

The Prevalence of Depressive Symptoms among Caregivers of
Children with Mental Disorders drawn at Kenyatta National
Hospital.

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the award of the Master of Science Degree in Clinical Psychology
of the University of Nairobi

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Dedication

To all caregivers of children with mental disorders.

Abstract

Introduction: Care giving to children suffering from mental disorders places emotional demands on the caregivers. This may lead to the development of depressive symptoms in the caregivers. This depression in the caregivers may affect the quality of care that they give to children with mental disorders as living with such children is very stressful. The prevalence of depressive symptoms among care givers of children with mental disorders is well document in the rest of the world. In Kenya, studies in this area are limited. Mental disorders among children attending the KNH psychiatric clinics pose a significant concern. As the caregivers strive to provide proper care for these children, it is important to find ways of helping and supporting them.

Objective: To determine the prevalence of depressive symptoms among caregivers of children with mental disorders.

Method: A cross sectional descriptive study. The participants were caregivers whose children attended the child psychiatry and youth clinics of Kenyatta National Hospital in Nairobi. Data was collected using the socio demographic questionnaire and Beck's Depression Inventory. Data was entered and analyzed using SPSS. The results were then presented in the form of tables, charts and descriptions.

Results: A total of 176 participants were analyzed. The mean age was 45.5 years, (76.1 %) were female. Most of the participants were married (64.2%), had secondary level of education (46.6 %), and were employed (59.1%). Clinical depression was at (56.2%).The study revealed that clinical depression among caregivers was related to gender ($p=0.007$). Other factors such as age, income, level of education, number of children in the home and duration of care did not make a difference in the development of depressive symptoms, the study found.

Conclusion: Caregivers of children with mental disorders are more likely than the general public to have clinical depression. Professional assistance, public awareness of mental disorders, support by the government, private sector, and non-governmental organizations (NGOs) are important in addressing the challenges faced by these caregivers.

Abbreviations/ Acronyms

ADHD	Attention Deficit Hyperactivity Disorder
ASD	Autism Spectrum Disorder
BDI II	Beck Depression Inventory
CDC	Centre for Disease Control
CHADD	Children and Adults with Attention-Deficit/Hyperactivity Disorder
DSM IV-TR	Diagnostic and Statistical Manual Version IV Text Revision
ENT	Ear, Nose and Throat
KNH	Kenyatta National Hospital
MDD	Major Depressive Disorder
MUPS	Medically Unexplained Physical Symptoms
NFCSP	National Family Caregiver Support Program
NICHD	National Institute of Child Health and Human Development
NIMH	National Institute of Mental Health
PSC	Patient Support Centre
PTSD	Post-Traumatic Stress Disorder
SAMHS	Substance Abuse and Mental Health Services
SED	Severe Emotional Disturbance
SPSS	Statistical Package for Social Sciences
U.S.	United States
U.O.N.	University of Nairobi
WHO	World Health Organization
WHR	World Health Report

Operational Definitions

Depression

Depression is a common mental disorder, characterized by sadness, loss of interest or pleasure, feelings of guilt or low self-worth, disturbed sleep or appetite, low energy and poor concentration. Other symptoms include loss of confidence and self-esteem, inappropriate guilt, thoughts of death and suicide, diminished concentration, and disturbance of sleep and appetite. A variety of somatic symptoms may also be present.

Caregiver

Any person 18 years or older who cares for a child with a mental disorder most of the day in the home. They provide emotional and physical support for patients and often play a central role in clinical decision making.

Care giving

Care giving is a time-consuming responsibility, creating social, emotional, behavioural and financial problems for the caregivers

Child

By Kenyan laws, a child is anyone below the age of 18 years.

Children with mental disorders

Any child who has a mental disorder that is diagnosed in infancy, childhood or adolescence. These disorders adversely affect the psychological, social and educational functioning of the child.

Contents

DECLARATION.....	i
CERTIFICATE OF APPROVAL.....	ii
ACKNOWLEDGEMENTS	iii
Dedication	iv
Abstract	v
Operational Definitions	vii
Contents	viii
Chapter 1 INTRODUCTION.....	1
1.0. Overview.....	1
1.1. Background.....	1
1.1.1. Definition of Depression.....	3
1.1.2. Definition of depressive disorder-.....	3
1.1.3. Types of depression-	3
1.1.4. Levels/ severity of depression	4
1.2. Problem Statement	5
1.3. Justification of the study	6
1.4. Objectives of the study.....	6
1.4.1. Main objective.....	6
1.4.2. Specific Objectives.....	6
1.5. Scope of Study	7
1.6. Hypotheses	7
1.7. Output of the Study.....	7
Chapter 2 LITERATURE REVIEW.....	8
2.1. Introduction.....	8
2.2. Depression among caregivers	8
2.2.1. Prevalence of depression among caregivers.....	9
2.2.2. Predictors of depression among caregivers	10
2.2.3. Barriers to effective recognition/treatment of depression among caregivers	11
2.2.4. Effects of caregiver depression on the child	12
2.3. Care giving of children with mental disorders	13

2.4. Caregiver socio-demographic characteristics and depression	14
2.4.1. Caregiver’s age	14
2.4.2. Caregiver’s gender	14
2.4.3. Caregiver’s relationship to child with mental health problems	15
2.4.4. Caregiver’s income	15
2.4.5. Number of children in the home	15
2.4.6. Caregiver’s social networks	15
2.4.7. Caregiver’s Marital Status	16
Chapter 3 METHODOLOGY	17
3.1. Introduction	17
3.2. Research design	17
3.3. Study setting	17
3.4. Sampling procedure	18
3.5. Data collection Instruments	18
3.5.1 Socio-demographic Questionnaire	18
3.5.2. Beck Depression Inventory	18
3.6.0. Inclusion Criteria	19
3.6.1. Exclusion Criteria	19
3.7. Sample size	19
3.8. Data collection procedure	20
3.9. Data analysis and presentation	20
3.10. Ethical Considerations	21
Chapter 4 RESULTS	22
4.1.1 Age	23
4.1.2 Gender	23
4.1.3 Relational/Marital Status	23
4.1.4 Caregiver Education	23
4.1.5 Caregiver Employment	24
4.1.6 Caregiver Income	24
4.2 Others Characteristics of Care giving	25
4.2.1 Number of Children in the Home	25
4.2.2 Relationship of the Caregiver to the Child	25

4.2.3 Age of the Child with a Mental Disorder	25
4.2.4 Number of years of providing Care for the Child	26
4.2.5 Coping Strategies.....	26
Table 3 – Symptom Severity.....	28
4.3.1. Depression among Caregivers.....	29
Chapter 5 Discussion	32
Chapter 6 CONCLUSION AND RECOMMENDATIONS	37
Time Schedule	39
Budget	39
REFERENCES	40
APPENDICES.....	47
Appendix 1 - Socio Demographic Questionnaire	47
Appendix 2 – Coping strategy.....	48
Appendix 3 – Beck Depression Inventory.....	50
Appendix 4–Informed Consent Explanation for study participants	52
Appendix 5-Consent Form.....	53
Appendix 6 -Flow Chart	54
 Figure 1 Depressive symptoms among caregivers of children younger than 5 years old at baseline.....	 10

Chapter 1 INTRODUCTION

1.0. Overview

Depressive symptoms in caregivers of children with mental disorders in Kenya remain largely unnoticed. When depressive symptoms are noticed, they may not be taken seriously and no medical attention sought or given. In addition, when these caregivers take their children to the health care providers, the focus is always on the child and not the caregiver. The traditional family system in Kenya was close knit as such it acted as a buffer against various kinds of stresses. Due to rapid urbanization and industrialization, the traditional family system has broken down. This has left the nuclear family more vulnerable to stresses and less equipped to handle mentally ill members (Sethi & Manchanda, 1978), and as a result, a caregiver for a child with a mental disorder finds that there is no one to support them.

In the child psychiatric clinic and the youth centre at Kenyatta National Hospital (KNH), it is not uncommon that caregivers often express feelings of sadness, hopelessness and helplessness as a result of the child's mental disorder. The shame of having a child with a disorder and the fear of what the future holds leads to a lack of interest in forming meaningful relationships. The caregivers also lack motivation to seek help for themselves even when they feel unwell.

1.1. Background

The global burden of mental disorder is on the increase (WHO, 2011). Researchers generally agree that mental disorder represents a burden to the caregiver and family. A study by (Ohaeri 2002) concluded that the experience of burden was the norm and was significantly associated with patient's disruptive behavior. The results of this study underscored the need for continued intervention with families in order to improve the quality of care. In an earlier study by Baronet (1999) the conclusion was that mental health consequences of care giving were linked to the burden of care giving. This was because the needs of the care recipients were placed before the needs of the caregiver. Loukissa, (1995), found that besides the patient and caregiver characteristics national differences in mental healthcare service provision may influence the burden on caregivers and relatives of people with mental disorders. The U.S. Department of Health and Human Services, 1999 reported that one in every five children and adolescents have a diagnosable emotional or

behavioural disorder in a population of between 14 to 20 percent of children and adolescents the world over. Out of these, between 5 percent and 7 percent have a severe emotional disturbance (SED) that causes extreme functional impairment (Finch, and Phillips 2005).

In Kenya, mental health falls under the ten elements of primary health care. It is therefore provided through dispensaries and health centres and by mental health nurses and general health workers (WHO, 2005). In some cases these health facilities do not have trained mental health workers. As a result caregivers who present with mental disorders may be misdiagnosed leading to long term effects on the caregiver, the child and the whole family. Children with mental disorders in Kenya often receive health services in general wards except those who have been referred to the child psychiatric clinic or the youth centre at Kenyatta National Hospital. These children often require to be cared for by family members who in most cases are mothers, sisters, aunts or grandparents.

Caregivers within the family have often been described as forgotten patients. A study by Medalie (1994) suggested that caregivers' symptoms such as mood swings, fatigue, headaches, joint and muscle pains, marital, family conflicts and financial problems may have been a reflection of caregivers' stress. Depression in caregivers is one of today's all-too silent health crises. Family Caregiver Alliance, Fact Sheet (2001), reported that depression appears to be the most common disorder with 30% to 59% of caregivers reporting depressive disorders or symptoms. In a study by Schulz et al., (1999), they consistently report higher levels of depressive symptoms and mental health problems among caregivers than among their non care giving peers. Another study by Lin Jin-Ding et al., (2009) found that as compared to the general population, primary caregivers are more frequently depressed and anxious. They are also more likely to use psychotropic medications, and exhibit more symptoms of psychological distress. According to England M.J. and Sim L.J. (2009), in general, women caregivers experience depression at a higher rate than men. In an earlier study by Maputo (2003), the findings gave a female to male ratio of 2:1 to 3:1 in industrialized countries.

Care giving per se does not cause depression because not everyone who provides care will experience the negative feelings that go with depression. However, the emotional involvement of a care giver in care giving which is common among those providing care to those suffering from mental disorder, suffer a psychological burden or strain. The resulting

feelings of anger, anxiety, sadness, isolation, exhaustion and the guilt for having these feelings can exert a heavy toll. Feelings of depression are often seen as a sign of weakness rather than a sign that something is out of balance.

People experience depressive symptoms in different ways. The type and degree of symptoms vary by individual and can change over time.

Definition of Depression

Depression is characterized by a number of symptoms, in addition to a lowering of mood. These include loss of interest, poor concentration and forgetfulness, lack of motivation, tiredness, irritability, poor sleep and changes in appetite (DSM IV TR, 2000). The “negative” attitude of the depressed individuals is perhaps the most disabling aspect of the illness. According to the DSM IV-TR (2000) the symptoms, if experienced for more than two consecutive weeks, may indicate depression.

1.1.2. Definition of depressive disorder- A depressive disorder is an illness that involves the body, mood, and thoughts. It affects the way a person eats and sleeps, the way one feels about oneself, and the way one thinks about things. A depressive disorder is not a sign of personal weakness but a condition that requires treatment without which symptoms can last for weeks, months, or years.

1.1.3. Types of depression- There are three types of clinical depression. The most severe is major depression and presents with all the classic symptoms (anhedonia and lethargy and sleep disturbance and despondency and morbid thoughts and feelings of worthlessness and sometimes attempted suicide). These symptoms interfere with the ability to work, sleep, eat and enjoy once pleasurable activities. The symptoms occur without any apparent cause and deepen and persist day-in and day-out for two weeks or longer. Depression strikes more women than men. The lifetime risk of suffering from major depression is 10-25% for women and 5-12% for men with an average age of onset is 25 years old.

Formerly called manic-depressive illness, bipolar involves cycles of depression and elation (mania). The mood switches are dramatic and rapid, but most often they are gradual. When in the depressed cycle, a person can have any or all of the symptoms of depression. When in the manic cycle, any or all manic symptoms (extreme outbursts of energy or unusual

activity, abnormally high moods that swing from elation to despair), may be experienced Kessler et al., (2005).

Dysthymia- is marked by mild to moderate depressive symptoms that last at least two years. People with this condition tend to have fewer symptoms than those with major depression, but the symptoms last longer and develop more slowly. Sometimes people with dysthymia also experience major depressive episodes. This referred to as double depression Evans et al., (1992).Dysthymia often presents itself during childhood or adolescence. Symptoms such as poor school performance, social withdrawal, shyness, irritability, hostility and frequent conflicts with parents are the first indicators of the affliction. The disorder can also develop later in life.

1.1.4. Levels/ severity of depression

Mild to Moderate Depression- This category includes symptoms like self-doubt, poor peer relations, negative self-concepts, poor adjustment, poor coping skills, low self-esteem, and social withdrawal. A score of 10-19 on the BDI is interpreted as mild to moderate depression.

Moderate to Severe Depression- This category is explained as loss of emotional expression (flat affect); a persistently sad, anxious or empty mood; feelings of hopelessness, pessimism, guilt, worthlessness, or helplessness; social withdrawal; unusual fatigue, low energy level, a feeling of being slowed down; sleep disturbance with insomnia, early-morning awakening, or oversleeping; trouble concentrating, remembering, or making decisions; unusual restlessness or irritability; persistent physical problems such as headaches, digestive disorders, or chronic pain that do not respond to treatment; thoughts of death or suicide or suicide attempts. A score of 20-63 on the BDI is interpreted as moderate to severe depression.

1.2. Problem Statement

Care giving for any child places a burden on the caregiver. When this child has a mental disorder then the demands on the caregiver to provide care for them on a regular basis places extra strain on the caregiver. Mental disorder disrupts the lives of everyone around them in school and at home, more so the caregivers. Often children with mental disorders are rejected by their peers, school authorities and the society at large. In the clinic where the researcher has interacted with caregivers, it is evident that these caregivers despair, are desperate for solutions, feel hopeless and even helpless. The overwhelming responsibility the caregivers experience in their care of children with mental disorders leads to the development of depressive symptoms. Research evidence suggests that depressive symptoms in caregivers of children with mental disorders are quite widespread in the developed world.

Similarly, in the third world countries the problem could just be as widespread as it is globally but is not being recognized due to lack of available research in the area. There is very little that has been done on depressive symptoms among caregivers of children suffering from mental disorders. However, majority of caregivers that the researcher has interacted with at the child and youth clinics express feelings of hopelessness and helplessness in their care of the mentally ill. Despite this problem, very little is being done to ensure that the caregiver's psychological needs are met so that they are able to cope and to provide quality care for the children. The focus is always on the children who they bring for treatment. They are often ignored during the child's treatment and not considered a central part of the therapeutic process. This leaves the caregiver feeling psychologically distressed and may develop depressive symptoms.

Out of this experience arose the researcher's interest in the study area. Little if anything has been done towards the research and delivery of services in this area hence a need for the study. The current study has therefore, focused on depressive symptoms in caregivers of children with mental disorders and suggests ways of coping so that caregivers provide quality care and without symptoms.

1.3. Justification of the study

Depressive symptoms and psychological distress among caregivers affect the mental health of children who are under their care. Research has demonstrated that children are better able to cope with their vulnerabilities when their adult caregiver is healthy and able to provide love and cognitive stimulation (Richter, Foster & Sherr 2006). In Kenya, there are few studies on depressive symptoms among these caregivers, thus the need for more studies in this area. This study aimed to investigate the prevalence of depressive symptoms among caregivers. The findings of this study are important for the empowerment of caregivers of children with mental disorders. Awareness on the prevalence of depressive symptoms among caregivers will enable stakeholders put in place structures that will improve the lives of the caregivers. This in turn would improve the lives of children who have mental disorders. This study also forms a base for other scholars to do more research in the area.

1.4. Objectives of the study

1.4.1. Main objective

To establish the prevalence of depressive symptoms among caregivers of children with mental disorders.

1.4.2. Specific Objectives

- To determine the socio–demographic characteristics of care givers of children with mental disorders.
- To determine levels of and depressive symptoms among caregivers of children with mental disorders.
- To determine the relationship between the socio-demographic characteristics, and depressive symptoms of caregivers of children with mental disorders.
- To determine how the caregivers cope with care giving for the children with mental disorders.
- Based on the findings, recommend interventions for the caregivers of children with mental disorders who may be suffering and not receiving help.

1.5. Scope of Study

This study focused on caregivers of children below the age of 18 who attend clinic at the child psychiatric clinic and the youth centre Kenyatta National Hospital. The child psychiatric clinic is housed at the Patient Support Centre (PSC). For the purposes of this study, the researcher interviewed only caregivers of patients below the age of 18.

1.6. Hypotheses

Null Hypothesis

There is no statistically significant difference between the prevalence of depressive symptoms among caregivers of children with mental disorders and that of the general population (6-15%).

Alternative Hypothesis

There is a statistically significant difference between the prevalence of depressive symptoms among caregivers of children with mental disorders and that of the general population (6-15%).

1.7. Output of the Study

Document and report the prevalence of depressive symptoms among caregivers of children with mental disorders. Help caregivers understand depressive symptoms to enable them seek intervention early enough.

Chapter 2 LITERATURE REVIEW

2.1. Introduction

Mental health is the state of well being. It includes the biological, psychological, social and spiritual aspects of an individual. This state of well being enables one to realize their potential, face everyday challenges of life, be productive and fruitful in society (WHO, 2001). This is essential for a caregiver to be able to provide care for a child with a mental disorder. Care giving for any child places a lot of responsibilities and strain on the caregiver. This is more so when besides having to care for the child singlehandedly, the care giver has other duties either within or away from the home. These role conflicts and the emotional demands of giving care may lead to development of depressive symptoms among the caregivers. As a result the prevalence especially of depressive symptoms among caregivers of mentally ill is higher than in the general population 6-15% (Shabana et al, 2005).

There are very few studies in Kenya on depressive symptoms among caregivers of children with mental disorders. Care giving in Kenya is made more challenging by the shame and embarrassment that goes with mental disorders especially in childhood.

2.2. Depression among caregivers

Angold et al (1998) reported that little attention had been paid to the psychological distress resulting from caring for children and adolescents with mental disorders, even in developed countries. Depressive feelings are common, especially after experiencing setbacks in life. Care giving can be a major setback for the caregiver as it robs them of their freedom.

Depressive disorder is diagnosed only when the symptoms reach a threshold and last at least two weeks. Depression can vary in severity from mild to very severe. It is most often episodic but can be recurrent or chronic. Depression is more common in women than in men with a female to male ratio of 2:1 to 3:1 in industrialized countries (Maputo, 2003). In the primary care setting, depression is highly associated with multiple somatic symptoms. In as many as 84 percent of depressed patients, there is no identifiable organic cause for the somatic complaints that bring them to the physician (Smith 1995). In related studies, Panzarino(1998)& Escobar,(1998), it was evident that fifty percent of patients presenting to a primary care setting had no medical illness. A further 20 to 30 percent of patients had multiple medically unexplained physical symptoms (MUPS)(Üstün 1995). Pain is the most

common presentation associated with underlying depression (Schatzberg 2004 and Pincus, 2001). Among the caregivers who bring children to the two clinics where the study is to be conducted, it is not uncommon for the caregivers to complain of pain. They often attribute this pain to the strain of having to take care of and to bring the child to the clinic. However they do not see any reason to seek treatment for themselves.

Physical symptoms are some of the most important signs of depression. Symptoms ranging from pain (especially musculoskeletal pain, such as back, neck, and shoulder pain) and headache to gastrointestinal disturbance, chest tightness, fatigue, and appetite or weight changes frequently are markers for underlying depression. Pain markers often escalate when one's mood worsens from normal to depression to major depressive disorder MDD (Ohayon 2003). Many behavioural symptoms will be evident as well as sadness, loss of pleasure, difficulty concentrating, sleep problems, or feelings of worthlessness.

2.2.1. Prevalence of depression among caregivers

Depression appears to be the most common disorder. 30% to 59% of caregivers report depressive disorders or symptoms (Family Caregiver Alliance, 2001). The prevalence of informal caregivers who are at risk for depression is almost three times higher than in general populations of similar age (Schulz, Tompkins, & Rau, 1998). Libby et al., (2007) in a study for child welfare system found that a quarter of caregivers had a score indicating major depression at baseline. Some caregivers met the strict criteria used to define major depression. More than a third of caregivers (37.0%) met a broader criterion of having felt sad, blue, or depressed for 2 or more consecutive weeks during the 12 months before the assessment. Individuals who reported depressed mood also reported high levels of corresponding depressive symptoms, such as fatigue, losing interest in most things, and having trouble concentrating or sleeping (Figure 1).

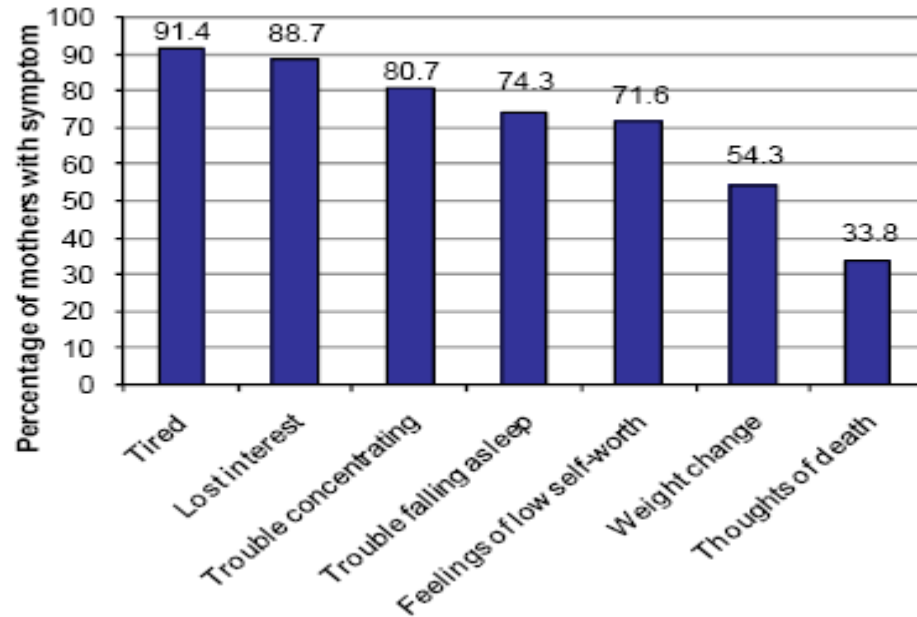


Figure 1: Depressive symptoms among caregivers of children younger than 5 years old at baseline – National Survey of Child and Adolescent Well-Being Research Brief, 2007.

2.2.2. Predictors of depression among caregivers

Psychological wellbeing is the area of a caregiver’s daily life that is most affected by providing care. Schulz et al., (1999) reported higher levels of depressive symptoms and mental health problems among caregivers than among their non-care giving peer. Caregivers of children with mental disorders are no exception to these findings. Mbugua et al., (2007) found that seventy nine percent (79%) of caregivers were at risk of clinical depression.

A child with good mental health is able to achieve and maintain optimal psychological, social functioning and well-being. The child has a sense of identity, self-worth, sound family and peer relationships. There is an ability to be productive, learn, and a capacity to tackle developmental challenges. Mental disorders rob children of these abilities and as a result a caregiver has to provide care for them on a regular basis. A child with mental difficulties is a heavy burden for the family as there is a great need for support from the community and society (Mbwilo et al., 2010). In related studies in Kenya, Ndeti et al., (2009) found that relatives perceived that the mentally ill patients caused financial constraints and had various disturbed behaviours. Of particular concern was verbal and physical aggression and refusal of the patient to take medicine or go to hospital which affected the family in different ways.

Apparent helplessness of the care receiver's condition places the caregiver at a risk of depression. This is because the caregiver is not able to improve the life situation of the child. For instance, when a child has a behavioural problem there is increased parent-child conflict and stress. These behavioural problems also lead to more child noncompliance, hostility and disruption. All these lead to a poorer sense of competence in parental role, greater parenting stress and maternal depression, (CHADD, 2005)

Another predictor of depression is the unreasonable burdens put on the self by the caregivers in an effort to provide the best possible care for the child. Caregivers often sacrifice their own physical and emotional needs. The emotional and physical experiences involved with providing care can strain even the most capable person.

Depression depletes the caregiver's own resources, increasing care costs for both caregiver and care recipient. When caregivers feel depressed and over-whelmed by their care giving tasks, they are more likely to suffer burnout and may make the often agonizing decisions.

2.2.3. Barriers to effective recognition/treatment of depression among caregivers

The challenge for primary care providers is to recognize depressive symptoms among the caregivers that bring patients to the health centres. Health care providers traditionally respond to complaints of fatigue in a patient by sending the individual for a blood test or urinalysis. They should however consider symptoms of depression when making a differential diagnosis. A study by Goff, (2002), found that general practitioners miss 30% to 50% of diagnosis of depression in the primary care setting. Further, even when depression is accurately diagnosed, it is often undertreated. Patients with mental health issues on the other hand may not even be aware that depression can contribute to many of their physical problems. As a result, it is the primary health care providers who should differentiate somatic complaints secondary to depression from the wide range of medical diagnoses with which patients may present.

Stigma is another barrier to recognition of depression among caregivers of children with mental disorders. Symptoms have often been viewed as the result of flawed character or weakness. This is viewed as inconsistent with African resilience. This may result in the caregiver not seeking help from the health care facility when they feel unwell. In the Kenyan context, there is a belief that demonic possession plays a role in mental disorders of children. When a caregiver feels weighed down these symptoms of depression are then attributed to demonic possession.

Many caregivers do not have the time to address their own health concerns. They often focus on the needs of those they take care of and neglect their own health needs. Research findings have shown that caregivers with higher depressive symptoms are no more likely than non caregivers to seek medical help (Polen & Green, 2001).

Financial consequences of general health care are far beyond the reach of many. When mental health issues come up then one is required to seek specialized treatment. This means that the expense involved is much greater. As a result, treatment is either not sought at all or delayed. In some instances, treatment is sought from non-mental health professionals, friends, family, traditional healers or the faith community (Shibre 2008).

Other expressions of depression include substance abuse, compulsivity at work, reckless behaviour and violent or abusive behaviour by the caregivers. All these may mask underlying depression making it very difficult to get effective treatment (NIMH, 2003)

Effective caregiver support services include specialized information, caregiver training and education, family counselling, caregiver support groups, respite care, and in-home care. Unlike in Kenya, such services are available in other countries especially for the care of the elderly. For instance, The National Family Caregiver Support Program (NFCSP) was enacted as part of the reauthorization of the Older Americans Act in 2000.

When a caregiver takes a child with a mental disorder to the health care provider, the focus is always on the child. This is however the best point at which a caregiver at risk can be identified and referred to the needed service. At the clinics where the research is to be carried there is a lack of simultaneous evaluation and treatment of the caregiver and the child. Hooker et al., (2002) outlined that in a bid to address this, models should be designed to include the care of caregivers by their primary care professional.

2.2.4. Effects of caregiver depression on the child

Parental mental health problems can adversely affect the development, and in some cases the safety, of children (Meltzer et al., 2000). Emotional impact of any psychiatric disorder on caregivers can vary from frustration, anxiety, fear, depression and guilt to grief. Grief may be for the loss of the child that the caregiver expected to have. This grief can lead to unconscious hostility and anger (Ostman & Hansson, 2004). Depression is the most common of the emotions, as experienced by caregivers. Depression is common among mothers of young children and is a significant risk factor for child maltreatment (Kotch et al.,

1999). Children of depressed mothers are at increased risk for psychiatric illness (Burke, 2003). Depression among mothers has been associated with a variety of adverse outcomes in their children's infancy and childhood (Pettersen & Albers, 2001). Depression may disrupt a mother and child's early relationship, which is critical to the healthy development of the child (Ainsworth & Eichberg, 1991). Children of depressed mothers tend to have poorer mental, motor, and language skills development. Compared to children of non depressed mothers, children of depressed mothers have less capacity to concentrate; fewer abilities across a broad spectrum of emotional skills; more negative responses to their environment; and more behavioural difficulties (Murray & Cooper 1997, NICHD Early Child Care Research Network, 1999, Peterson & Albers, (2001).

Burns et al (2010) found high levels of clinical need among the children of care giver with depressive symptoms. Libby et al., (2007) reported rates consistent with the Burns et al. (2010). These findings indicated a link between clinically significant behaviour difficulties in children and their caregivers' mental health and substance abuse problems. Moreover, caregivers' mental health and substance abuse problems were linked with impaired parenting.

Research has extensively described how depression interferes with the emotional sensitivity and responsiveness of mothers toward their infants and young children. Depressed mothers are more helpless, hostile, critical, disorganized, avoidant, and impatient, as well as less competent, than non depressed mothers (Lovejoy et al., 2000). Moreover, studies have found that depressed mothers tend to have difficulties managing distressed infants. These mothers perceive parenting as difficult. They tend to be inconsistent and feel irritated by the young child's needs, and sometimes report thoughts of harming their children. All of these factors lead to a hostile interaction and can eventually lead to the physical abuse or neglect of the child (Cassell, & Coleman, 1995).

2.3. Care giving of children with mental disorders

Quality of care giving can be good if the care giver is able to care for the child. This involves ensuring that the child adheres to their medication, attends to appointments regularly, has good personal hygiene and maintains good physical health. This however is not often possible as many caregivers have chronic health problems; suffer depression and excess stress when the burden of care giving or work increases (WHO, 2003).

Care giving can take many forms within various contexts. Of late a growing interest in care giving research has focused on grandparents raising their grandchildren. These grandparents are thrust out of their more traditional role as mediator, provider of cohesion and identity, and transmitter of values back into care giving. Hirshorn (1998) suggested that grandparents raising their grandchildren often redraw the boundaries within the family. They have to reorganize and redefine family relationships when mental health problems of the grandchild come into play. This places a heavy burden on the grandparents. Pruchno, (2000), found that assuming the role of surrogate a parent was both stressful and satisfying for grandparents. Increased levels of depressive symptoms and decreased physical health have been noted in grandmothers raising grandchildren when compared to non care giving grandmothers (Fuller- Thomson & Minkler, 2000a).

2.4. Caregiver socio-demographic characteristics and depression

World studies exist on socio demographic variables of caregivers in relation to depressive symptoms. Locally, Mbugua et al., (2007) found socioeconomic factors to be key in depression among caregivers.

2.4.1. Caregiver's age

Studies by Goodhead and McDonald (2007), found that younger caregivers experience higher levels of burden as they may be offering substantial care as the sole caregiver, or have lesser levels in a supportive role to the primary caregiver. In related studies by Sandy et al., (2007), it was found that younger caregiver was predictive of higher levels of caregivers' depressive symptoms.

2.4.2. Caregiver's gender

Women react to care giving with a greater tendency to become distressed and to feel burdened by care giving. Goodhead and McDonald (2007) reported this as being a result of women experiencing more care giving stressors, such as higher social expectations and lower social support. This may suggest that women have different coping strategies and social supports as compared to men (both known mediators in caregiver burden).Mbugua et al., (2007) found gender was significantly associated with risk of depression.

2.4.3. Caregiver's relationship to child with mental health problems

The relationship of the caregiver to the ill or disabled individual has been demonstrated to be related to caregiver burden (Brannan & Heflinger, 2006). Literature on caregiver burden is based on samples of caregivers of parents or spouses with dementia, or parents of children with mental health or behavioural conditions. Heflinger and Brannan's (2006) found that being a biological parent increased subjective internalized strain of the caregiver. The caregiver had more negative feelings such as worry, guilt, sadness, and fatigue in regards to their child with a mental health or substance abuse problem. Biological parents, single parents, and parents with fewer resources reported higher levels of parental stress.

2.4.4. Caregiver's income

Lower socio-economic status has been linked to increased caregiver burden in numerous studies (Baldwin et al., 1995; Brannan & Heflinger, 2001). Ndeti et al., (2004) found that relatives perceived that the mentally ill patients caused financial constraints. Mbugua et al., (2007) also found a statistically significant association between unemployment and risk of depression. Unemployed caregivers have little or no income.

2.4.5. Number of children in the home

A caregiver with more children in the home may perceive his or her environmental demands as outweighing their resources. Generally a child who did not have behavioural problems or interpersonal difficulties would be easier to parent, especially in the case of more than one child in the home. When there is a child with behavioural problems, conflicts between family members arise, high irritability and overprotection in families comes to the fore which in turn affect the family social life leading to limitations on time, personal freedom, and privacy (Taylor-Richardson et al., 2006)

2.4.6. Caregiver's social networks

Social support is considered a protective factor against psychological difficulties. Feldman et al., (2007) found that participants who scored above the Beck Depression Inventory's (BDI) cut off point received less social support than participants without depressive symptoms. Benson, (2006) discovered that informal support reduced levels of parental stress and depression.

2.4.7. Caregiver's Marital Status

Spouses form part of informal social support for caregivers of children with mental disorders. Social support has been linked to an increase in psychological well being of caregivers in numerous studies (Baldwin et al., (1995); Baronet, (1999); Brannan & Heflinger, 2001, 2006).

Caregivers who were single, widowed, or divorced were also more likely to be depressed (35.7%) than married caregivers (18.2%). Being single was also associated with depression at baseline, a risk factor that suggests that isolation, lack of social support, and the burden of providing and being solely responsible for young children may play a role in maternal depression and that interventions may need to take these features into account.

(44.7%) of the depressed caregivers were married. This is because in the African culture, intellectual disability is associated with stigma and, hence, the risk of higher levels of depression among the married. This may be due to lack of emotional support from the spouse (Mbugua et al., 2007). The divorced/separated and single may on the other hand have adapted coping strategies to deal with the situation (Frey et al.1989).

Chapter 3 METHODOLOGY

3.1. Introduction

In order for research findings to be valid it is necessary to systematically subject both the data collection and data analysis to credible and rigorous standards. This chapter of the dissertation explains how data collection and analysis was handled. It provides insight into the epistemology, choice of sample size and sampling design, details of how the data was collected and analyzed as well as considerations regarding how to present the data.

3.2. Research design

This was a cross sectional descriptive study to determine the prevalence of depressive symptoms among caregivers of children with mental disorders.

3.3. Study setting

The setting of this study was the Child Psychiatric Clinic and the Youth Centre, at Kenyatta National Hospital (KNH). These two clinics cater for children and adolescents with mental disorders.

The child psychiatric clinic at Kenyatta National Hospital is conducted once a week under the supervision of two consultant psychiatrists assisted by Masters of Medicine, Psychiatry students, Master of Science, Clinical Psychology students and Master of Arts, Counseling Psychology students. There is a clerk and nurses charged with the responsibility of organizing the clinic by ensuring that files for the patients that have been booked for the day are retrieved from the hospital registry and the required stationary for the day is available at the clinic. The outpatient clinic which runs every Monday is open to a maximum of 16 children ages 0 to 12 years, with at least 10 being follow up cases whereas a maximum of 6 patients attending the clinic for the first time.

The first time patients are often referrals from other departments in the hospital such as the child filter clinic, the E. N. T. department, the child neurology clinic or the occupational therapy unit. At the youth clinic, a total of 20 patients are attended to each week. Due to their age, these patients are often accompanied by caregivers with a minority who are between the age of 15 and 18 years either opting to come unaccompanied or are sent by their parents or guardians to the clinic alone. The Youth Center caters for those with mental

disorders who are 13 to 24 years old however the majority of patients are between the ages of 13 and 18 years. This center holds its mental health clinic day on Tuesdays and Fridays (9 a.m. to 4 p.m.) under the supervision of at least two consultant psychiatrists, four nurse counselors and has Masters Degree students from various specializations. The clinic is however open to patients who come in for psychotherapy the rest of the week and in cases of emergencies then there is always a doctor on call who will come in. On the mental health clinic day, a maximum of 20 patients can be attended to and it is common to find that these patients are accompanied by care givers especially on the first visit and only on subsequent visits when their condition has not stabilized or the therapists have requested due to the nature of their therapy needs.

3.4. Sampling procedure

Purposive sampling was used to select the participants. Participants attending the Child Psychiatry Clinic and the Youth clinic at Kenyatta National Hospital were approached and selected as they came until the desired number was achieved. Participation was voluntary and only those caregivers who met the inclusion criteria and gave informed consent were enlisted for the study.

3.5. Data collection Instruments

The survey instruments utilized to collect data included a researcher designed Socio Demographic Questionnaire and Beck Depression Inventory II (BDI II).

3.5.1 Socio-demographic Questionnaire

This was researcher designed and was used to collect data on the participant's age, gender, education level, socioeconomic status, number of the children in the household, employment status, monthly income, relationship to the child under their care, age of the child, duration of care giving and marital status.

3.5.2. Beck Depression Inventory

The BDI is the 'gold standard' of self-report scales intended to assess severity of depressive symptoms, if present. The Beck Depression Inventory (BDI, BDI-II), created by Dr. Aaron T. Beck, is a 21-question multiple-choice self-report inventory, one of the most widely used instruments for measuring the severity of depression. It was developed in response to the American Psychiatric Association's publication of the Diagnostic and Statistical Manual of

Mental Disorders, Fourth Edition, which changed many of the diagnostic criteria for Major Depressive Disorder.

In its current version the questionnaire is designed for individuals aged 13 and over, and is composed of items relating to symptoms of depression such as hopelessness and irritability, cognitions such as guilt or feelings of being punished, as well as physical symptoms such as fatigue, weight loss, and lack of interest in sex, Beck (2006).

3.6.0. Inclusion Criteria

Caregivers aged 18 and above and had been caring for the child on a regular basis.

Caregivers who gave informed consent.

3.6.1. Exclusion Criteria

Caregivers below the age of 18

Caregivers who did not give consent

Caregivers who could not understand or speak English or Kiswahili

Person who had not been caring for the child but had been asked by the regular caregiver to bring the child for the appointment

3.7. Sample size

To determine the sample size of caregivers were drawn from the targeted population, the researcher will adopted the Cochran (1963:75) formula

$$n_0 = \frac{Z^2 pq}{e^2}$$

n_0 = sample size

Z = standard deviation corresponding to 95% with the confidence interval set at 1.96

p = hypothesized prevalence level of depression

q = 1-p

e = desired level of precision set at 5% (0.05)

On substitution of values,

$$n_0 = \frac{1.96^2 * 0.52(1-0.52)}{0.05^2}$$

$$n_0 = 384$$

The sample size in this study was adjusted to the two clinics where the study was carried out. In the Child Psychiatry a total of 64 caregivers bring children to the clinic per month. And at the Youth centre, 80 caregivers are seen in a month. Over the two month period when the researcher wishes to collect data, the projected number would be 288. The adjustment was done using the finite population correction

$$n = \frac{n_0}{1 + \frac{(n_0 - 1)}{N}}$$

$$n = \frac{384}{1 + \frac{384 - 1}{288}}$$

$$n = 165$$

3.8. Data collection procedure

Data was collected at KNH from the child psychiatric clinic every Monday and from the youth clinic every Tuesday and Friday for a period of two months or until the desired sample size was achieved. The researcher approached the care givers in the waiting area where they were informed about the study and then ushered into a private room. In the private room the researcher explained to the caregivers the nature of the study and sought their informed consent. Those who gave consent to participate in the study signed the consent form and thereafter, the researcher administered the socio demographic questionnaire and the Beck Depression Inventory II. This took 30- 45 minutes and the process was repeated on all clinic days.

The collected data was then be cleaned, coded and entered into a data sheet for computer analysis.

3.9. Data analysis and presentation

Descriptive and inferential analysis was done using the Statistical Package for Social Sciences (SPSS) version 12. Frequency distributions were performed on all variables and

then subjected to other analysis like chi-square test statistics. The chi-square test was used to look at the statistical significance of association between pairs of variables. Results with a p-value of $p < 0.05$ and a confidence interval of 95% were considered as statistically significant. The results were then presented using bar graphs, pie charts, frequency tables and narratives.

3.10. Ethical Considerations

Research clearance was obtained from the Kenyatta National Hospital Research and Ethics Committee.

- The caregivers received an explanation on voluntary participation and the right to withdraw from the study at any time with no consequences of doing so.
- They were informed that there are no direct personal benefits in being a part of the study except for a clinical evaluation on the caregiver and referral to relevant health services for intervention where necessary and follow up.
- The researcher ensured equity among potential participants and conducted the study in an honest manner
- The participants were informed that a clearer understanding of the burden of psychiatric illnesses would be a benefit to other caregivers and ultimately society. In general this is an important part of management of the child or adolescent with a mental disorder.
- To ensure confidentiality of information, only the outpatient registration numbers and not caregiver names were indicated on the questionnaires.
- The caregivers' questionnaires, whose codes were only known to the supervisor, were matched for clinical purposes at the time of data entry.
- Informed consent explanation
- Consent form

Chapter 4 RESULTS

The study involved 176 caregivers of children with mental disorders. Demographic data was collected on the caregiver's age, gender, and marital status, level of education, employment and income (Table 1). Other factors included the number of children living in the home, age of the child, relationship to the child, duration of care and coping strategies (Table 2).

The BDI II, a 21 question self report inventory was used to measure the levels/severity of depression among the caregivers (Table 3).

Table 1- Social demographic characteristics (N=176)

	Male		Female		Total	Percentage (%)
	N	(%)	N	(%)		
Gender						
Female			134	(76.1)	176	76.1
Male	42	(23.9)				23.9
Age of care giver in years						
18 – 35	11	(6.3)	49	(27.8)	60	34.1
36 – 55	27	(15.3)	76	(43.2)	103	58.5
56 and above	4	(2.3)	9	(5.1)	13	7.4
Marital status						
Single	3	(1.7)	23	(13.1)	26	14.8
Married	35	(19.9)	78	(44.3)	113	64.2
Divorced	0	(0)	1	(0.6)	1	0.6
Separated	3	(1.7)	17	(9.6)	20	11.3
Widowed	1	(0.6)	15	(8.5)	16	9.1
Level of education						
No formal	0	(0)	3	(1.7)	3	1.7
Primary	6	(3.4)	33	(18.8)	39	22.2
Secondary	22	(12.5)	60	(34.1)	82	46.6
Tertiary	14	(7.9)	38	(21.6)	52	29.5
Employment						
Fulltime	32	(18.2)	72	(40.9)	104	59.1
Not working	3	(1.7)	35	(19.9)	38	21.6
Part time	6	(3.4)	25	(14.2)	31	17.6
Volunteering	1	(0.6)	2	(1.1)	3	1.7
Income in KShs.						
Below 5,000	5	(2.8)	46	(26.1)	51	28.9
5,001 – 10,000	5	(2.8)	28	(15.9)	33	18.7
10,001 – 15,000	9	(5.1)	15	(8.5)	24	13.6
15,001 and above	23	(13.1)	42	(24)	65	37.1
No income	0	(0)	3	(1.7)	3	1.7

4.1.1 Age

Caregiver age ranged from 20 years to 68 years with a majority 57.95% (n=102) in their middle adulthood (36 to 55 years). Young adults caregivers (19 to 35 years) were 34.1% (n=60) whereas the older caregivers (56 years and above) were 7.95% (n=14).

4.1.2 Gender

Of the 176 caregivers, 76.1% (n=134) were female and 23.9% (n=42) were male (Figure 1).

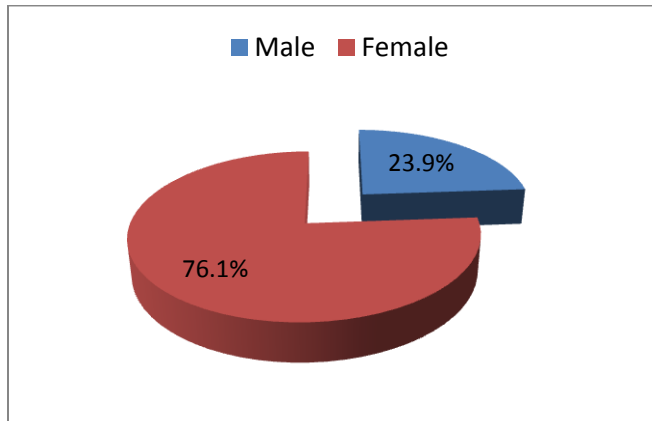


Figure 1: Gender Distribution

4.1.3 Relational/Marital Status

Most of the caregivers were married 64.2% (n=113), singles were 14.8% (n=26), separated were 11.4% (n=20), widowed were 9.1% (n=16) and 0.6% (n=1) was divorced.

4.1.4 Caregiver Education

About half the caregivers 46.6% (n=82) had secondary education, 29.5% (n=52) had tertiary education while 22.2% (n=39) were primary school graduates or dropped out. Of all the caregivers only 1.7% (n=3) did not have any formal education (Figure 2).

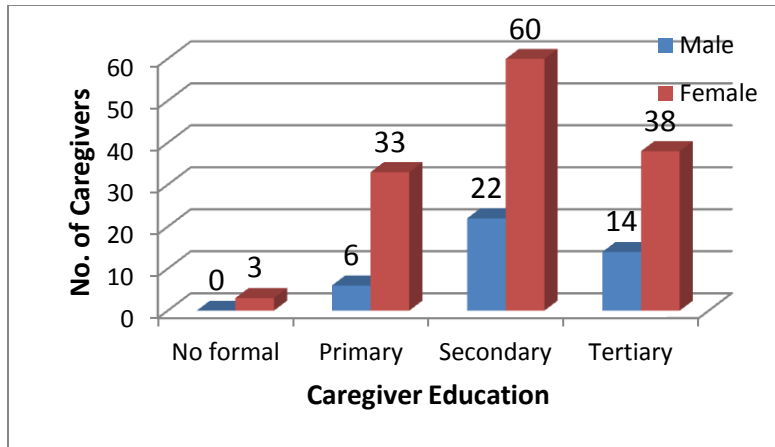


Figure 2: Caregiver Education

4.1.5 Caregiver Employment

Most of the caregivers were in full time employment 59.1% (n=104), those who were not working away from home were 21.6% (n=38), those in part time employment were 17.6% (n=31) and 1.7% (n=3) were volunteers.

4.1.6 Caregiver Income

Income ranged from below Kshs. 5,000/- 29% (n=51), those earning Kshs. 5,001/-to 10,000/- were 18.8% (n=33), caregivers who earned Kshs. 10,001/- to 15,000/- were 13.6% (n=24). Although a good number of caregivers 36.9% (n=65) earned Kshs. 15,001/- and above, there were 1.7% (n=3) of caregivers who did not have an income and depended on friends and relatives to care for their children (Figure 3).

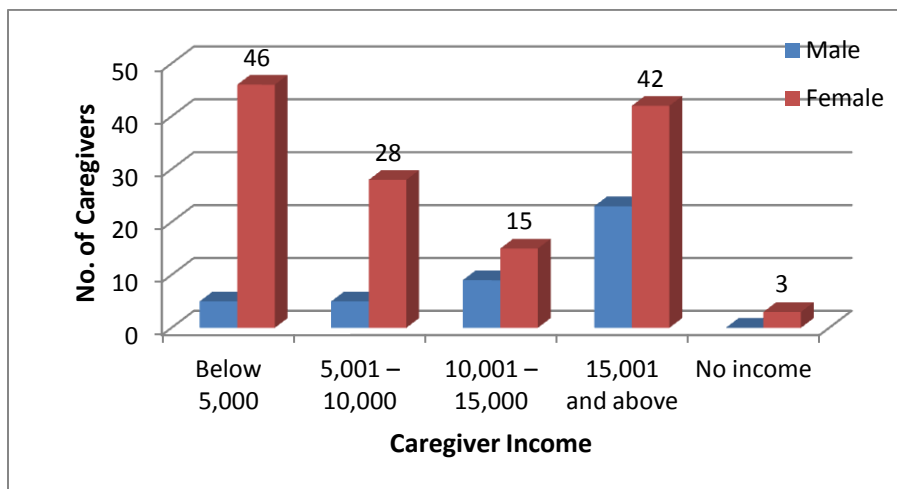


Figure 3: Caregiver Income

4.2 Others Characteristics of Care giving

4.2.1 Number of Children in the Home

Caregivers had other children who needed their care besides the one with a mental disorder. More than half the caregivers 50.57% (n=89) have a total of 4 to 6 children in the home, 27.84% (n=49) of caregivers had between 7 and 9 children, 19.89% (n=35) had up to 3 children in the home. 1.7% (n=3) of caregivers had 10 children living in the home.

4.2.2 Relationship of the Caregiver to the Child

Biological parents were the majority of caregivers 84.1% (n=148) of these 34 were males and 114 were females, there were 5.7% (n=10) grandparents who were giving care, 3.4% (n=6) were brothers, 1.7% (n=3) were sisters, 1.1% (n=2) were cousins, 3.4% (n=6) were either aunts or uncles and 0.6% (n=1) was a neighbor (Figure 4).

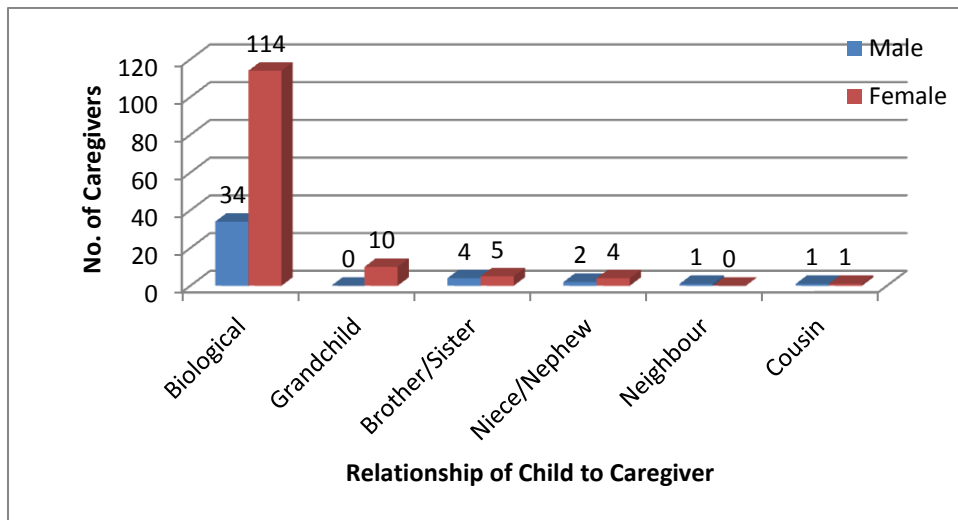


Figure 4: Relationship of Caregiver to Child

4.2.3 Age of the Child with a Mental Disorder

Most of the caregivers 66.5% (n=117) during the period of study had children whose age ranged from 12 to 18 years being cared for. 25% (n=44) of caregivers were caring for children whose age was between 6 to 11 years, those caring for children between 4 and 5 years were 6.8% (n=12). Only 1.7% (n=3) caregivers had a child below the age of 3 years.

4.2.4 Number of years of providing Care for the Child

Caregivers were found to have given care for the children for varied duration, 42% (n=74) had been caring for more than 5 years, 34.1% (n=60) had cared for the child for between 1 and 5 years and 23.9% (n=42) had cared for less than 1 year (Figure 5).

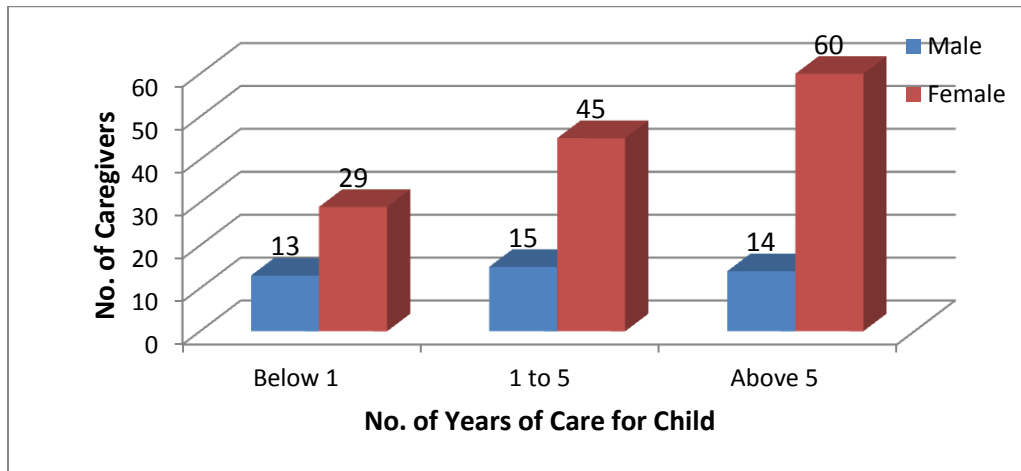


Figure 5: No. of Years of Care for the Child

4.2.5 Coping Strategies

Caregivers reported that they mainly used a combination of the problem focused strategy with social support strategy 42.6% (n=75). Only 1.1% (n=2) of caregivers were found to have been giving up the attempt to cope whereas 56.3% (n=99) of caregivers were found to have used problem focus only. This strategy involves taking action to try and make the situation better. Some care givers reported that they learnt to live with the problem by accepting the reality, others took action to try and make the situation better. Bringing the child to the clinic was one way of making the situation better as they received education on the child's condition.

Table 2- Other Caregiver characteristics in relation to child (n=176)

	Male		Female		Total	Percentage
	N	(%)	N	(%)		(%)
Number of children in home						
1 – 3	31	(17.6)	95	(53.9)	126	71.5
4 – 6	10	(5.7)	32	(18.2)	42	23.9
7 – 9	1	(0.6)	4	(2.3)	5	2.9
10 and above	0	(0)	3	(1.7)	3	1.7
Child age in years						
2 – 3	2	(1.1)	6	(3.4)	8	4.5
4 – 5	4	(2.3)	14	(8)	18	10.3
6 – 11	4	(2.3)	35	(19.9)	39	22.2
12 – 18	32	(18.2)	79	(44.8)	111	63
Relationship of Child						
Biological	34	(19.3)	114	(64.8)	148	84.1
Grandchild	0	(0)	10	(5.6)	10	5.6
Brother/Sister	4	(2.3)	5	(2.8)	9	5.1
Niece/Nephew	2	(1.1)	4	(2.3)	6	3.4
Neighbour	1	(0.6)	0	(0)	1	0.6
Cousin	1	(0.6)	1	(0.6)	2	1.2
No. of years of Care						
Below 1 year	13	(7.4)	29	(16.5)	42	23.9
1 – 5 years	15	(8.5)	45	(25.5)	60	34
Above 5 years	14	(8)	60	(34.1)	74	42.1
Coping Strategies						
Problem Focused	22	(22.2)	77	(77.8)	99	56.3
Social Support	20	(11.4)	55	(31.5)	75	42.6
Avoidant	0	(0)	2	(1.1)	2	1.1
Combined (P F and S S)	20	(11.4)	55	(31.5)	75	42.6

4.3 Prevalence of Depression among Caregivers

To determine the levels and prevalence of depressive symptoms among caregivers of children with mental disorders, the BDI II was used to measure depressive symptomatology. Results showed that the caregiver's BDI scores ranged from 0 to 47, with a mean score of 16.24 (SD = 9.74).

Table 3 – Symptom Severity

	Frequency N	Percentage %	Cumulative Percentage %
Minimal (0-13)	77	43.8	43.8
Mild (14-19)	38	21.6	65.4
Moderate (20-28)	45	25.6	91.0
Severe (29-63)	16	9.0	100
Total	176	100	

The result presented on the table above indicate that of the 176 caregivers who participated in the study, 43.8% (n=77) had minimal depression, 21.6% (n=38) had mild depression, 25.6% (n=45) had moderate depression and 9% (n=16) had severe depression.

4.3.1. Depression among Caregivers

Figure 6 below indicates that of the 176 caregivers, 56.2% had symptoms of depression ranging from mild to severe while 43.8% had minimal depression

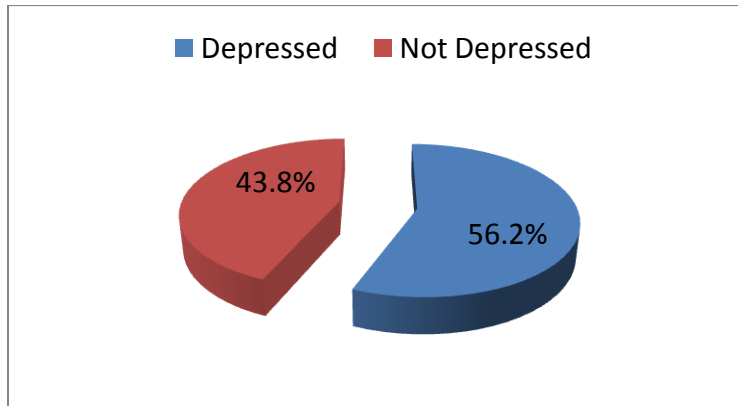


Figure 6: Prevalence of Depression

4.4 Association between the Prevalence of Depression and Other Characteristics of Caregivers

A significant difference in depression scores was found by gender ($p = .007$) with 62.7% ($n=84$) female and 35.7% ($n=15$) male having BDI levels ranging from mild to severe depression (Tables 3 and 5).

Table 5- Correlation of Depression with Social demographic characteristics (n=176)

Social demographic Characteristic	Depression				P value
	Yes		No		
	N	(%)	N	(%)	
Gender					0.007
Female	84	(62.7)	50	(37.3)	
Male	15	(35.7)	27	(64.3)	
Age of care giver in years					0.418
18 – 35	28	(46.7)	32	(53.3)	
36 – 55	62	(63.7)	40	(36.3)	
56 and above	9	(64.3)	5	(35.7)	
Marital status					0.531
Single	14	(51.9)	13	(48.1)	
Married	59	(52.7)	53	(47.3)	
Divorced	0	(0)	1	(100)	
Separated	12	(55.0)	8	(45.0)	
Widowed	14	(87.5)	2	(12.5)	
Level of education					0.281
No formal	3	(100)	0	(0)	
Primary	25	(63.4)	14	(36.6)	
Secondary	49	(58.8)	33	(41.3)	
Tertiary	22	(42.3)	30	(47.7)	
Employment					0.806
Fulltime	53	(51.5)	51	(48.5)	
Not working	26	(63.4)	13	(36.6)	
Part time	20	(59.4)	11	(40.6)	
Volunteering	0		2		
Income in KShs.					0.202
Below 5,000	36	(67.9)	15	(32.1)	
5,001 – 10,000	20	(59.4)	13	(40.6)	
10,001 – 15,000	11	(45.8)	13	(54.2)	
15,001 and above	31	(47.8)	34	(52.2)	
None	1		2		

Table6- Correlation of Depression with other caregiver characteristics (n=176)

There was no significant difference found in depression scores of caregivers based on the number of children living in the home, age of the child with a mental disorder, relationship to the child, number of years of care and the coping strategies (Table 6).

Social demographic Characteristic	Depression				P value
	Yes		No		
	N	(%)	N	(%)	
Number of children					0.700
1 – 3	18	(51.2)	17	(48.8)	
4 – 6	53	(59.6)	36	(40.4)	
7 – 9	25	(51)	24	(49)	
10 and above	3	(100)	0	(0)	
Child age in years					0.926
2 – 3	2	(66.7)	1	(33.3)	
4 – 5	4	(33.3)	8	(66.7)	
6 – 11	23	(53.3)	21	(46.7)	
12 – 18	50	(51.5)	47	(48.5)	
Relationship of Child					0.651
Biological	85	(57.4)	63	(42.6)	
Grandchild	7	(70)	3	(30)	
Brother/Sister	3	(33.3)	6	(66.7)	
Niece/Nephew	4	(66.7)	2	(33.3)	
Neighbour	0	(0)	1	(100)	
Cousin			2	(100)	
No. of years of Care					0.057
Below 1 year	20	(47.6)	22	(52.4)	
1 – 5 years	39	(65)	21	(35)	
Above 5 years	40	(54.1)	34	(45.9)	
Coping Strategies					0.806
Problem Focused	93	(56)	73	(44)	
Social Support	50	(66.7)	25	(33.3)	
Avoidant	0		2	(100)	
Combined (P F and S S)	0		2		

Chapter 5 DISCUSSION

The mean age of majority caregivers 63.7% (n=62) with depressive symptoms was 45.5 years with both gender spread across that age bracket 36 to 55 years. These findings are unlike those of earlier studies which found that caregivers in the 18-35 year age bracket may have been offering substantial care as the sole care giver. Sandy et al., (2007), found that being a younger caregiver was predictive of higher levels of depressive symptoms. In a similar study, Goodhead and McDonald (2007) found that younger caregivers experience higher levels of burden.

Marital status differed by gender and married caregivers were the majority 64.2% (n=113), followed by the singles 14.8% (n=26), separated 11.4% (n=20), widowed 9.1% (n=16) and then the divorced 0.6% (n=1) were the least. Mbugua et al., 2007 found that married caregivers were likely to have a higher prevalence of depressive symptoms. This they argued may be due to lack of emotional support from the spouse. The findings of the current study are consistent with those of Mbugua et al., 2007 who found 52.7% (n=59) of caregivers who were married to have depressive symptoms.

In the current study, 56.2% (n=99) of the caregivers were found to be at risk of clinical depression as derived from BDI II. This prevalence is higher than the general population which is 6 to 15%. This finding is consistent with that of Family Caregiver Alliance, 2001 which reported a 30% to 59% rate of caregiver depressive disorders or symptoms. In a related study, prevalence of informal caregivers who are at risk for depression was almost three times higher than in the general populations of similar age (Schulz, Tompkins, & Rau, 1998). The lifetime risk of suffering from major depression is 10-25% for women and 5-12% for men with an average age of onset is 25 years old. Mbugua et al. (2007), in their study, found a high rate (79%) of clinical depression among caregivers. These findings were not consistent with the findings in the current study and this could be attributed to the varied setting in which their study was conducted that is rural setting while the current study was in urban setting.

5.1 Socio demographic factors and clinical depression

The levels of depressive symptoms among the caregivers in this study ranged from minimal to severe. The prevalence of clinical depression (mild to severe) according to the BDI II was 56.2%. The study found that 43.8% (n=77) of caregivers had minimal depression, 21.6% (n=38) had mild depression, 25.6% (n=45) had moderate depression and 9% (n=16) had severe depression.

The socio-demographic factors found to be significantly associated with depression in the caregivers in the current study were gender and number of years of care. **Being female was found to be a statistically significant risk factor to the development of depressive symptoms with a $p = 0.007$.** Goodhead and McDonald (2007) 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.

Gender is also one of the factors that interacts with culture and has a bearing on the epidemiology of depression (Patel, 2001). Depressive disorders represent the fifth greatest burden for women, and the seventh greatest burden for men, across all physical and mental illnesses (Lopez and Guarnaccia, 2000).

In the African context, and as the study results show, care giving falls mainly on the female members. Besides care giving the woman may be pursuing her education, career, marriage, childbearing, child rearing and taking care of the other adults in the homestead. These provide the emotional context within which depression may take hold. When the child has a mental disorder and more so behavioural problems which lead to non compliance, there is increased parent-child conflict and stress, hostility and disruption. All these result in a poorer sense of competence in parental role, greater parenting stress and maternal depression (CHADD, 2005).

In the current study, the results showed that the longer the duration of care, the worse the level of symptoms (Table 6). This is in keeping with a study by Saunders J. C., (2003) which found that caring exerts pressure on the caregiver. As the stressors increase and the condition persist, the caregiver symptoms may worsen. This deterioration of caregiver health

may impact on their ability to continue their role responsibility. However, in this study the number of years of care with a $p = 0.057$ was not a statistically significant risk factor to the development of depressive symptoms.

In studies that have addressed caregiver depression it was found that younger caregivers experienced higher levels of burden hence have depressive symptoms. This was as a result of offering substantial care as the sole caregiver, or having lesser levels in a supportive role to the primary caregiver. In related studies Sandy et al., (2007), also found that being a younger caregiver was predictive of higher levels of caregivers' depressive symptoms.

In the current study there was no statistically significant association between younger caregivers (19 to 35 years) and the risk of clinical depression. The researcher presupposes this may be due to the fact that the caregivers in this study were mainly siblings who lived with their parents or relatives who provided for them. In cases where the caregivers were young and married they expressed their satisfaction with the support they got from their spouses while caring for the child with a mental disorder. In a study by Feldman et al., (2007) on caregiver social networks, it was found that participants who scored above the Beck Depression Inventory's (BDI) cut off point received less social support than participants without depressive symptoms. It is therefore, apparent that social support was a protective factor for the young caregivers.

Mbugua et al., (2007) found married caregivers to be at a higher risk of depression due to lack of emotional support from the spouse. In the current study, relational/marital status had no statistically significant association with clinical depression. In earlier studies, Frey et al.(1989) found that divorced/separated and single caregivers may have adopted coping strategies therefore had a lower risk of clinical depression compared to married caregiver. In this study, married caregivers were the majority 64.2% ($n= 113$). Of these, 52.7 % ($n= 59$) were found to have clinical depression, a trend that is similar to that found in the study by Mbugua et al. There was only 0.6% ($n=1$) divorced care giver. This may not be adequate to show a clear association with clinical depression. Separated caregivers were 11.4% ($n=20$).

The current study found no statistically significant relationship between caregiver education and depressive symptoms. This was not in line with other studies which found that caregivers who had lower levels of education were more likely to report depressive symptoms (McLearn et al., 2006; McLennan et al., 2001). However, the association between

caregiver education and level of education was in the direction similar to previous studies (i.e., lower education associated with more depressive symptoms) (Table 5). A larger sample of primary caregivers of children with mental disorders may have resulted in a clearer association between caregiver depression and levels of education.

Poverty dramatically increases the risk of common mental disorders, such as depression (Dohrenwend BP, Dohrenwend BS 1974, 1969) Poverty was revealed by parents as being responsible for their inability to meet certain important needs of the mentally ill child. This included the inability to buy drugs for the children and at times even getting bus fare to get to hospital (Ambikile and Outwater, 2012, Emerson, 2003). Unemployed caregivers with little or no income were also found to be at risk of depression (Brannan & Heflinger, 2001, Mbugua et al., 2007). In the current study, the researchers findings were not significant but showed a trend that those caregivers with lower incomes (below Kshs 5,000) had a 69.9 % (n= 36) prevalence rate of depressive disorders compared to those with an income above Kshs.15, 001 where rates dropped to 47.8% (n=31).

Employment status too was not significantly related to depressive symptoms. The study found that caregivers who were not working away from home had been involved in small groups (chamas), run their kiosks and as a result were satisfied with their lives. Of all the caregivers in this study, 1.7 % (n=3) caregivers did not have an income at all but were either married and the spouses were very supportive or were young caregivers who lived with their parents.

Studies on care giving have reported biological parents to have higher levels of parental stress. Heflinger and Brannan's (2006) found that being a biological parent increased subjective internalized strain of the caregiver. The caregiver had more negative feelings such as worry, guilt, sadness, and fatigue in regards to their child with a mental health. Though in this study there was no statistically significant association between being a biological parent of the child with mental disorder and clinical depression, it is important to note that most of the biological parents were female (57.4%). More female (62.7%) were found to have clinical depression than their male counterparts (35.7%).

Limitations of the Study

- 1) Earlier diagnosis of caregiver depression was not taken into consideration. It was therefore difficult to establish whether care giving led to the development of clinical depression or there was pre-existing depression prior to the role of caring for the child.

- 2) Some caregivers declined participation in the study. It is possible that caregivers who declined participation experienced more depressive symptoms than those who consented. Their participation may have influenced the findings.

- 3) The cross-sectional nature of the study limits the ability to draw conclusions about the course of depressive symptoms and the directional nature of the association found between caregiver depressive symptoms and demographic characteristics, For example, the nature of the relation between child health status and caregiver depressive symptoms is unclear (i.e., Does the nature of the mental disorder lead to depressive symptoms or vice versa).

Chapter 6 CONCLUSION AND RECOMMENDATIONS

6.1. Summary

The World Health Organization (WHO) predicts that depression will be the most common illness in the world by the year 2020 (WHO, 1992). There is a high prevalence of depression among caregivers as have been reported in various studies. The Beck Inventory scores in this study indicated that majority of caregivers of children with mental disorders had scores indicating risk of mild, moderate, and severe depression (clinical depression).

The results of this study suggest some risk factors for caregiver depressive symptoms occur across populations (e.g., gender and duration of care). The researcher however feels that each population has additional unique risk factors that may predispose or be protective. Recognition of mental disorder specific risk factors associated with the development of caregiver depressive symptoms will guide clinical care and the design of future interventions.

The results of this study have implications for clinical practice, training and policy initiatives. The low level of awareness among caregivers suggested that dissemination of accurate information about psychological/ psychiatric problems and available help seeking avenues are imperative. There is a need to plan models of service delivery in the child psychiatric clinics and focus on the integration of mental health into general health care of the whole family.

6.2. Recommendations

It is important to **routinely screen caregivers of children with mental disorders for depressive symptoms**. This would be consistent with the U.S. Preventive Services Task Force's (USPSTF, 2002) recommendations that all adults be screened for depression and referrals for comprehensive assessment and intervention provided.

There is **need to avail a support system to prevent or reduce the risk of depression** in these caregivers either at the clinics or refer them for the same within their communities. This may include specialized information, caregiver training, education and family counselling aimed at a more holistic way of care.

Education of the public by empowering caregivers to be able to speak out their needs and those of the children they are caring for. This can be extended in the local schools

and neighborhood, which in turn may positively affect others in their area that are being impacted by the presence of mental illness.

A longitudinal study should be the next step in understanding the natural history of depressive symptoms among caregivers of children with mental disorders. This would make it clearer whether care giving leads to depression or being depressed worsens the child/caregiver depression as a result higher prevalence rates.

Larger populations randomly selected from a national sample may be the focus in future studies to determine with more confidence the incidence of depression among caregivers of children with mental disorders.

Time Schedule

ACTIVITY	July 2011 to Feb2012	March 2012	April 2012	May 2012	June 2012	July 2012	August 2012	Feb 2013	Mar-Sept. 2013
Proposal Development									
Departmental Approval									
Research & Ethics Committee Approval									
Data Collection									
Data analysis									
Presentation of Results									
Report Writing, Examination & Submission									

Budget

Item	Cost in Kshs	Subtotal in Kshs
Stationary, printing, Photocopy	25,000/=	25,000/=
Lap top, internet services	40,000/=	65,000/=
Researcher costs, Ethics Committee charges, Ministry of Education, Science and Technology	15,000/=	80,000/=
Data analysis, report writing, printing, photocopy and binding	35,000/=	115,000/=
Miscellaneous	15,000/=	Grand Total 130,000/=

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APPENDICES

Appendix 1 - Socio Demographic Questionnaire

Date_____

Serial number_____

1. What is your age? _____

2. What is your gender? Male_____ Female_____

3. What is your current relationship status?

Single (never married) _____ Married_____

Divorced_____ Separated_____

Widowed_____ Co habiting_____

4. What is your highest level of education?

No formal Education_____ Primary_____

Secondary_____ Tertiary (College/University)_____

5. What is your employment status?

Not working outside the home_____ Working part-time (hours per week: _____)

Working full-time (hours per week: _____) Volunteering (hours per week: _____)

6. What is your income?

Less than Kshs 5,000_____ Kshs 5,000 to Kshs 10,000_____

Kshs 10,000 to Kshs 15,000_____ Kshs 15,000 and above_____

7. How many children live in your home? _____

8. What is your relationship to the child or adolescent you are caring for?

Biological child _____

Adopted child _____

Foster child _____

Niece/nephew _____

Grandchild _____

Other, specify _____

9. What is the age of the child you are caring for? _____

10. How long have you been caring for the child?

Less than 1 year _____

1 to 5 years _____

More than 5 years _____

Other, specify _____

Appendix 2 – Coping strategy

As a caregiver of a child with a mental disorder, how have you been coping with care giving?

1. "I've been taking action to try to make the situation better"- **Problem focused coping**

a) By learning to live with it by accepting the reality of the fact that my child has a problem

b) I've been trying to see the child's problem in a different light, to make it seem more positive.

c) I've been taking action to try to make the situation better.

d) I've been concentrating my efforts on doing something about the child's problem.

Explain.....
.....
.....
.....
.....

2. " I've been turning to my friends, relatives, my church whenever I need help in taking care of the child"- **Social support**

a) I get emotional support from them

b) I get comfort and understanding from them

c) I've been getting help and advice from other people.

d) I've been trying to get advice or help from other people about what to do.

Explain.....
.....
.....
.....
.....

3. "I've been giving up the attempt to cope"- **Avoidant coping**

- a) Telling myself that this isn't real and my child will get better
- b) Refusing to believe that my child has a problem

Explain.....
.....
.....
.....

Appendix 3 – Beck Depression Inventory



V 0477

Beck Depression Inventory

CRTN: _____ CRF number: _____ Page 14 patient initials: _____

Baseline



Name: _____ Marital Status: _____ Age: _____ Sex: _____
 Occupation: _____ Education: _____

Instructions: This questionnaire consists of 21 groups of statements. Please read each group of statements carefully, and then pick out the **one statement** in each group that best describes the way you have been feeling during the **past two weeks, including today**. Circle the number beside the statement you have picked. If several statements in the group seem to apply equally well, circle the highest number for that group. Be sure that you do not choose more than one statement for any group, including Item 16 (Changes in Sleeping Pattern) or Item 18 (Changes in Appetite).

<p>1. Sadness</p> <p>0 I do not feel sad.</p> <p>1 I feel sad much of the time.</p> <p>2 I am sad all the time.</p> <p>3 I am so sad or unhappy that I can't stand it.</p> <p>2. Pessimism</p> <p>0 I am not discouraged about my future.</p> <p>1 I feel more discouraged about my future than I used to be.</p> <p>2 I do not expect things to work out for me.</p> <p>3 I feel my future is hopeless and will only get worse.</p> <p>3. Past Failure</p> <p>0 I do not feel like a failure.</p> <p>1 I have failed more than I should have.</p> <p>2 As I look back, I see a lot of failures.</p> <p>3 I feel I am a total failure as a person.</p> <p>4. Loss of Pleasure</p> <p>0 I get as much pleasure as I ever did from the things I enjoy.</p> <p>1 I don't enjoy things as much as I used to.</p> <p>2 I get very little pleasure from the things I used to enjoy.</p> <p>3 I can't get any pleasure from the things I used to enjoy.</p> <p>5. Guilty Feelings</p> <p>0 I don't feel particularly guilty.</p> <p>1 I feel guilty over many things I have done or should have done.</p> <p>2 I feel quite guilty most of the time.</p> <p>3 I feel guilty all of the time.</p>	<p>6. Punishment Feelings</p> <p>0 I don't feel I am being punished.</p> <p>1 I feel I may be punished.</p> <p>2 I expect to be punished.</p> <p>3 I feel I am being punished.</p> <p>7. Self-Dislike</p> <p>0 I feel the same about myself as ever.</p> <p>1 I have lost confidence in myself.</p> <p>2 I am disappointed in myself.</p> <p>3 I dislike myself.</p> <p>8. Self-Criticalness</p> <p>0 I don't criticize or blame myself more than usual.</p> <p>1 I am more critical of myself than I used to be.</p> <p>2 I criticize myself for all of my faults.</p> <p>3 I blame myself for everything bad that happens.</p> <p>9. Suicidal Thoughts or Wishes</p> <p>0 I don't have any thoughts of killing myself.</p> <p>1 I have thoughts of killing myself, but I would not carry them out.</p> <p>2 I would like to kill myself.</p> <p>3 I would kill myself if I had the chance.</p> <p>10. Crying</p> <p>0 I don't cry anymore than I used to.</p> <p>1 I cry more than I used to.</p> <p>2 I cry over every little thing.</p> <p>3 I feel like crying, but I can't.</p>
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V 0477

Beck Depression Inventory

CRTN: _____ CRF number: _____

Baseline

Page 15 patient initials: _____

11. Agitation

- 0 I am no more restless or wound up than usual.
- 1 I feel more restless or wound up than usual.
- 2 I am so restless or agitated that it's hard to stay still.
- 3 I am so restless or agitated that I have to keep moving or doing something.

12. Loss of Interest

- 0 I have not lost interest in other people or activities.
- 1 I am less interested in other people or things than before.
- 2 I have lost most of my interest in other people or things.
- 3 It's hard to get interested in anything.

13. Indecisiveness

- 0 I make decisions about as well as ever.
- 1 I find it more difficult to make decisions than usual.
- 2 I have much greater difficulty in making decisions than I used to.
- 3 I have trouble making any decisions.

14. Worthlessness

- 0 I do not feel I am worthless.
- 1 I don't consider myself as worthwhile and useful as I used to.
- 2 I feel more worthless as compared to other people.
- 3 I feel utterly worthless.

15. Loss of Energy

- 0 I have as much energy as ever.
- 1 I have less energy than I used to have.
- 2 I don't have enough energy to do very much.
- 3 I don't have enough energy to do anything.

16. Changes in Sleeping Pattern

- 0 I have not experienced any change in my sleeping pattern.

- 1a I sleep somewhat more than usual.
- 1b I sleep somewhat less than usual.

- 2a I sleep a lot more than usual.
- 2b I sleep a lot less than usual.

- 3a I sleep most of the day.
- 3b I wake up 1-2 hours early and can't get back to sleep.

17. Irritability

- 0 I am no more irritable than usual.
- 1 I am more irritable than usual.
- 2 I am much more irritable than usual.
- 3 I am irritable all the time.

18. Changes in Appetite

- 0 I have not experienced any change in my appetite.

- 1a My appetite is somewhat less than usual.
- 1b My appetite is somewhat greater than usual.

- 2a My appetite is much less than before.
- 2b My appetite is much greater than usual.

- 3a I have no appetite at all.
- 3b I crave food all the time.

19. Concentration Difficulty

- 0 I can concentrate as well as ever.
- 1 I can't concentrate as well as usual.
- 2 It's hard to keep my mind on anything for very long.
- 3 I find I can't concentrate on anything.

20. Tiredness or Fatigue

- 0 I am no more tired or fatigued than usual.
- 1 I get more tired or fatigued more easily than usual.
- 2 I am too tired or fatigued to do a lot of the things I used to do.
- 3 I am too tired or fatigued to do most of the things I used to do.

21. Loss of Interest in Sex

- 0 I have not noticed any recent change in my interest in sex.
- 1 I am less interested in sex than I used to be.
- 2 I am much less interested in sex now.
- 3 I have lost interest in sex completely.

Subtotal Page 2

Subtotal Page 1

Total Score

3 4 5 6 7 8 9 10 11 12 A B C D E

NR15645

Appendix 4–Informed Consent Explanation for study participants

I, Mary Anyango Otieno, an MSc Clinical Psychology student at the Department of Psychiatry, UON wish to conduct a study on the prevalence of depressive symptoms among caregivers of children with mental disorders attending the child psychiatry and youth centre clinics at Kenyatta National Hospital.

There are limited locally published research findings on the levels of depressive symptoms among caregivers of children with mental disorders. There is also a lack of information on the relationship between caregiver socio-demographic characteristics and depressive symptoms. At the health care facilities, the focus is often on the child and not the caregiver whose mental health determines the management of children with mental disorders.

This study aims to establish the magnitude of depressive symptoms among caregivers of children with mental disorders. This research will be carried out under the supervision of Dr. A. Obondo and Dr. R Kang'ethe who are both lectures at the U.O.N.

The study will involve individual interviews with caregivers of children with mental disorders on their socio-demographic characteristics and their depressive symptoms.

Voluntarism: Participation in this study is on a voluntary basis. A decision not to take part will not result in any penalty. If you agree to take part then you are free to withdraw at any given time. You are also free to decline to answer any questions that make you uncomfortable.

Confidentiality: All the information you give will remain anonymous and confidential. Each participant will be assigned a code and no names will appear on the questionnaires. All data is for academic purposes.

Risks: There are no known risks for participating in this study. You may however experience some anxiety as a result of the participation.

Benefits: No direct benefits will accrue from taking part in the study. The results of this study will be used for planning interventions that will benefit caregivers of children with mental disorders.

Contact: Questions or concerns about the study to me on 0733 293 579 or to any of my supervisors, Dr. A. Obondo or Dr. R. Kang'ethe or to the Department of Psychiatry, U.O.N. You may also forward any concerns to The Secretary, KNH/UON- Ethics and Research Committee- (Tel: 726300-9 or P.O. Box 20773, Nairobi.)

Appendix 5-Consent Form

I the undersigned do hereby agree/volunteer to participate in this study. Mary Anyango Otieno has fully explained to me the nature and purpose of the study.

I understand that all the information gathered will be used only for the purposes of the study.

Signature_____ Date_____

Caregiver_____

Serial No. _____

Signature_____ Date_____

Mary A. Otieno

Appendix 6 -Flow Chart

