychiatric disorders in spouse caregivers of care recipients with Alzheimer's disease and matched controls: A diathesis–stress model of psychopathology. *Journal of Abnormal Psychology, 104*(1), 197-204.
72. Emanuel EJ, Fairclough DL, Slutsman J, Emanuel LL (2000). Understanding economic and other burdens of terminal illness: the experience of patients and their caregivers. *Ann Intern Med.*132:451-459.
73. Given, C. W., Strommel, M., Given, B., Osuch, J., Kurtz, M. E., & Kurtz, J. C. (1993). The influence of cancer patients' symptoms and functional states on patients' depression and family caregivers' reaction and depression. *Health Psychology, 12*(4), 277-285.
74. Billings, D. W., Folkman, S., Acree, M., & Moskowitz, J. T. (2000). Coping and physical health during caregiving: The roles of positive and negative affect. *Journal of Personality and Social Psychology, 79*, 131-142.
75. Lyons, K. S., Stewart, B. J., Archbold, P. G., Carter, J. H., & Perrin, N. A. (2004). Pessimism and optimism as early warning signs for compromised health for caregivers of patients with Parkinson's disease. *Nursing Research, 53*(6), 354-362.
76. Ferketich, A. K., Schwartzbaum, J. A., Frid, D. J., & Moeschberger, M. L. (2000). Depression as an antecedent to heart disease among women and men in the NHANES I study. National Health and Nutrition Examination Survey. *Archives of Internal Medicine, 160*(9), 1261-1268.
77. Schulz, R., & Beach, S. (1999). Caregiving as a risk factor for mortality: The caregiver health effects study. *Journal of the American Medical Association, 282*, (23), 2215-2219.
78. Antonovsky, A. (1993). The structure and properties of the sense of coherence scale. *Social Science and Medicine, 36*(6), 725-733.
79. Haley, W. E., Roth, D. L., Coleton, M. I., Ford, G. R., West, C. A. C., Collins, R. P., et al. (1996). Appraisal, coping, and social support as mediators of well-being in black

- and white family caregivers of patients with Alzheimer's disease. *Journal of Consulting and Clinical Psychology*, 64(1), 121-129.
80. Cooper, C., Katona, C., Orrell, M., & Livingston, G. (2008). Coping strategies, anxiety and depression in caregivers of people with Alzheimer's disease. *International Journal of Geriatric Psychiatry*. In-press.
81. McMillan, S. C., Small, B. J., Weitzner, M., Schonwetter, R., Tittle, M., Moody, L., et al. (2006). Impact of coping skills intervention with family caregivers of hospice patients with cancer: A randomized clinical trial. *Cancer*, 106(1), 214-222.
82. Gallant, M. P., & Connell, C. M. (2003). Neuroticism and depressive symptoms among spouse caregivers: Do health behaviors mediate this relationship? *Psychology and Aging*, 18(3), 587-592.
83. Jang, Y., Clay, O. J., Roth, D. L., Haley, W. E., & Mittelman, M. S. (2004). Neuroticism and longitudinal change in caregiver depression: Impact of a spouse-caregiver intervention program. *Gerontologist*, 44(3), 311-317.
84. Kurtz, M. E., Kurtz, J. C., Given, C. W., & Given, B. (2005). A randomized, controlled trial of a patient/caregiver symptom control intervention: Effects on depressive symptomatology of caregivers of cancer patients. *Journal of Pain and Symptom Management*, 30(2), 112-122.
85. Nijboer, C., Tempelaar, R., Triemstra, M., Van Den Bos, G., & Sanderman, R. (2001). The role of social and psychologic resources in caregiving of cancer patients. *Cancer*, 91(5), 1029-1039.
86. Mausbach, B. T., Patterson, T. L., Von Kanel, R., Mills, P. J., Dimsdale, J. E., Ancoli-Israel, S., et al. (2007). The attenuating effect of personal mastery on the relations between stress and Alzheimer caregiver health: A five-year longitudinal analysis. *Aging & Mental Health*, 11(6), 637-644.
87. Bedard, M., Molloy, D. W., Squire, L., Dubois, S., Lever, J. A., & O'Donnell, M. (2001). The Zarit Burden Interview: a new short version and screening version. *Gerontologist*, 41(5), 652-657.
88. Bedard, Pedlar, Martin, Malott, & Stones, 2000 Burden in caregivers of cognitively impaired older adults living in the community: Methodological issues and determinants. *International Psychogeriatrics*, 12(3), 307-332.
89. Butler, S. B., Turner, W., Kaye, L. W., Ruffin, L., & Downey, R. (2005). Depression and caregiver burden among rural elder caregivers. *Journal of Gerontological Social Work*, 46(1), 56.

90. Lim, P. P., Sahadevan, S., Choo, G. K., & Anthony, P. (1999). Burden of caregiving in mild to moderate dementia: An Asian experience. *International Psychogeriatrics*, *11*(4), 411-420.
91. Brody, E. M., Litvin, S. J., Hoffman, C., & Kleban, M. H. (1995). Marital status of caregiving daughters and co-residence with dependent parents. *Gerontologist*, *35*(1), 75-85.
92. Chang, B. L., Brecht, M. L., & Carter, P. A. (2001). Predictors of social support and caregiver outcomes. *Women Health*, *33*(1-2), 39-61.
93. Levesque, L., Ducharme, F., & Lachance, L. (1999). Is there a difference between family caregiving of institutionalized elders with or without dementia? *Western Journal of Nursing Research*, *21*(4), 472-491; discussion 491-477.
94. Weitzner, M. A., Haley, W. E., & Chen, H. (2000). The family caregiver of the older cancer patient. *Hematology/Oncology Clinics of North America*, *14*(1), 269-281.
95. Grant, J. S., Elliott, T. R., Weaver, M., Glandon, G. L., Raper, J. L., & Giger, J. N. (2006). Social support, social problems-solving abilities and adjustment of family caregivers of stroke survivors. *Archives of Physical Medicine and Rehabilitation*, *87*, 343-350.
96. Williams, I. C. (2005). Emotional health of black and white dementia caregivers: A contextual examination. *Journal of Gerontology*, *60B*, (6), 287-295.
97. Coon, D. W., Rubert, M., Solano, N., Mausbach, B., Kraemer, H., Arguelles, T., et al. (2004). Well-being, appraisal, and coping in Latina and Caucasian female dementia caregivers: findings from the REACH study. *Aging and Mental Health*, *8*(4), 330-345.
98. Butler, S. B., Turner, W., Kaye, L. W., Ruffin, L., & Downey, R. (2005). Depression and caregiver burden among rural elder caregivers. *Journal of Gerontological Social Work*, *46*(1), 56.
99. Sorenson S, Pinquart M, Habil Dr, et al (2005). How effective are interventions with caregivers? An updated meta-analysis. *Gerontol 2002*; *42*(3):356–372.
100. Rogerson & Kim, 2005. Who is the carer? Experiences of family caregivers in palliative care. In S. Payne, & C. Ellis-Hill (Eds.), *Chronic and terminal illness: New perspectives on caring and carers* (pp. 83-98). New York: Oxford University Press.
101. National Alliance for Caregiving & AARP. (2006). *Caregiving in the U.S.* Washington, D.C. Retrieved June 14, 2013, from <http://www.caregiving.org/data/04finalreport.pdf>.

102. National Association of Social Workers. (2008). Professional Self-Care and Social Work. Presented at the NASW Delegate Assembly, Washington, DC. Social Work Speaks, 268-272. Retrieved from <http://www.socialworkers.org/nasw/memberlink/2013/supportfiles/ProfesionalSelf-Care.pdf>
103. Mungai wanjiru(2008). A dissertation submitted as part fulfillment for the award of Masters of Science in Clinical Psychology. *The prevalence of depression and burden of care among family caregivers of cancer patients seen at the Nairobi Hospice, Nairobi, Kenya.*
104. Mulemi Benson, 2010. *Coping with cancer and adversity*. Hospital ethnography in Kenya. African Studies centre, African studies collection, vol. 22
105. Mbugua Margaret Njeri, Mary W. Kuria and David Ndeti (2010). International Journal of Family Medicine Volume 2011, Article ID 534513: *The prevalence of depression among family caregivers of Children with Intellectual Disability in a Rural setting in Kenya.*
106. Otieno mary (2013). A dissertation submitted as part fulfillment for the award of Masters of Science in Clinical Psychology. *Prevalence of depression in caregivers of children with mental disorders*
107. Goodhead A & mcDonald J 2007; *Informal caregivers literature review*. Health services Reseach Centre, Victoria University of Wellington.
108. Carey et al (1991). Appraisal and care giving burden in family members caring for patients receiving chemotherapy. *Oncology nursing Forum*, 18: 1341-1348'
109. Steven L. Dubovsky, M.D, Amelia N. Dubovsky, B.A. *Consice guide to mood disorders*.(2003)

APPENDICES

APPENDIX 1: CONSENT AND EXPLANATION FORM

My name is Elizabeth Adol, a clinical psychology student at the University of Nairobi. I would like to invite you to participate in a study entitled: Prevalence of depressive symptoms in care givers of cancer patients attending palliative care at Kenyatta National Hospital.

The study will explore factors which contribute to depression in family caregivers. It will help in providing care to the caregiver as well as to the patient with terminal illness. The care may be preventive or curative.

Voluntarism

Your participation will be purely voluntary and you have the right to withdraw from the study at will. The participation should only occur after you will have understood about the study. 2 Questionnaires will be administered to you in succession and you will read and tick the answer that correctly reflects your situation. There will be no monetary gain associated with the study.

Benefits of participating in the study

In case you have emotional distress as a result of answering sensitive questions, you will be given counseling immediately after filing the questionnaire. If have clinical depression, you will be referred to mental health department for further patient support at the mental health department. This will both improve your health as well as equip you with coping strategies as you provide care to the patient.

Risks

There may be risks of information leaking out accidentally but care will be taken to avert this from happening by maintaining confidentiality and keeping the records safely. There can be emotional distress as a result of answering some of the questions about depression.

Data collected will be kept safely under lock and key in a safe place. Your name or true identity will not be used in this study. It may be used when there is need for referral for further patient support. You are free to ask any questions by calling the researcher, ethics committee or the researcher's supervisors.

Thank you.

Researcher- Elizabeth Adol

Tel 0722839847

Msc Clinical psychology

University Of Nairobi

Supervisors;

Dr Anne Obondo

Tel 0721849686

Department of psychiatry

University of Nairobi.

Dr. Pius Kigamwa

Tel 0722521261

Department of Psychiatry

The Secretary

Ethics and review committee-(KNH/UON-ERC)

P.o box 20723 code-00202

Nairobi .

Tel 020-2726300-9

KISWAHILI VERSION OF CONSENT EXPLANATION FORM: IDHINI NA KIDATO MAELEZO

Jina langu ni Elizabeth Adol, kliniki saikolojia katika Chuo Kikuu cha Nairobi. Mimi na nia ya kuandika dissertation juu ya maambukizi ya dalili ya huzuni katika wanaotoa huduma ya wagonjwa wa kansa kuhudhuria huduma tulivu na faraja katika Hospitali ya Taifa ya Kenyatta. Utafiti kuchunguza huduma anayetoa na vigezo mgonjwa ambayo kuchangia kwa huzuni katika walezi.

Utafiti huu ni sehemu ya kutimiza mahitaji kwa ajili ya shahada ya uzamili katika saikolojia kliniki katika Chuo Kikuu cha Nairobi.

Hatari

Hakuna uwezekano wa hatari kuliona kuhusishwa na utafiti.

Faida ya utafiti

Inawezekana faida kutokana na utafiti ni pamoja na kupata madawa ya unyogovu na psychotherapy. Katika kesi una matatizo ya kliniki, utakuwa inajulikana idara ya afya ya akili kwa ajili ya matibabu. Mhudumu wa afya anaweza kuagiza madawa ya unyogovu, au kisaikolojia au wote wawili.

Muda wa matibabu itategemea majibu yako kwa dawa na tiba. Hii itasaidia kupunguza dalili ya huzuni kama vizuri kama kuandaa kwa mikakati ya kukabiliana kama wewe kutoa huduma kwa mgonjwa.

Ushiriki wako ni wa hiari na una haki ya kuondoka kutoka utafiti katika mapenzi. Hakuna gharama za au malipo ni kuhusishwa na utafiti. Jina lako au utambulisho wa kweli si kutumika katika utafiti huu.

Wewe ni huru kuuliza maswali yoyote kwa kupiga mtafiti, kamati ya maadili au wasimamizi mtafiti.

Asante.

Mtafiti-Elizabeth Adol

Tel 0722839847

MSC Hospitali saikolojia

Chuo Kikuu cha Nairobi

Wasimamizi;

Dr Anne Obondo

Simu 0721849686

Idara ya psychiatry

Chuo Kikuu cha Nairobi.

Dr Pius Kigamwa

Simu 0722521261

Idara ya psychiatry

Chuo kikuu cha Nairobi.

Katibu

Madili na kamati ya utafiti-(KNH/UON-ERC)

Hospitali ya taifa, Kenyata

P.o box 20723 -00202

Nairobi .

Simu 0202726300-9

APPENDIX II: PARTICIPANTS CONSENT FORM

I (Code number) hereby give consent to voluntarily participate in the research study entitled:

Prevalence of depression among caregivers of patients receiving palliative care in Kenyatta National Hospital.

It has been explained to me that the project is in partial fulfilment of a Masters of Psychology Degree in the Department of Psychology at the University of Nairobi. The purpose of this research has been explained to me and I understand that I have the right to withdraw from participating in the research study at any time, without redress.

I understand that my identity will be kept anonymous at all times. I understand that after the project has been written; all the materials used in data collection will be destroyed to ensure confidentiality at all times.

I am aware that the researcher can assist by referring me to an appropriate counselor if sensitive information spoken about during the interview causes me to feel emotionally distressed or if I have depression.

Signature: Participant Date:

Signature: Researcher Date:

PARTICIPANT'S CONSENT FORM IN KISWAHILI: FOMU WASHIRIKI IDHINI

Mimi (Code idadi) natoa idhini kwa hiari kushiriki katika utafiti wa utafiti iitwayo:

Kiwango cha maambukizi ya huzuni kati ya walezi wa wagonjwa kupokea huduma tulivu na faraja katika Hospitali ya Taifa ya Kenyatta.

Nimeelezwa kuwa mradi huo ni kutimia nusu kwa Masters ya Saikolojia Shahada ya Idara ya Saikolojia katika Chuo Kikuu cha Nairobi. Madhumuni ya utafiti huu imekuwa alielezea kwa mimi na mimi kuelewa kwamba nina haki ya kutoa kushiriki katika utafiti wakati wowote, bila ruhusa yoyote.

Naelewa kwamba utambulisho wangu yatawekwa bila majina wakati wote.

Naelewa kwamba baada ya mradi kimeandikwa; vifaa vyote kutumika katika ukusanyaji wa data wataangamizwa kuhakikisha usiri wakati wote.

Ninatambua kuwa mtafiti inaweza kusaidia kwa kurejea mimi na mshauri sahihi kama mimi kukutwa na unyogovu.

Sahihi Mshiriki

Tarehe

Sahihi Mtafiti

Tarehe

APPENDIX III: LETTER OF APPROVAL FROM ETHICS AND RESEARCH COMMITTEE



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

KNH/UON-ERC
Email: uonknh_erc@uonbi.ac.ke
Website: www.uonbi.ac.ke



KENYATTA NATIONAL HOSPITAL
P O BOX 20723 Code 00202
Tel: 726380-9
Fax: 725272
Telegrams: MEDSUP, Nairobi

Ref: KNH-ERC/A/154

Link: www.uonbi.ac.ke/activities/KNHuoN

15th May 2014

Elizabeth Adol
Dept. of Psychiatry
School of Medicine
University of Nairobi

Dear Elizabeth

RESEARCH PROPOSAL: PREVALENCE OF DEPRESSION AMONG CAREGIVERS OF PATIENTS RECEIVING PALLIATIVE CARE IN KENYATTA NATIONAL HOSPITAL (P543/10/2013)

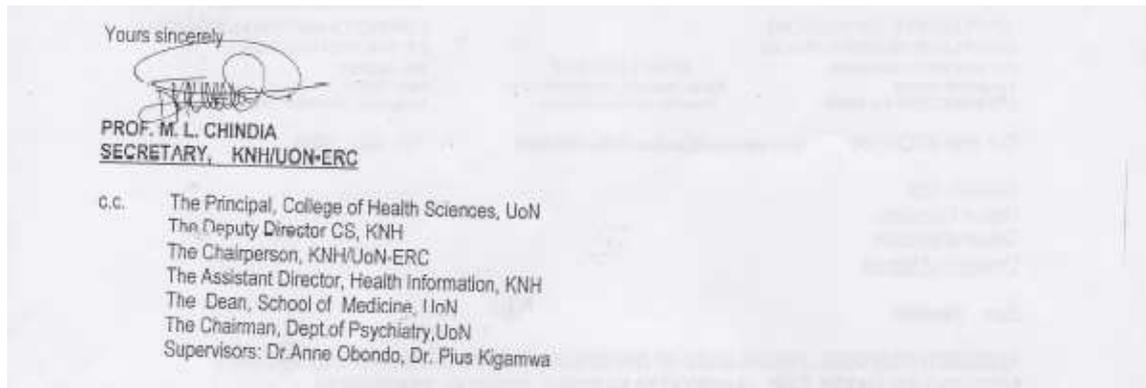
This is to inform you that the KNH/UoN-Ethics & Research Committee (KNH/UoN-ERC) has reviewed and approved your above proposal. The approval periods are 15th May 2014 to 14th May 2015.

This approval is subject to compliance with the following requirements:

- a) Only approved documents (informed consents, study instruments, advertising materials etc) will be used.
- b) All changes (amendments, deviations, violations etc) are submitted for review and approval by KNH/UoN ERC before implementation.
- c) Death and life threatening problems and severe adverse events (SAEs) or unexpected adverse events whether related or unrelated to the study must be reported to the KNH/UoN ERC within 72 hours of notification.
- d) Any changes, anticipated or otherwise that may increase the risks or affect safety or welfare of study participants and others or affect the integrity of the research must be reported to KNH/UoN ERC within 72 hours.
- e) Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. (*Attach a comprehensive progress report to support the renewal*).
- f) Clearance for export of biological specimens must be obtained from KNH/UoN-Ethics & Research Committee for each batch of shipment.
- g) Submission of an *executive summary* report within 90 days upon completion of the study. This information will form part of the data base that will be consulted in future when processing related research studies so as to minimize chances of study duplication and/or plagiarism.

For more details consult the KNH/UoN ERC website www.uonbi.ac.ke/activities/KNHuoN.

Protect to Discover



APPENDIX IV: BECKS DEPRESSION INVENTORY

BDI (Beck's Depression Inventory)

On this questionnaire there 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 can't snap of it
 3. I am sad, unhappy that I can't 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 that I have failed more than the average (normal) 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 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
5.
 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
- 6.

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
- 7
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
- 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 unusual
 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 any more
- 14
0. I don't feel I look any worse than I used to
 1. I am worried that I am old or unattractive

2. I feel that there are 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 from doing almost anything
3. I am 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 upsets stomach; or constipation
2. I am very worried about my 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

Kiswahili BDI

Nambari _____

Tarehe _____

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

1

0. Sina huzuni
1. Nina huzuni
2. Nina huzuni wakati wote na siwezi kijiondoa 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. Nkiangalia maisha yangu yaliopita naona nimeanguka sana
3. Nahisi nimeanguka kabisa maishani

4

0. Naridhika na mambo kama ilivyo kawaida yangu
1. Sija furahi 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 kujiua
1. Nina wazo la kujiua
2. Ningetaka kujiua
3. Nitajiua nikipata nafasi

10

0. Sili 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 awaki
3. Siwezi tena kufanya uamuzi wa jambo lolote lile

14

0. Sihisi kuwa naonekana vibaya zaidi ya nilivyokuwa
1. Nina wasi wasi kuwa naonekana sivutii
2. Ninahisi kuwa kuna mabadiliko yasio ondoka kwenye umbo langu yanayofanya nisivutie
3. Nina amini kuwa nina sura mbaya

15

0. Naweza kufanya kazi kama vile ilivyokuwa hapo awali
1. Nilazima nifinye bidii, ndipo nianze kufanya jambo lolote
2. Inabidi nijilazimishe sana ili niweze kufanya jambo lolote
3. Sitaweza 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 mbaya zaidi 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 wa kuonekana 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

20

0. Sina wasiwasi usio wa kawaida kuhusu haki yangu ya afya
1. Nina wasiwasi kuhusu shuda za mwili kama vile maumivu hapa na pale; au shida ya tumbo, au kufunga choo
2. Nina wasiwasi kuhusu matatizo ya mwili mpaka inakuwa ni vigumu kuwaza jambo lengine lolote

3. Nina wasiwasi kuhusu matatizo ya mwili mpaka siwezi kuwaza jambo lengine lolote

21

0. Sijaona mabadiliko yoyote hivi karibuni kuhusu hamu 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

APPENDIX V: SOCIODEMOGRAPHIC DATA OF CAREGIVER

Instructions

- Tick where appropriate
- Fill in the blank spaces appropriately
- Give the correct information

Date.....

Study number.....

1. What is your gender?

Male

Female

2. What is your age category?

Below 18 years

18-28 years

29-39 years

40-50 years

51-60 years

61 and above years

3. Marital status

- Single
- Married
- Separated
- Divorced
- Cohabiting

4. Level of education

- Primary
- Secondary
- Tertiary
- None

5. Occupation

- Employed
- Self-employed
- Retiree
- Not employed

6. Religion

- Muslim
- Christian
- None
- Other (specify)

7. Number of children under your care

- None
- 1-3
- 4-6
- More than 6

8. Race

- African
- Asian
- European
- Other (specify)

9. Duration of care giving

- 1-6 months
- 7-12 months
- 1-5 years
- 6-10 years
- More than 10 years

10. What is your relationship with the patient?

- Child
- In-law
- Wife
- Husband
- Other specify.....

11. What is your income range?

- Less than 10000
-

10001 – 20000

20001 – 30000

30001 and above

**KISWAHILI VERSION OF SOCIODEMOGRAPHIC DATA-ZENU ZA KIJAMII
DATA WA MLEZI**

Maelekezo

- Jibu ambapo sahihi
- Jaza katika nafasi tupu ipasavyo
- Kutoa taarifa sahihi

Tarehe.....

Utafiti idadi

1. Ni jinsia gani?

Kiume

Kike

2. Ni jamii umri wako ni nini?

chini ya umri wa miaka 18

Miaka 18-28

Miaka 29-39

Miaka 40-50

Miaka 51-60

61 na zaidi ya miaka

3. Hali ya ndoa

- Bado ndoa
- Ndoa
- Kinachotenganishwa
- Talaka

4. Kiwango cha elimu

- Kanuni ya
- Sekondari
- Elimu ya juu
- Hakuna

5. Kazi

- Kuajiriwa
- Kujijiri
- Mstaafu
- Si walioajiriwa

6. Dini

- Muslim
- Mkristo
- Hakuna
- Nyingine (eleza).....

7. Idadi ya watoto chini ya uangalizi yako

- Hakuna
- 1-3
- 4-6
- Zaidi ya 6

8. Mbio

- Afrika
- Asia
- Ulaya
- Nyingine (eleza)

9. Muda wa huduma ya kutoa

- Miezi 1-6
- Miezi 7-12
- Miaka 1-5
- Miaka 6-10
- Zaidi ya miaka 10

10. Ni uhusiano wako na mgonjwa nini?

- Mtoto
- Inlaw
- Mke
-
-

Mume

Nyingine (bayana)

11. Ni mapato mbalimbali yako ni nini?

- Chini ya 10,000
- 10,001-20,000
- 20,001-30,000
- 30,001 na juu ya

APPENDIX VI: PROPOSED WORK PLAN- FLOW CHART

TIME SCHEDULE

Development of proposal	January - August 2013
Approval of proposal	August - September, 2013
Ethics committee	October 2013- March, 2014
Data collection	May-June, 2014
Data analysis and reporting	July, 2014
Presentation	July, 2014
Completion of the work and binding of the book	December,2014

APPENDIX VII: BUDGET

Financial implications of the study will be:

Proposal preparation

Typing and printing	1500
KNH/UON/ERC	2000
Internet/ communication	3000

Stationery

Foolscaps 1 ream	400
A4 printing papers	600
1 dozen Pencils	240
5 Rubbers	750
Pens 1dozen	250
2 Rulers	100
Pins (1 pack)	250
Paper punch	1000

Storage devices

Flash disc (2GB)	3500
CD-RW (20pcs)	600

Data collection expenses **45,000**

Data processing

Analysis	30000
Dissertation	

Printing and photocopy	2000
Book binding	6000
Total	96590

Kenyatta National has funded Kshs 89,690