

THE PREVALENCE OF ANXIETY AND DEPRESSION AMONG
CAREGIVERS OF HIV-POSITIVE CHILDREN

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
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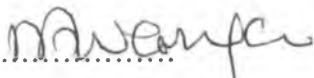
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DEDICATION

This work is dedicated to Children of God Relief Institute (COGRI), its founder, sponsors, workers, parents and well-wishers who continue to offer love and compassion to children. It is also dedicated to the children who courageously show desire to overcome the challenges associated with HIV infection. Finally, it is dedicated to all people of goodwill who in various ways seek to promote the welfare of disadvantaged persons through material, social, spiritual, psychological or intellectual development.

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ABBREVIATIONS

AIDS – Acquired Immune Deficiency Syndrome.

ARVs – Antiretroviral drugs.

BAI – Beck Anxiety Inventory

BAI-Y – A version of the Beck Anxiety Inventory that has been adapted for specific use among the youth

BDI – Beck Depression Inventory

BDI II - A second version of BDI that was developed to reflect revisions in the Fourth Edition Text Revision of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR)

CES-D – The Center for Epidemiological Studies Depression Scale

COGRI – Children of God Relief Institute.

DNA – Deoxyribonucleic Acid

DSM IV – Fourth Edition of the Diagnostic and Statistical Manual of Mental Disorders

DSM-IV-TR – Fourth Edition Text Revision of the Diagnostic and Statistical Manual of Mental Disorders

HIV – Human Immunodeficiency Virus.

KAIS - Kenya AIDS Indicator Survey

KDHS - Kenya Demographic and Health Survey

NCI – National Cancer Institute

OVC - Orphans and Vulnerable Children

PCR – Polymerase Chain Reaction

PMTCT – Prevention of Mother to Child Transmission

RNA – Ribonucleic acid

SES – Socio-economic Status

SPSS – Statistical Package for the Social Sciences

UNGASS – United Nations General Assembly Special Session on HIV and AIDS

UNICEF – United Nations Children’s Fund

UNAIDS – Joint United Nations Programme on HIV/AIDS

USAID – United States Agency for International Development.

WHO – World Health Organization

DEFINITION OF TERMS.

Caregiver – Any person, usually an adult who is involved in providing goods and services for the welfare of the HIV-positive child, including material and social support, and follows up the clinical management of the child. For this study, it is the person who brings the child to the clinic on the day of the interview.

Stigma – A negative, moral, or judgmental definition of a person that often aims to discredit, disgrace, or blame the person for any undesirable or discrediting attribute that the individual possesses, thus reducing that individual's status in the eyes of the society. Stigma includes real or imagined fear of societal attitudes and potential discrimination arising from a particular undesirable attribute, or the actual experience of discrimination with resultant negative consequences (Brown, Macintyre, and Trujillo 2003).

ABSTRACT

HIV/AIDS has changed from an acute disease to a chronic one due to comprehensive care accorded to those infected by the virus, especially due to the use of antiretroviral medicines (ARVs). One of the effects of HIV infection is that it predisposes people to and perpetuates anxiety and depression. Studies done in some parts of the world show that there is high prevalence of anxiety and depression among people infected or affected by HIV/AIDS. Many researches have been done regarding the welfare of adults suffering from HIV, but not much has been done regarding the caregivers of HIV-positive children. This study involved caregivers of HIV-positive children receiving comprehensive care at Lea Toto clinic in Kibera, Nairobi. The aim was to determine the prevalence of anxiety and depression among the caregivers. The study identified the socio-demographic details of each caregiver and then assessed the caregiver for features of anxiety and depression.

OBJECTIVES: The objectives of the study were to describe the socio-demographic profiles of caregivers of HIV-positive children, to determine prevalence of anxiety and depression among caregivers of children infected with HIV, and to determine the relationship between anxiety and depression and socio-demographic factors of caregivers.

STUDY DESIGN: Cross-sectional descriptive survey

METHOD: The study targeted all the eligible primary caregivers of children aged 2-18 years. The caregivers who fulfilled the inclusion criteria were recruited consecutively. The interviews took place in the months of May and June 2012.

The data collection tools were:

- a) A researcher-designed socio-demographic questionnaire.
- b) BAI – Beck Anxiety Inventory.
- c) BDI – Beck Depression Inventory.

DATA ANALYSIS: The data was entered into a computer using Statistical Package for the Social Sciences (SPSS) version 17 for analysis. The results were presented in tables, graphs and descriptive form.

RESULTS: A total of 228 caregivers were interviewed in the study. 30 (13.2%) were male while 198 (86.8%) were female. 67.5% of the caregivers were the biological parents of the children.

The study showed a high prevalence of anxiety and depression among the caregivers of HIV-positive children, a result that is consistent with studies done in other parts of the world. 68 (29.8%) of the caregivers had anxiety, 147 (64.5%) had depression and 67 (29.4%) had both anxiety and depression. Factors that had statistically significant association with anxiety were gender of a caregiver ($p = 0.024$), level of formal education ($p = 0.000$), family's monthly income ($p = 0.048$), and the existence of a child's biological parents ($p = 0.039$). Depression had a statistically significant association with a caregiver's gender ($p = 0.003$), occupation ($p = 0.027$), level of education ($p = 0.001$), family monthly income ($p = 0.041$), and provision of care to a child who was on ARVs ($p = 0.004$). The results also showed a high level of co-morbidity between anxiety and depression.

CONCLUSION: There is a high prevalence of both anxiety and depression among the caregivers of HIV-positive children, features that are associated with various socio-demographic characteristics like being female, having little or no formal education, and having a low or unreliable family income.

RECOMMENDATIONS: There needs to be better policies towards comprehensive care for HIV positive children that address the needs of their caregivers as well, in particular those aged 30-49 years, and those who are engaged in irregular, non-guaranteed casual labor.

CHAPTER 1

INTRODUCTION

1.1 BACKGROUND INFORMATION

The HIV/AIDS problem has been known in the world since 1981 when the first person was diagnosed with the infection. HIV is transmitted from one person to another mainly through body fluids like blood, semen, vaginal fluid and breast milk, by vertical transmission from a mother to her unborn baby, and through the use of contaminated cutting or piercing instruments like the needles and syringes used by intravenous drug users. In the early years of the pandemic, many of the people infected with the virus died because there were no medicines that acted directly against the HIV virus. However, since the discovery and use of ARVs begun, there has been a decline in the rate of death resulting from HIV infection.

Diagnosis of HIV infection is usually confirmed by laboratory tests. Antibody tests are useful for adults and any children above 18 months of age because by then maternal antibodies are expected to have left the child's body. However, HIV infection before the age of 18 months is confirmed either by polymerase chain reaction (PCR) or by checking for the viral RNA in the child's blood. The polymerase chain reaction is a scientific technique used to amplify a single copy or a few copies of a piece of DNA to generate thousands or millions of copies of a particular DNA sequence.

Many of the children born to HIV-positive mothers are not considered to be HIV-positive while they are below the age of 18 months. This is because most of them have only been investigated using antibody tests. Hence, for this study, only caregivers of children who were 2 years old or more were considered to be eligible for inclusion. Such caregivers were already verified to be caring for a child known to be confirmed HIV-positive.

There are difficulties associated with providing care for HIV-positive children, especially in the context of poverty and when the parents of the children are either in poor health status or dead. The caregivers of such children are usually older siblings, parents of the children, grand parents,

other relatives or other adults who are not relatives. Home-based care has become a central component of the response to the HIV/AIDS epidemic. While increasing interest has been paid to HIV/AIDS care with a focus on ailing adults and orphan foster care, the issue of caring for children living with HIV has received little attention (Hejoaka 2009).

There are certain significant issues that relate to this study on the prevalence of anxiety and depression among the caregivers of the HIV- infected children. These issues include the direct effects of HIV/AIDS on an infected individual and on his/her family, HIV-associated stigma, fear associated with HIV/AIDS infection, differences that exists between caregivers who are themselves HIV-positive and those who are either HIV- negative or do not know their HIV status, and the care burden differences between male and female caregivers. These significant issues have been explained in detail below.

1.1.1 DISEASE EFFECTS

Although it has been well established that a chronic childhood illness has implications for all family members and increases the likelihood of psychosocial impairment among family members, little is known about the parental adjustment to caring for an HIV-infected child. AIDS is unique in that it is a chronic and life-threatening illness that potentially can lead to the death of the entire family (Wiener, Riekert, Theut et al. 1995). Caring for a child with HIV/AIDS can be overwhelming and utterly exhausting, both emotionally and physically (Rose and Clark-Alexander 1999). Effective care-giving helps to sustain the physical and psychological well-being of children with HIV/AIDS, but only a few empirical studies have reported on the effect that this care-giving has on the caregivers themselves. Although a growing literature demonstrates that people in areas of sub-Saharan Africa hard hit by HIV/AIDS have experienced erosion of capital assets through loss of labour of both the ill person and their caregiver, and through treatment and funeral expenses, little is known about the experiences and perceptions of either those who provide the care, or those receiving care, despite the process often extending over several years and having a greater impact upon the livelihood security and well-being of the household than the actual death of the ill person (Thomas 2006).

Caregiver problems associated with HIV-positive children include isolation, shame, anger, stigmatization, ostracism, fear of disclosure, uncertainty, terminal illness, and preparation for the HIV-positive child's death (Hansell, Hughes, Caliandro et al. 1999). Some researchers have found that high work load, low social support, perception of the child as 'difficult', negative life events, child caretaking hassles, having many children in the family, high maternal age and having a child with a disability or a chronic health condition increase parenting stress (Potterton, Stewart and Cooper 2007).

In a situation where parents are HIV-positive, they must often cope with their own terminal illness in addition to that of their child/children. Deterioration in the health of the child and a caregiver's inability to handle material requirements worsen the situation, particularly because worries of the caretakers are frequently related to poverty (Brouwer, Lok, Wolffers, et al 2000). The HIV-positive parents face the challenge of parenting while struggling with a stigmatizing and life-threatening illness. This situation can be particularly stressful, especially if the children turn out to be troublesome. It is out of this scenario that some HIV-positive mothers have found it difficult to discipline their children appropriately for fear of being remembered after death as having been harsh and punitive (Kasese-Hara, Mayiseko, Modipa et al. 2008).

1.1.2 STIGMA

A major distinction between HIV/AIDS and other chronic or terminal illnesses is the stigma associated with the disease. According to Kristin Close, stigma could be defined as a negative, moral, or judgmental definition of a person or social situation that often aims to discredit, disgrace, blame, and to ascribe responsibility for certain conditions (Close 2009). Stigma could also be defined as an undesirable or discrediting attribute that an individual possesses, thus reducing that individual's status in the eyes of the society (Brown, Macintyre, and Trujillo 2003). HIV-related stigma adds an additional layer to the burden of care, causing tension between the secrecy surrounding the disease and the openness required in providing care and receiving social support. Tension between disclosure and concealment of the disease shapes the care-giving work and may hinder care by limiting potential social support. Since HIV/AIDS care is often shaped by secrecy, many caregivers not only face difficulties concealing the disease and the treatment but also have to justify regular visits to hospital.

1.1.3 FEAR

HIV/AIDS infection causes fear in many people due to various reasons, among them stigma, financial difficulties when a person is unable to work, deterioration of the body's general condition, and the threat of prolonged hospitalization or foreseeable death. Many mothers of HIV-infected children are afraid of telling their husbands, their relatives and community members when their children test HIV-positive. The mothers fear the reactions of those to whom they disclose the children's HIV-positive status. The reactions seem to vary depending on one's knowledge about AIDS and their opportunities to care for the HIV-infected person (Brouwer, Lok, Wolffers, et al 2000).

1.1.4 HIV-POSITIVE VERSUS HIV-NEGATIVE CAREGIVERS

Some caregivers of HIV-positive children are themselves people living with HIV, particularly the biological parents of the children. There is evidence from international research that the prevalence of depression and anxiety in people living with HIV or AIDS is higher than the prevalence of these disorders in HIV-negative controls (Thom 2009). For HIV-positive caregivers, HIV/AIDS is both a personal health crisis and a caregiver crisis. Not only must these HIV-positive caregivers focus on the needs of the ill child but must also cope with the experience of being ill from a progressive illness with an unpredictable course (Hansell, Hughes, Caliandro et al. 1999). In a study conducted in Florida, USA, the results showed that HIV-positive women exhibited a significantly higher rate of major depressive disorder and more symptoms of depression and anxiety than did a group of HIV-negative women with similar demographic characteristics (Morrison, Pettito, Have et al. 2002).

1.1.5 GENDER DIFFERENCES IN CARE BURDEN

Some studies have shown a gender difference in the experiences of burden among caregivers of chronically ill patients. In a Canadian study interviewing male and female family caregivers of demented patients, it was found that female caregivers had a 2.6 times higher odds for having a higher burden of care-giving. However, the odds ratio comparing women to men with respect to a high level of depressive symptoms was not significant (Gallicchio, Siddiqi, Langenberg et al. 2002). Here in Kenya, research has shown that the greater burden of caring for HIV-positive family members is shouldered by women and that difference is supported by cultural factors. In a

study conducted at Maseno, the researchers found out that there is a negative attitude, induced by socio-cultural factors, in the Kenyan community that hinder male involvement in caring for HIV-positive family members (Makori, Onyango, Kakai, et al. 2011).

In another study done in Uganda to assess the burden of care for male and female family caregivers of AIDS patients, it was found that the high burden of care-giving puts family caregivers at risk for a lower health status, social isolation and depression. However, both male and female caregivers reported similar care burden scores for the same responsibilities (Kipp, Tindyebwa, Karamagi et al. 2006)

1.2 STATEMENT OF THE PROBLEM

According to the Kenya National HIV and AIDS Estimates of 2010, the cumulative number of children infected with HIV was estimated to be 184,052 by 2009, indicating that HIV infection in children has been a growing problem in recent times (UNGASS 2010). The impact of the illness causes psychological effects in children and their caregivers, whether the caregivers are the biological parents of the children, other relatives of the children or other non-relative adults.

JUSTIFICATION

Statistics of HIV infection in the world today indicate that HIV is mainly affecting people who live in Sub-Saharan Africa. Most of the studies on the prevalence of anxiety and depression among caregivers of HIV-positive children have been conducted outside Kenya and hence there is a deficit of analyzed data from Kenya. In particular, the available data has not shown any specific study that targeted caregivers of HIV-positive children living in Nairobi. Hence this study aimed at providing data on the situation of caregivers of HIV-positive children in Nairobi.

RESEARCH QUESTIONS:

- (a) What are the socio-demographic profiles of caregivers of HIV-positive children?
- (b) What is the prevalence of anxiety disorders among caregivers of HIV-positive children?
- (c) What is the prevalence of depression among caregivers of HIV-positive children?
- (d) What is the association between anxiety disorders and socio-demographic factors of caregivers?
- (e) What is the association between depression and socio-demographic factors of caregivers?

HYPOTHESES

Null Hypothesis:

The caregivers of HIV-positive children do not suffer anxiety and depression.

Alternative hypothesis:

The caregivers of HIV-positive children suffer anxiety and depression.

OBJECTIVES

General objective:

To establish the prevalence of anxiety and depression among caregivers of HIV-positive children.

Specific objectives:

- i) To describe the socio-demographic profiles of caregivers of HIV-positive children.
- ii) To determine the prevalence of anxiety disorders among the caregivers.
- iii) To determine the prevalence of depression among the caregivers.
- iv) To determine the association between anxiety disorders and socio-demographic factors of caregivers.
- v) To determine the association between depression and socio-demographic factors of caregivers.

CHAPTER 2

LITERATURE REVIEW

The literature review has been carried out under the following sub-topics:

- i) HIV/AIDS statistics.
- ii) Caregivers of diverse backgrounds.
- iii) When the HIV-positive mother is the caregiver.
- iv) Grandmothers as caregivers.
- v) Prevalence of anxiety and depression.

2.1 HIV/AIDS STATISTICS

2.1.1 Global picture of HIV/AIDS.

UNAIDS estimates that there were 33.3 million people living with HIV globally at the end of 2009 compared to 26.2 million in 1999. The estimated number of children living with HIV increased to 2.5 million in 2009. Sub-Saharan Africa still bears an inordinate share of the global HIV burden, calculated at 22.5 million people, that is, 68% of the global total. East and Southern Africa remains the region most heavily affected by the HIV epidemic. Out of the total number of people living with HIV worldwide in 2009, 34% resided in 10 countries of Southern Africa (GLOBAL REPORT 2010). Statistics show that the HIV epidemic remains a major global public health challenge. In 2008 alone, 2.7 million people were newly infected with HIV (WHO, UNICEF, UNAIDS 2010).

The annual number of new HIV infections has been steadily declining since the late 1990s, and there are fewer AIDS-related deaths due to the significant scale-up of antiretroviral therapy over the past few years. The number of deaths among children is also declining. This trend reflects the steady expansion of services to prevent transmission of HIV to infants and an increase in access to treatment for children. The net effect of these factors is that the number of people living with HIV worldwide has increased (GLOBAL REPORT 2010). As more people gain access to antiretroviral therapy, there has been transition of HIV from an acute, terminal disease to a sub-

acute, chronic disease. This has produced significant implications regarding increased psychosocial and rehabilitation needs of the people who are infected or directly affected.

2.1.2 HIV in Kenya

According to the 2010 Kenyan report to United Nations General Assembly Special Session on HIV and AIDS (UNGASS 2010), the Kenya AIDS Indicators Survey of 2007 estimated the average HIV prevalence among the general population aged 15-49 at 7.4% while the Kenya Demographic and Health Survey (KDHS 2008-09) estimated prevalence for the same population at 6.3%. The estimated number of people living with HIV in 2010 was between 1.3 million and 1.6 million. New infections were estimated at 100,000 in 2009 for people over 15 years (UNGASS 2010).

The situation in Kenya reflects the global picture as described by UNAIDS. According to WHO, Kenya faces a severe, generalized HIV/AIDS epidemic that continues to have a devastating impact on all sectors of society (WHO 2005). The Ministry of Health in Kenya reported an adult prevalence of 13.5% in 2001, which declined to 10.2% in 2002 and then to 6.7% in 2005. An estimated 1.2 million people were living with HIV/AIDS in Kenya in 2005 (WHO 2005).

The number of HIV-infected children has also continued to rise in Kenya over the years. It was estimated that 22,259 children got newly infected in 2009. The number of children tested for HIV increased from 30,640 in 2008 to 49,344 in 2009. Pediatric treatment has also increased during the reporting period (from 13,000 children treated in 2007 to 20,517 in 2008 and 28,370 in 2009) covering about 24.2% of the children in need of ART (UNGASS 2010). It is estimated that more than 2.4 million Kenyan children were orphans in 2009, and half of them were orphans due to HIV and AIDS. With regard to support given to OVC, KAIS 2007 reported that 21.4% of the OVC lived in households that received at least one type of free external support to help the households care for the children, while the majority of OVC and their households (78.6%) had never received any kind of support (UNGASS 2010).

2.1.3 Deaths due to HIV/AIDS

At least 180,000 people died from AIDS annually as at 2005 (WHO 2005). More than 1.6 million Kenyan children younger than 15 years (3.7% of the total population) had been orphaned through the death of their mother (WHO 2005). Available statistics show that deaths among children younger than 15 years of age from AIDS-related illnesses are declining. The estimated 260,000 children who died from AIDS-related illnesses globally in 2009 were 19% fewer than the estimated 320,000 who died in 2004. In sub-Saharan Africa in 2009, an estimated 370,000 children [220,000–520,000] contracted HIV during the perinatal and breastfeeding period, down from 500,000 [320,000–670,000] in 2001 (GLOBAL REPORT 2010).

2.1.4 Effect of antiretroviral therapy (ARVs) on the HIV-associated death rate

The number of HIV-associated deaths has reduced over time mainly due to the use of antiretroviral therapy. At the end of 2009, 5.25 million people were reported to be receiving antiretroviral therapy in low and middle-income countries. This represents an increase of over 1.2 million people from December 2008, the largest increase in one year. Sub-Saharan Africa had the greatest increase in the absolute number of people receiving treatment in 2009, from 2,950,000 in December 2008 to 3,910,000 a year later. About 356,400 children less than 15 years of age were receiving antiretroviral therapy at the end of 2009, up from 275,300 at the end of 2008, an increase of 29% in one year. These children represented an estimated 28% [21–43%] of all children less than 15 years estimated to need antiretroviral therapy in low- and middle-income countries, up from 22% [16–34%] in 2008 and 7% [5–11%] in 2005 (WHO, UNICEF, UNAIDS 2010).

2.2 CAREGIVERS OF DIVERSE BACKGROUNDS

A study done by Felicity Thomas in Namibia showed an in-depth insight into intra-household experiences of long-term illness and caring for HIV positive people. Drawing upon research undertaken in the Caprivi Region of Namibia, the findings indicate that HIV/AIDS can have considerable adverse impacts on households (Thomas 2006). The information that has been recorded demonstrates that while compassion and sympathy towards the ill person are evident in

the early stages of illness, the long-term nature of HIV/AIDS makes caring a considerable burden upon household livelihood security. It also harms the intra-household relations as the patient's condition deteriorates over time. Hence the caregivers are prone to develop a form of fatigue after a long duration of supporting a chronically ill family member (Thomas 2006).

In a study of the psychosocial impact of HIV/AIDS, framed as a 'family infection' rather than looking only at the infected individual, DeMatteo, Wells, Goldie et al. (2002) showed a complex web of personal, health and family concerns. The study involved 101 adults who were members of 91 Canadian families, and who were known through their biological or care relationship to children known to be perinatally exposed to HIV (DeMatteo, Wells, Goldie et al. 2002). The study showed that the most significant contributors to parental and family stress included living with uncertainty, family finances, signs of illness (real or projected), medical tests or treatments, thinking about AIDS too much, raising children, condoms (their use or non-use), personal relationships and differences in how various family members dealt with HIV/AIDS.

The study also revealed that the parents of HIV-positive children had various personal challenges. The parents described the initial period following diagnosis as personally traumatic characterized by feelings of despair, anger, sadness, uncertainty and loss. One in five adults experienced separation or partner abandonment following diagnosis of HIV infection, with a similar number reporting emotional or physical abuse as an on-going concern. The parents worried about the financial, emotional and physical burden that care and guardianship of children would place on relatives, especially elderly parents (DeMatteo, Wells, Goldie et al. 2002).

Lv, Zhao, Li et al. (2010) conducted a study in rural China to examine the symptoms of depression among caregivers of rural AIDS orphans (i.e., children who had lost one or both of their parents to HIV/AIDS) and vulnerable children (i.e., children who were living with HIV-infected parents), and to explore factors associated with the presence of symptoms of depression among caregivers. Cross-sectional data was collected from 160 adult caregivers (parents, relatives, or other adults) from a rural area in China where many residents were infected with HIV through unhygienic blood collection. The Center for Epidemiological Studies Depression Scale (CES-D) was used to assess the symptoms of depression among the caregivers. The study

results indicated an elevated level of depression symptoms among caregivers of orphans and vulnerable children (OVC) and underscored the need for psychological support and intervention for their caregivers, especially for those with lower family socio-economic status (SES), and those from families with an adult or pediatric HIV infection. The data indicated that the depression symptoms were significantly higher among caregivers who had adult family members living with HIV in their households and who were also caring for HIV- infected children. The strong association between family SES and depression found in this study were consistent with the results of previous studies reporting that many households affected by HIV were experiencing significant financial hardship which might be an important contributor to caregiver anxiety and depression (Lv, Zhao, Li et al. 2010).

In 2010, Fawzi, Eustache, Oswald et al. did an analysis of baseline data collected from a pilot psychosocial support intervention for 492 young people (10-17 years old, 4% of whom were HIV-positive) and their 330 caregivers (of whom 88.7% were HIV-positive) in Haiti (Fawzi, Eustache, Oswald et al. 2010). The caregivers reported a high level of depressive symptoms, such as feeling low energy (73%), feeling that everything is an effort (71%), and sadness (69%). Parents' depressive symptoms were positively associated with their children's psychological symptoms and psychosocial functioning. Other prevalent symptoms included feeling lonely (59.7%), crying easily (47.5%), and feeling hopeless about the future (46.9%). Nearly 43% had feelings of worthlessness and over 19% of caregivers reported suicidal thoughts. The high level of anxiety experienced by the youth was coupled with a significant degree of depressive symptoms among their caregivers, nearly 89% of whom were HIV-positive and approximately 73% of whom were women. The study showed that the psychosocial functioning of youth can impact the levels of depression in their caregivers. These findings were observed despite all of the participants having access to free and comprehensive HIV treatment including antiretroviral therapy and hence suggest that there is an important role for interventions specifically designed to address anxiety, depression and parent – child relationships within the context of medical care of HIV-infected and affected people (Fawzi, Eustache, Oswald et al. 2010).

Wiener, Riekert, Theut et al. conducted a longitudinal study to assess parental adaptation to having a HIV-infected child in the Pediatric Branch of the National Cancer Institute (NCI),

Bethesda, Maryland, USA. The study aimed at finding out whether the levels of anxiety, depression, and anticipatory grief found during the initial assessment of caregivers remained consistent after a six month interval. 101 caregivers were invited to participate in this study, of whom 75% were the HIV-infected child's biological parent. Standardized scales were used to measure anxiety, depression, coping, and anticipatory grief (Wiener, Riekert, Theut et al. 1995). The results showed that the levels of anticipatory grief, depression, anxiety and self-blame remained consistently high over the six month period. In particular, depression scores indicated that 35% of the parents fell within the normal range, 36% were minimally depressed, 14% fell in the mild to moderately depressed range, and 15% scored above the moderately depressed range.

The findings indicated that parents of a HIV-infected child are at high risk for psychiatric distress and that this risk remains present over time (Wiener, Riekert, Theut et al. 1995). These findings also indicate that regardless of how ill the child currently is, the knowledge that HIV/AIDS is ultimately fatal places a heavy emotional burden upon the parents and results in increased levels of anticipatory grief, anxiety, and depression. Differences in coping were found to be associated with the age of the child at diagnosis (Wiener, Riekert, Theut et al. 1995). That is, if the HIV-positive diagnosis is made in infancy, the parents accept from the very beginning to live with a HIV-positive child. However, if the diagnosis is made in an older child, the parents have to adjust an already existing optimistic relationship towards the child and acknowledge the limitations placed in the life of the child by the HIV infection.

2.3 WHEN THE HIV-POSITIVE MOTHER IS THE CAREGIVER

A study by Fabienne Hejoaka in Bukina Faso was aimed at gaining understanding of the situation encountered by women mothering and caring for children and adolescents living with HIV in resource-limited countries. Based on ethnographic material gathered in Burkina Faso, it considered mothers' social experience of HIV/AIDS, and of providing care in a context of poverty where the access of the populations to health care is precarious and inequitable. It showed that in daily care mothers face many great challenges, ranging from the routine of pill-taking to disturbing discussions with children asking questions about their health or treatment (Hejoaka 2009).

Mothers caring for HIV-positive children have many difficulties to deal with. Since the effectiveness of antiretroviral drugs is dependent on the regularity of the treatment, precise hours are specified to ensure patients' adherence. The mothers' struggle to respect the physicians' recommendations and the time prescriptions creates anxiety-provoking situations. As part of caring for a HIV-positive child, a mother's work extends to include administration of medicines, a job that makes her a healthcare provider. However, when the child continues to be sick despite antiretroviral treatment, e.g., failure to gain weight and development of opportunistic infections, the mothers' work could be seen as suspect in terms of administration of the medicine. Such situations are emotionally difficult to endure particularly when the mother observes improvements in the health of other children during hospital visits (Hejoaka 2009).

Some mothers encounter transport problems in taking the children to clinics for regular reviews. Others are constantly concerned about the possibilities of transmission of the disease in the domestic space by exposure to blood through the common use of certain things, e.g., razor blades used to cut nails and needles used to fasten the hair. Other caregivers have problems in communicating with the children they care for, especially when it comes to disclosure of the HIV status of the child. One of the most common barriers to disclosing HIV status to children is adults' perceptions of children's inability to maintain secrecy. Caregivers often underestimate children's knowledge and understanding of HIV/AIDS and the stigmatization associated with it. Therefore, when children who are not expected to be aware of their status ask questions referring to HIV/AIDS, parents are particularly upset, and yet the decision of whether and how to disclose HIV status lies mostly with mothers or the primary caregivers (Hejoaka 2009).

In a study to examine the family structure and parenting challenges among mothers infected with HIV, Tompkins, Henker, Whalen et al. assessed the issues that were of concern to women from different ethnic backgrounds in Los Angeles (Tompkins, Henker, Whalen et al. 1999). Initial comparisons of the CES-D scores showed that the sero-positive women had greatly elevated depression scores compared to the non-infected women and that women who were mothers were more depressed than those with no children. The depression scores of 58% for the sero-positive women and 27% for the non-infected women were at clinically significant levels (Tompkins,

Henker, Whalen et al. 1999). However, despite the high figures showed by the results, the study showed that many people appreciate awareness of their HIV status even when the test is reactive. Although HIV/AIDS is a catastrophic illness, some mothers have said that their realization of their HIV-positive status has given them a new positive dimension in life. The knowledge is a motivating force that has called them to plan ahead and to get organized for the sake of their children's future, and improved relations with their significant others. As these mothers confront the possibilities of foreshortened lives and, for some, face guilt over their past actions, they are seeking and finding not only closer bonds with friends and family but also new meaning and renewed optimism in their lives. As one mother phrased it, "HIV is my life sentence, not a death sentence" (Tompkins, Henker, Whalen et al. 1999).

Kasese-Hara, Mayiseko, Modipa et al. (2008), conducted a study in Soweto, South Africa, aimed at investigating the differences between two groups of mothers, each with at least one child aged 3 years or less, regarding their concerns, depressive symptoms, life-events, and social standing. The study group comprised twenty mothers who were HIV-positive and were attending a HIV clinic for mothers and babies, while the control group comprised another twenty mothers who were either HIV-negative or did not know their status (and lived a seemingly normal life). The two groups were comparable in terms of demographic characteristics. The study revealed no significant difference between the two groups in all the variables included in the study. The results suggest that a positive HIV status is not a significant stressor in relation to the other stressors affecting mothers in Soweto (Kasese-Hara, Mayiseko, Modipa et al. 2008). Hence the lack of significant difference between the sample and control groups in relation to depression scores may be explained by most Soweto mothers' pervasive exposure to adversity (Kasese-Hara, Mayiseko, Modipa et al. 2008).

Potterton, Stewart and Cooper conducted a study to determine the extent of parenting stress in caregivers of children infected with HIV in South Africa. One hundred and twenty two consecutive HIV-positive children and their primary caregivers were enrolled in the study. The families that participated in this study came from very poor socio-economic backgrounds. Caregivers completed a demographic questionnaire and the Parenting Stress Index/ Short form at baseline and after 6 and 12 months. The analysis of the data indicated that parenting stress of

caregivers of young children infected with HIV is extremely high (Potterton, Stewart and Cooper 2007). High parenting stress levels in mothers could result from the fact that they are dealing with their own diagnosis, that of their child, as well as possibly their partner. Caregivers with higher levels of education, better housing and those who have fewer adults in the household were the ones who were most likely to experience decreased levels of parenting stress (Potterton, Stewart and Cooper 2007).

2.4 GRANDMOTHERS AS CAREGIVERS

Two measures of psychological health, i.e., depressed mood and anxiety, were examined in a sample of 90 women recruited from a number of diverse sites in USA (Musil 2010). The aim of the cross-sectional survey was to examine grand-parenting stresses, coping, social supports, and health in a sample of grandmothers who live with one or more grandchildren, and to examine whether differences exist between those with primary and those with partial responsibility for care-giving. The sampled women lived in the same home as one or more grandchildren and provided all or part of their care. The analysis of the data showed that grandmothers in both groups reported high depression and anxiety scores (Musil 2010).

2.5 PREVALENCE OF ANXIETY AND DEPRESSION

While healthy people experience a wide range of moods and feel in control of their mood and affect, people with mood disorders have a loss of that sense of control and a subjective experience of great distress. Recent surveys have shown that major depressive disorder has the highest lifetime prevalence (almost 17 percent) of any psychiatric disorder (Sadock and Sadock 2007). Anxiety disorders are also common in the general population and occur more frequently in women than in men (Sadock and Sadock 2007). Although everyone experiences some anxiety as an adaptive response that has lifesaving qualities, anxiety disorders occur when a person's response to a perceived threat becomes excessive and produces somatic, emotional, cognitive and behavioral features of distress.

There has been very little published research work done on the prevalence of anxiety and depression in Kenya. While the researcher has been able to get some data on the prevalence of anxiety and depression in Kenya among the people seeking health care services in different levels of healthcare institutions, the researcher has not come across any local data available on the prevalence of these conditions in the general population. One such study was a descriptive cross-sectional study conducted in 10 health facilities in Kenya by Ndetei, Khasakala, Kuria et al. (2009). The researchers sought to determine the prevalence of common psychiatric disorders in adult (aged 18 years and over) inpatients and outpatients seen in various Kenyan general hospitals. A total of 2,770 male and female inpatients and outpatients participated in the study. Although the doctors who were treating the patients had detected and documented mental illness in only 4.1% of all the patients studied, 42.3% of all the patients screened using the BDI had mild, moderate or severe symptoms of depression (Ndetei, Khasakala, Kuria et al. 2009).

In another study by Ndetei, Khasakala, Nyabola et al. (2008) carried out in order to establish the prevalence of anxiety and depressive symptoms and syndromes in Kenyan children and adolescents, it was shown that the prevalence rates of anxiety and depression symptoms and syndromes varied widely depending on sex and age, and on the different instruments used to carry out the study. The researchers examined 3,775 randomly sampled students drawn from a stratified sample of 34.7% of all public secondary schools in Nairobi, Kenya. In that study, clinical diagnostic scores for depression were recorded in 43.7% of all the students while anxiety was recorded in 12.9% of all students (Ndetei, Khasakala, Nyabola et al. 2008). The researchers concluded that there was a high level of anxiety and depression disorders in the study population.

Outside of Kenya, the researcher has found out that only a few studies have been carried out in Africa regarding the prevalence of anxiety and depression in the general population. In a study carried out in central Uganda regarding psychiatric disorders in two villages, it was found that 20% of all the adults had disorders just above threshold level, and a further 5% had more definite disorders (Orley, Blitt and Wing 1979). In that study, 206 out of the 221 adults living in two small Ugandan villages at the time of the study were examined using a standard psychiatric examination and standard methods of case identification and diagnosis. Most of the diagnosed conditions were depressive, but hypomanic and anxiety states were also represented (Orley, Blitt

and Wing 1979). In another study conducted in the Kabarole district of Western Uganda, Kasoro, Sebudde, Kabagambe-Rugamba et al. (2002) aimed at estimating the prevalence of psychiatric disorders in the district. Data collected from a random sample of 384 households showed an estimated prevalence of mental illness at 30.7% among adults (Kasoro, Sebudde, Kabagambe-Rugamba et al. 2002).

In a meta-analysis whose objective was to determine the efficacy of psychological treatments for depression and anxiety disorders in low and middle- income countries, Hof, Cuijpers, Waheed et al. (2011) established that on a global scale, approximately 150 million people suffer from a major depressive disorder at any moment, and almost a million commit suicide each year. According to the analyzed data, major depression was ranked as the fourth most disabling medical disorder worldwide in 1990 and 2002, and is expected to be the second most disabling disorder after HIV/AIDS in 2030 (Hof, Cuijpers, Waheed et al. 2011). This serious effect of depression is compounded by co-morbidity with anxiety. Studies have shown that there tends to be a high rate of co-morbidity between depression and anxiety such that many people who have depressive symptoms are also diagnosed with anxiety disorders (Gorman 1997).

CHAPTER 3

METHODOLOGY

3.1 STUDY DESIGN

A cross-sectional descriptive study.

3.2 STUDY AREA

The study was conducted at the Lea Toto clinic in Kibera which is one of the clinics under the Lea Toto program in Nairobi. The program provides comprehensive care to children below the age of 18 years. This includes newborns who are exposed to HIV before birth (that is, those born to HIV-positive mothers) and older children who have been confirmed to be HIV-infected. The children live in their homes with their primary caregivers. The Kibera clinic had 343 primary caregivers of HIV-positive children aged 2-18 years as at 11/10/2011.

Lea Toto program was established in 1998 to complement the work of Nyumbani Children's Home, the latter having been founded by the late Father Angelo D'Agostino in 1992 to provide a home for HIV-positive abandoned orphans. Lea Toto program started initially as a mobile outreach initiative in an effort to reach out to HIV-positive children within the slum communities in Nairobi. In September 1999, Lea Toto became a fully-fledged Community Home Based Care Program initially focusing on Kangemi slums and being funded by the United States Agency for International Development (USAID). At present, the program also depends on other well-wishers to finance some of the activities not fully funded by the USAID.

The overall goal of Lea Toto program is to mitigate the impact of HIV/AIDS and to decrease the risk of HIV transmission through the provision of a comprehensive home-based care package. Since June 2005, the program has incorporated similar activities in other areas of Nairobi, including Kibera and Kawangware. The activities of Nyumbani Children's Home and Lea Toto program are implemented under the common umbrella of Children of God Relief Institute (COGRI).

3.3 STUDY POPULATION

The study targeted primary caregivers of children who were already confirmed to be HIV-infected. Since many of the laboratory tests used to establish HIV infection are antibody based and they confirm the infection in a child only after 18 months of age, the researcher chose to use the age of 2 years and above as a criterion for selecting the children whose caregivers were eligible to participate in the study.

The study population thus constituted the caregivers of HIV-positive children aged 2-18 years and receiving services at the Kibera Lea Toto clinic during the duration of the study and who were willing to consent for the study.

Inclusion criteria:

- i) Caregiver must be over 18 years old.
- ii) Caregivers must be caring for a HIV-positive child aged 2-18 years and attending the Kibera Lea Toto clinic for services.
- iii) Caregiver must give consent.
- iv) Caregiver must be able to communicate in English or Kiswahili.

Exclusion criteria:

- i) Caregiver who is less than 18 years old.
- ii) Any caregiver who is not caring for a HIV-positive child aged 2-18 years and attending the Kibera Lea Toto clinic for services.
- iii) Caregiver not willing to participate voluntarily by giving consent.
- iv) Caregiver not able to communicate in English or Kiswahili.

3.4 SAMPLE SIZE

The expected total population of primary caregivers of children aged 2 to 18 years receiving services at Kibera Lea Toto clinic was 343 as at 11/10/2011. This was the figure in the records of the clinic. However, some of the children were taken to the clinic for services by non-adult caregivers who were not eligible to participate in the study.

The researcher chose to include all the caregivers in the study as long as they fulfilled the inclusion criteria and gave consent to participate in the study.

Hence the study participants were recruited consecutively until all the eligible caregivers were interviewed.

3.5 RECRUITMENT AND CONSENTING PROCEDURES

The researcher liaised with the Lea Toto clinic staff to notify the caregivers who brought the children to the clinic on any particular day during the study that there was a study going on at the clinic. The researcher requested to be allocated a place at the clinic for an opportunity to meet with each of the caregivers privately. The researcher then approached every eligible caregiver individually, introduced himself to the caregiver, and then explained to the caregiver the details of the study. At this point, any questions that a caregiver had regarding the study were addressed. Every caregiver who accepted the invitation to participate in the study was then requested to express that he/she had given consent by signing the consent form. Every caregiver who met the inclusion criteria was enrolled into the study. Every caregiver who did not meet the inclusion criteria, e.g., by being less than 18 years of age or declining to give consent, was thanked and left free to carry on with the other activities associated with the clinic visit.

For the caregiver who met the inclusion criteria, the interview proceeded. The researcher-designed socio-demographic questionnaire was administered first, then the BAI and then the BDI. Each of the above tools took an estimated five to ten minutes to administer. At the end of the interview, the caregiver was thanked and was told to carry on with the other activities associated with the clinic visit.

The researcher then approached another eligible caregiver, and repeated the above process until all the eligible and consenting caregivers were interviewed.

3.6 DATA COLLECTION PROCEDURE

The principal investigator conducted all the interviews of the research participants since the study had no research assistant.

The caregivers who fulfilled the inclusion criteria and signed the consent form were recruited consecutively and the interviews took place. The data collection instruments were completed by the researcher during the interview. The instruments were all filled in English or Kiswahili as they were available in both languages.

Initially, the researcher-designed socio-demographic questionnaire was administered.

Then the BAI and the BDI were administered.

The caregiver was then thanked for participating in the study.

3.7 VARIABLES

The dependent variable in this study was the presence of anxiety or depression, while the independent variable was caring for a HIV-positive child. The other variables included the age of a caregiver, gender of the caregiver, relationship of caregiver to the HIV-positive child, level of education of the caregiver, occupation of the caregiver, how long the caregiver had lived with the HIV-positive child, age of the HIV-positive child, whether the HIV-positive child was on ARVs or not, history of hospitalization of the child, and family monthly income of the caregiver.

3.8 DATA COLLECTION INSTRUMENTS

The data collection instruments included:

- i) A researcher-designed socio-demographic questionnaire that included data like caregiver's gender, age, education level, and relationship to the HIV-positive child.
- ii) BAI – Beck Anxiety Inventory.
- iii) BDI – Beck Depression Inventory.

These instruments were completed by the researcher during the interview.

3.8.1 Beck Anxiety Inventory (BAI).

The Beck Anxiety Inventory (BAI) was created by Aaron T. Beck and colleagues as a 21-item multiple-choice self-report inventory that measures the severity of anxiety in adults and adolescents for use in both clinical and research settings. Anxiety is the state of heightened, unpleasant, physical and emotional arousal caused, usually, by awareness of and attention to some feared consequence, condition, or perceived threat (Grant).

The BAI can be used to assess and establish a baseline anxiety level, as a diagnostic aid, to detect the effectiveness of treatment as it progresses, and to measure the post-treatment outcome. Because the items in the BAI describe the emotional, physiological, and cognitive symptoms of anxiety but not depression, it can help to discriminate anxiety from depression.

Advantages of the BAI include its fast and easy administration, repeatability, ability to highlight the connection between mind and body for those seeking help to reduce their anxiety, and its proven validity across languages, cultures, and age ranges (Grant).

Each of the items on the BAI is a simple description of a symptom of anxiety in one of its four expressed aspects:

- (1) subjective – feelings of discomfort and being unprepared to address the anticipated or current situation effectively, e.g., being unable to relax.
- (2) neurophysiologic – e.g., feeling of numbness, hyper-vigilance, and difficulty in concentrating.
- (3) autonomic – e.g., feeling hot, tachycardia and sweating.
- (4) panic-related – e.g., fear of losing control (Grant).

The BAI requires only a basic reading level and can be used with individuals who have intellectual disabilities. It can be completed in 5 - 10 minutes. Although the BAI may be administered and scored by paraprofessionals, it should be used and interpreted only by professionals with appropriate clinical training and experience.

When administering the BAI, respondents are asked to report the extent to which they have been bothered by each of the 21 symptoms in the week preceding (including the day of) their completion of the BAI. Each of the symptoms has four possible answer choices:

- a) Not at all (value =0)
- b) Mildly (value = 1), meaning “it did not bother me much”
- c) Moderately (value = 2), meaning “it was very unpleasant, but I could stand it”
- d) Severely (value = 3), meaning “I could barely stand it”

All the values of the various items are summed up giving a total score that ranges between 0 and 63 points. Interpretation of the level of anxiety is classified as follows:

- i) A score of 0 - 7 is interpreted as a minimal level of anxiety.
- ii) A score of 8 - 15 is interpreted as mild anxiety
- iii) A score of 16 - 25 is interpreted as moderate anxiety
- iv) A score of 26 - 63 is classified as severe anxiety

Clinicians examine specific item responses to determine whether the symptoms appear mostly subjective, neurophysiologic, autonomic, or panic-related. The clinician can then further assess using DSM-IV criteria to arrive at a specific diagnostic category and plan the necessary interventions. For clinical purpose, the total score falls into three ranges of the Beck Anxiety Inventory scoring system:

- a) A score ranging from 0 to 21 indicates a low anxiety level.
- b) A score ranging from 22 to 35 is an indication of a moderate level of anxiety. This indicates that the individual is suffering from stress that should be alleviated by using stress management techniques and relaxation methods.
- c) A score ranging from 36 to 63 indicates a high level of anxiety. It is an indication that the person generally needs to seek professional help (Hurley 2006)

BAI has been adapted for specific use among the youth as an inventory called the BAI-Y, which consists of twenty self report items rated on a three point scale that assess a child's fears, worrying, and physiological symptoms associated with anxiety.

3.8.2 Beck Depression Inventory (BDI).

Beck Depression Inventory (BDI), also called Beck Scale of Depression, is named after Aaron Beck, an expert and initiator of cognitive therapy who designed the scale. The Beck Depression Inventory is a scientific test used to measure the presence and severity of depression symptoms consistent with the criteria of the DSM-IV. The BDI helps to assess the intensity of depression in both adults and adolescents who are 13 years old or over on a self report scale. Although it is not meant to serve as an instrument of diagnosis, it is useful in research and for the evaluation of effectiveness of depression therapies and treatments. The BDI has been shown to be valid and

reliable although the test scores can be manipulated by a testing person if he/she decides not to give correct answers.

The BDI was originally developed to detect, assess, and monitor changes in depressive symptoms among people in a mental health-care setting but it is also used to detect depressive symptoms in a primary care setting. The BDI usually takes between five and ten minutes to complete as part of a psychological or medical examination (Polgar 2011). The BDI is designed for use by trained professionals although it can be self-administered.

The BDI was developed in 1961, adapted in 1969, and copyrighted in 1979. A second version of the inventory (BDI-II) was developed to reflect revisions in the Fourth Edition Text Revision of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) (Polgar 2011).

The long form of the BDI is composed of 21 questions or items, each with four possible responses. Each response is assigned a score ranging from zero to three, indicating the severity of the symptom (Polgar 2011). Individual questions of the BDI assess mood, pessimism, sense of failure, self-dissatisfaction, guilt, punishment, self-dislike, self-accusation, suicidal ideas, crying, irritability, social withdrawal, indecisiveness, body image, work difficulties, insomnia, fatigue, appetite, weight loss, bodily preoccupation, and loss of libido. Items 1 to 13 assess symptoms that are psychological in nature, while items 14 to 21 assess more physical symptoms. A shorter form of BDI is composed of seven questions and is designed for administration by primary care providers. BDI has been found to be efficient in assessing and evaluating the severity of depression in people since it covers both the emotional and physiological aspects of depression.

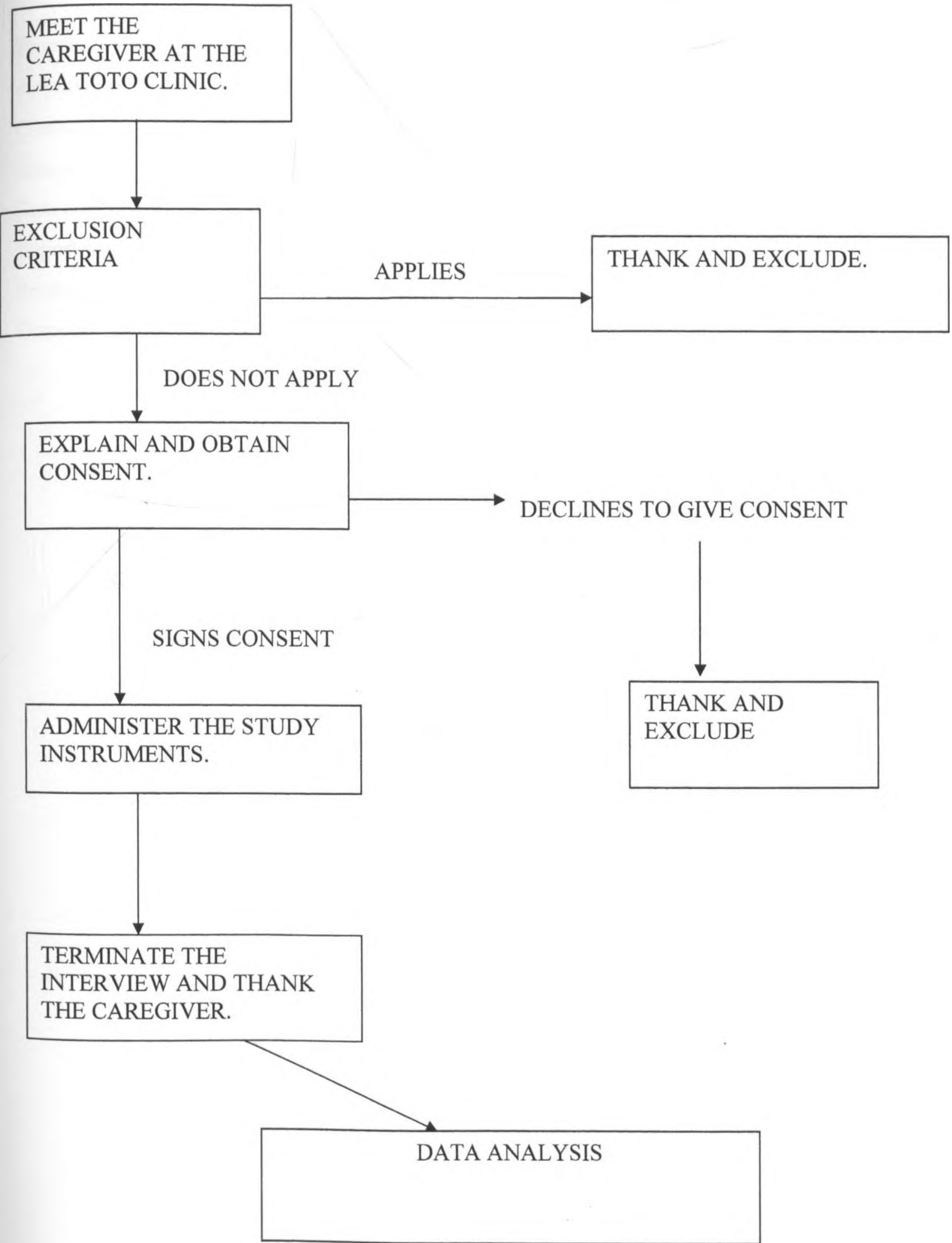
Interpretation of BDI results – The sum of all BDI item scores indicates the severity of depression. The test is scored differently for the general population and for individuals who have been clinically diagnosed with depression. For the general population, a score of 21 or over represents depression. However, for people who have been clinically diagnosed, scores are interpreted as follows:

- a) 0 to 9 represent minimal depressive symptoms,
- b) 10 to 16 indicate mild depression,

- c) 17 to 29 indicate moderate depression
- d) 30 to 63 indicate severe depression.

The BDI can distinguish between different subtypes of depressive disorders, such as major depression and dysthymia (a less severe form of depression) (Polgar 2011).

3.9 FLOW CHART



3.10 TIME SCHEDULE FOR THE STUDY:

Proposal development:	February 2011 – December 2011.
Approval by the department of Psychiatry:	December 2011.
Clearance by Ethics committee:	January 2012 – May 2012.
Data collection:	May 2012 – June 2012.
Data analysis:	June 2012.
Report writing:	June 2012 – July 2012.
Presentation:	July 2012.
Corrections:	July 2012.

ETHICAL CONSIDERATIONS

After obtaining permission to carry out the study from the department of Psychiatry of the University of Nairobi, the researcher sought approval from the Ethics Committee of Kenyatta National Hospital and also obtained permission from the board of Children of God Relief Institute (COGRI).

All the respondents in the study were provided with the details of the research and relevant information regarding the researcher, including his telephone contact, before having their consent obtained. They were informed that participation in the study was voluntary. The consent form was explained to them and they were informed that they would not be victimized for declining to participate or for withdrawing from the study. The respondents were assured that all information gathered in the research was to be treated confidentially. They were also notified that there would be no material or financial gain arising from participation in the study.

The respondents were informed that the study did not involve invasive procedures. The study did not predispose the respondents to any physical discomfort or injury and hence there was no significant risk to the respondent.

One of the benefits of the study was that it was hoped that the results would be helpful to future medical practice, and help in improving the welfare of people who take care of HIV-positive children.

DATA MANAGEMENT AND STATISTICAL ANALYSIS

The data was checked for completeness, coded and then entered into a computer using Statistical Package for Social Sciences (SPSS) version 17. The data was analyzed by applying differential and inferential statistics.

The presence of anxiety or depression was correlated with the various variables, including the age of caregiver, gender of the caregiver, relationship of caregiver to the HIV-positive child, level of education of caregiver, occupation of caregiver, how long the caregiver has lived with the HIV-positive child, age of the HIV-positive child, whether the HIV-positive child was on ARVs or not, history of hospitalization of the child, and family monthly income of the caregiver.

The results were then presented in tables, graphs and descriptive form.

CHAPTER 4

RESULTS

A total of 228 caregivers were interviewed in the study after which the data was entered into the computer and analyzed using Statistical Package for the Social Sciences (SPSS) version 17. Based on various socio-demographic characteristics, the caregivers were divided into different groups for the purposes of data analysis.

4.1 SOCIO-DEMOGRAPHIC CHARACTERISTICS

Of all the caregivers, 30 (13.2%) were male while 198 (86.8%) were female. They ranged in age between 18 and 66 years, with the majority being aged 30 to 49 years. Most of the caregivers were the biological parents of the children. Most of the caregivers had some formal education, although only 9 (3.9%) had tertiary education.

Although most of the caregivers had some form of employment or were self-employed, nearly half of the families of caregivers had an average monthly income of KSh 5,000 or less.

Most of the caregivers had lived with a HIV-positive child for more than 5 years although only 65 (28.5%) of the children were aged 11 years or more. These caregivers included the biological parents who had lived with the children since the children were born. Most of the children had at least one of their biological parents as a caregiver while 42 (18.4%) of the children were total orphans.

Most of the children under care had never been admitted in hospital, and over 90% of them did not have any HIV-positive sibling. 198 (86.8%) of the children were using ARVs at the time of the study and 74 (32.5%) of the children had already had their HIV-positive status disclosed to them.

The socio-demographic characteristics that describe the caregivers as individual persons are shown below in table 1, while the characteristics that describe the caregiver in relation to the child under care are shown in table 2.

Table 1: Socio-demographic characteristics of caregivers

	Frequency:		Total	Percentage (%) of total (N=228)
	Male	Female		
Gender				
Male			30	13.2
Female			198	86.8
Age of caregiver				
29 years and below	1	56	57	25.0
30-49 years	22	126	148	64.9
50 years and above	7	16	23	10.1
Level of Education				
None	0	15	15	6.6
Primary	18	137	155	68.0
Secondary	11	38	49	21.5
Tertiary	1	8	9	3.9
Occupation of caregiver				
Employed	5	15	20	8.8
Self employed	19	73	92	40.4
Casual	5	64	69	30.3
None	1	46	47	20.6
Family monthly income (in KShs.)				
Less than 5,000	12	100	112	49.1
5001 – 10,000	15	64	79	34.6
10,001 – 15,000	0	12	12	5.3
More than 15,000	3	22	25	11.0

Table 2: Characteristics of caregivers in relation to a HIV-positive child

	Frequency:		Total	Percentage (%) of total (N=228)
	Male	Female		
Relationship to child				
Parent	21	133	154	67.5
Step parent	0	8	8	3.50
Uncle/aunt	4	37	41	18.0
Grand parent	1	10	11	4.8
Sibling	3	8	11	4.8
Non-relative adult	1	3	3	1.3
Duration of living with the HIV-positive child				
5 years and below	5	75	80	35.1
6 – 10	15	88	103	45.2
11 years and above	10	35	45	19.7
Age of HIV-positive child				
5 years or less	2	48	50	21.9
6 – 10 years	16	97	113	49.6
11 years and above	12	53	65	28.5
Existence of child's parents				
Both alive	13	71	84	36.8
Single mother	1	75	76	33.3
Single father	12	14	26	11.4
Orphan	4	38	42	18.4
Child's history of hospitalization				
None	16	110	126	55.3
Once	7	51	58	25.4
2 times	1	21	22	9.6
3 times	4	9	13	5.7
4 and more times	2	7	9	3.9
Duration of latest hospitalization				
None	16	110	126	55.3
1 – 14 days	9	59	68	29.8
15 – 30 days	5	17	22	9.6
More than 30 days	0	12	12	5.3
Number of known HIV-positive siblings				
None	26	181	207	90.8
one	4	17	21	9.2
Whether the HIV-positive child is on ARVs				
Yes	27	171	198	86.8
No	3	27	30	13.2
Disclosure of HIV status to child				
Yes	15	59	74	32.5
No	15	139	154	67.5

4.2 PREVALENCE OF ANXIETY

The results showed that 68 (29.8%) of the caregivers had anxiety according to their BAI score. Of these, 60 (26.3%) had moderate anxiety while 8 (3.5%) of the caregivers had a high level of anxiety. The other 160 (70.2%) caregivers had no anxiety.

Table 3: Prevalence of anxiety

Anxiety level	BAI Score	Number (N)	Percentage (%)
Very low	0 - 21	160	70.2
Moderate	22 - 35	60	26.3
High	36 and above	8	3.5

4.3 ASSOCIATION BETWEEN THE PREVALENCE OF ANXIETY AND CHARACTERISTICS OF CAREGIVERS

Pearson's chi square test was applied to determine association between anxiety and depression and the socio-demographic characteristics of the caregivers. It was found that the gender of a caregiver, level of formal education, family's monthly income, and the existence of a child's biological parents had a statistically significant association with the presence of anxiety. 13.3% of the male caregivers had anxiety compared to 32.3% of the female caregivers ($p = 0.024$). As the level of education improved, the prevalence of depression decreased. Among the caregivers who had no formal education, 10 (66.7%) had anxiety while none of the caregivers with tertiary level education had anxiety ($p = 0.000$). 38.4% of the caregivers who had a monthly income of KSh. 5000 or less had anxiety while only 24% of the caregivers with a family monthly income of more than KSh. 15000 had anxiety ($p = 0.048$). Caring for a child who had only a single mother as the living parent was associated with a 42.1% prevalence of anxiety ($p = 0.039$).

Certain characteristics did not show any statistically significant association with presence of anxiety in the caregivers. These were the age of caregiver, occupation of the caregiver, duration of having lived with the HIV-positive child, relationship of caregiver to the child under care, age of the child under care, whether or not disclosure (of HIV-positive status) had been done to the child under care, and whether the child was taking ARVs or not. Those caregivers who were engaged in casual work rather than regular employment had the highest level of anxiety at 42%. Despite the level of anxiety increasing alongside the increase in the length of time that the caregiver had lived with the HIV-positive child, the association was not statistically significant.

Table 4: Association between anxiety and socio-demographic characteristics of a caregiver

	Anxiety			X ² (df)	P-value
	Yes	No	(N)		
Age					
Over 29 years	13 (22.8%)	44 (77.2%)	57	2.257 (2)	0.324
30 – 49 years	49 (33.1%)	99 (66.9%)	148		
50 years and above	6 (26.1%)	17 (73.9%)	23		
Level of education					
None	10 (66.7%)	5 (33.3%)	15	19.908 (3)	0.000*
Primary	51 (32.9%)	104 (67.1%)	155		
Secondary	7 (14.3%)	42 (85.7%)	49		
Tertiary	0 (0%)	9 (100%)	9		
Monthly income in KSh.					
Less than 5000	43 (38.4%)	69 (61.6%)	112	7.925 (3)	0.048*
5001 – 10000	16 (20.3%)	63 (79.7%)	79		
10001- 15000	3 (25%)	9 (75%)	12		
More than 15000	6 (24%)	19 (76%)	15		
Gender of caregiver					
Male	4 (13.3%)	26 (86.7%)	30	4.489(1)	0.024*
Female	64 (32.3%)	134 (67.7%)	198		
Occupation of caregiver					
None	11 (23.4%)	36 (76.6%)	47	7.373 (3)	0.061
Casual	29 (42.0%)	40 (58.0%)	69		
Self employed	22 (23.9%)	70 (76.1%)	92		
Employed	6 (30%)	14 (70%)	20		

* means the association is statistically significant (below 0.05).

Table 5: Association between anxiety and other characteristics (of a caregiver) that relate specifically to care-giving

	Anxiety			X ² (df)	P-value
	Yes	No	(N)		
Duration of living with HIV-positive child					
5 years or less	20 (25.0%)	60 (75.0%)	80	1.672	0.433
6 – 10 years	32 (31.1%)	71 (68.9%)	103	(2)	
11 years and above	16 (35.6%)	29 (64.4%)	45		
Whether child is on ARVs					
Yes	55 (27.8%)	143 (72.2%)	198	3.012	0.067
No	13 (43.3%)	17 (56.7%)	30	(1)	
Disclosure of HIV status to child					
Yes	23 (31.1%)	51 (68.9%)	74	0.83 (1)	0.444
No	45 (29.2%)	109 (70.8%)	154		
Relationship with child					
Parent	48 (31.2%)	106 (68.8%)	154	5.405	0.368
Grandparent	4 (36.4%)	7 (63.6%)	11	(5)	
Step parent	1 (12.5%)	7 (87.5%)	8		
Sibling	1 (9.1%)	10 (90.9%)	11		
Uncle/aunt	14 (34.1%)	27 (65.9%)	41		
Non-relative adult	0	3 (100%)	3		
Existence of child's parents					
Both parents alive	19 (22.6%)	65 (77.4%)	84	8.391	0.039*
Single mother	32 (42.1%)	44 (57.9%)	76	(3)	
Single father	6 (23.1%)	20 (76.9%)	26		
None (child an orphan)	11 (26.2%)	31 (73.8%)	42		
Age of HIV-positive child					
5 years or less	12 (24.0%)	38 (76.0%)	50	1.317	0.518
6 – 10 years	34 (30.1%)	79 (69.9%)	113		
11 years and above	22 (33.8%)	43 (66.2%)	65		

* means the association is statistically significant (below 0.05)

4.4 PREVALENCE OF DEPRESSION

The results of the study showed that 147 (64.5%) of the caregivers had depression. Of these, 48 (21.1%) had mild depression, 72 (31.6%) had moderate depression while 27 (11.8%) had severe depression. The other 81 (35.5%) had no depression.

Table 6: Prevalence of depression

Depression level	BDI Score	Number (N)	Percentage (%)
Minimal	0 - 9	81	35.5
Mild	10 -16	48	21.1
Moderate	17- 29	72	31.6
Severe	30 - 63	27	11.8

4.5 ASSOCIATION BETWEEN THE PREVALENCE OF DEPRESSION AND CHARACTERISTICS OF CAREGIVERS

The results showed that presence of depression had a statistically significant association with gender ($p = 0.003$), occupation ($p = 0.027$) and level of education ($p = 0.001$) of a caregiver, a caregiver's family monthly income ($p = 0.041$), and the fact that a child under care was on ARVs ($p = 0.004$). High prevalence of depression was noted in female caregivers, caregivers who do casual labor, those who have no formal education, those whose family income does not exceed KSh. 5,000 per month and those who take care of children that are not yet taking ARVs.

The presence of depression had no statistically significant relationship with the age of a caregiver, relationship of the caregiver to the child, duration of living with a HIV-positive child, disclosure of HIV status to the child, existence of the HIV-positive child's parents or the child's age. However, the level of depression seemed to increase alongside the increase in the age of the child and the duration of caring for that child. The caregivers of children who have only a mother as their living parent had the highest level of depression. Of all the caregivers, step parents had the highest prevalence of depression while non-relative adults had the lowest.

Table 7: Association between depression and socio-demographic characteristics of caregiver

	Depression			X ² (df)	P-value
	Yes	No	(N)		
Age					
29 years or less	36 (63.2%)	21 (36.8%)	57	1.940(2)	0.379
30 – 49 years	99 (66.9%)	49 (33.1%)	148		
50 years and above	12 (52.2%)	11 (47.8%)	23		
Level of education					
None	12 (80%)	3 (20%)	15	16.44 (3)	0.001*
Primary	110 (71%)	45 (29%)	155		
Secondary	22 (44.9%)	27 (55.1%)	49		
Tertiary	3 (33.3%)	6 (66.7%)	9		
Monthly income in KSh.					
Less than 5000	82 (73.2%)	30 (26.8%)	112	8.241(3)	0.041*
5001 – 10000	46 (58.2%)	33 (41.8%)	79		
10001- 15000	7 (58.3%)	5 (41.7%)	12		
More than 15000	12 (48.0%)	13 (52.0%)	25		
Gender					
Male	12 (40%)	18 (60%)	30	9.034 (1)	0.003*
Female	135 (68.2%)	63 (31.8%)	198		
Occupation of caregiver					
None	32 (68.1%)	15 (31.9%)	47	9.146 (3)	0.027*
Casual	53 (76.8%)	16 (23.2%)	69		
Self employed	50 (54.3%)	42 (45.7%)	92		
Employed	12 (60%)	8 (40%)	20		

* means the association is statistically significant (below 0.05)

Table 8: Association between depression and other characteristics (of a caregiver) that relate specifically to care-giving

	Depression			X ² (df)	P-value
	Yes	No	(N)		
Duration of living with HIV-positive child					
5 years or less	45 (56.3%)	35 (43.8%)	80	3.639 (2)	0.162
6 – 10 years	71 (68.9%)	32 (31.1%)	103		
11 years and above	31 (68.9%)	14 (31.1%)	45		
Child on ARVs					
Yes	121 (61.1%)	77 (38.9%)	198	7.428 (1)	0.004*
No	26 (86.7%)	4 (13.3%)	30		
Disclosure of HIV status to child					
Yes	47 (63.8%)	27 (36.5%)	74	0.044 (1)	0.473
No	100 (64.9%)	54 (35.1%)	154		
Relationship with child					
Parent	105 (68.2%)	49 (31.8%)	154	9.100 (5)	0.105
Grandparent	7 (63.6%)	4 (36.4%)	11		
Step parent	7 (87.5%)	1 (12.5%)	8		
Sibling	4 (36.4%)	7 (63.6%)	11		
Uncle/aunt	23 (56.1%)	18 (43.9%)	41		
Non-relative adult	1 (33.3%)	2 (66.7%)	3		
Existence of child parents					
Both parents alive	53 (63.1%)	31 (36.9%)	84	5.152 (3)	0.161
Single mother	56 (73.7%)	20 (26.3%)	76		
Single father	14 (53.8%)	12 (46.2%)	26		
None (child an orphan)	24 (57.1%)	18 (42.9%)	42		
Age of HIV-positive child					
5 years or less	32 (64%)	18 (36%)	50	0.432 (2)	0.806
6 – 10 years	71 (62.8%)	42 (37.2%)	113		
11 years and above	44 (67.7%)	21 (32.3%)	65		

* means the association is statistically significant (below 0.05)

4.6 ASSOCIATION BETWEEN THE PRESENCE OF ANXIETY AND THE PRESENCE OF DEPRESSION AMONG THE CAREGIVERS

The results showed a statistically significant association between anxiety and depression. 80 out of 81 (98.8%) of all the people who had anxiety also had depression.

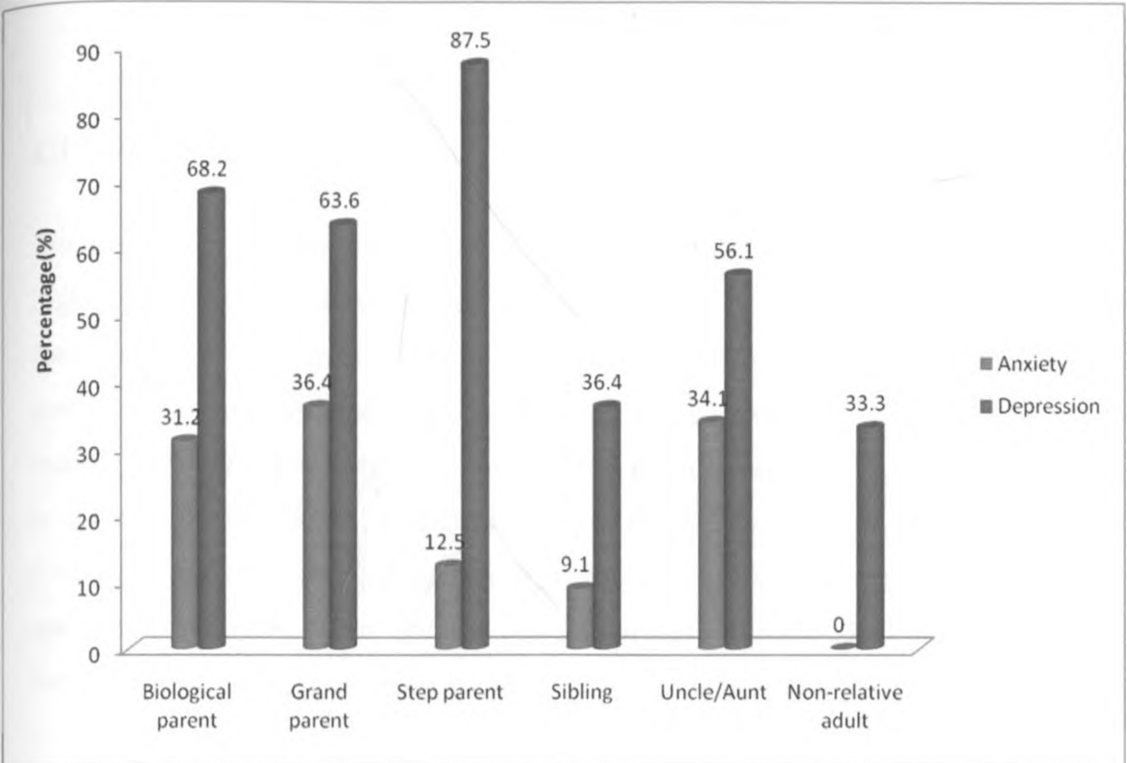
Table 9: Association between anxiety and depression

	Anxiety		X ² (df)	P value
	Yes	No		
Depression				
Yes	67(45.6%)	80(54.4%)	49.065 (1)	0.000*
No	1(1.2%)	80(98.8%)		

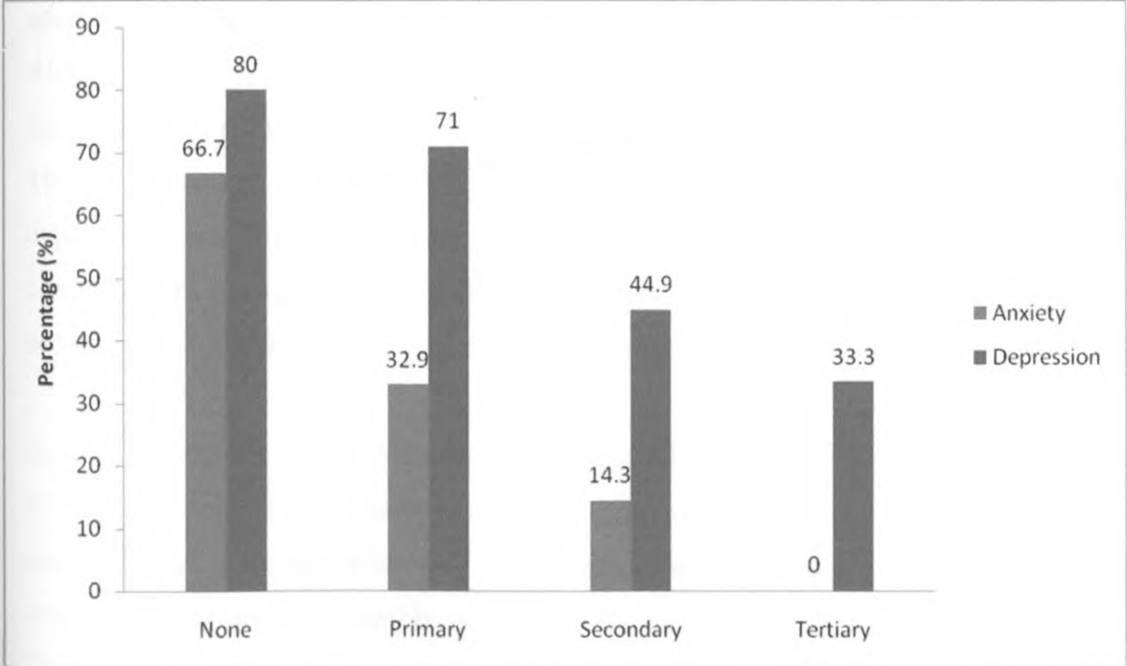
* means the association is statistically significant (below 0.05)

There are two bar graphs that elaborate the comparative prevalence of anxiety and depression among the caregivers, and the relative effect of formal education on the prevalence of the two conditions.

Graph 1: Relationship of caregiver to the HIV-positive child



Graph 2: Association between level of education and prevalence of anxiety and depression



CHAPTER 5

DISCUSSION

The results of this study conducted at the Kibera clinic of Lea Toto program, Nairobi, show a high prevalence of anxiety and depression among the caregivers of HIV-positive children. The findings suggest that many of the caregivers, majority of who live in the Kibera slum and its surroundings, manifest the features of anxiety and depression. The results also showed that anxiety and depression were closely associated with the stressful life conditions of being infected or affected by HIV/AIDS, particularly in the face of poverty and stigma. Some of the socio-demographic factors showed statistically significant association with the prevalence of anxiety and depression, some factors showed association that was not statistically significant, while some factors did not show any association at all.

The results from this study are consistent with studies in other parts of the world that have reported similarly high burdens of anxiety and depression. A study conducted in Haiti reported depressive symptoms in 73% of caregivers (Fawzi, Eustache, Oswald et al. 2010). Another study conducted at Bethesda, USA, showed a depression score of 65% among the caregivers (Wiener, Riekert, Theut et al. 1995) and a study in Los Angeles reported depression scores of 58% for the sero-positive women and 27% for the non-infected women (Tompkins, Henker, Whalen et al. 1999). This study results show that the caregivers had a higher prevalence of anxiety and depression than the general Kenyan population, as shown by previous studies that were conducted in different health facilities (Ndetei, Khasakala, Kuria et al. 2009) and in public secondary schools (Ndetei, Khasakala, Nyabola et al. 2008).

Among the reasons for the high prevalence of anxiety and depression could have been poverty among the caregivers and marital problems (especially where many female caregivers are single mothers). Caring for the children of single mothers was associated with the highest levels of both anxiety and depression, possibly because the single mothers were both HIV-positive and poor. This means that the single mother would be the primary caregiver to her HIV-positive child or another person could be taking care of the HIV-positive child and possibly of the child's mother as well. The male: female ratio of 1: 6.6 among the interviewed caregivers showed that most of

the caregivers bringing children to the clinic were female, whether the caregivers were parents, siblings or other adults. This finding of having more females than males as caregivers is consistent with some other studies; for example, a study done at Bethesda (Maryland, USA) had 80% of the parents being female and showed a prevalence of depression at 65% (Wiener, Riekert, Theut et al. 1995).

In situations where both parents of the HIV-positive child were alive, the child was highly likely brought to the clinic by a female caregiver (71 out of 84 children, or 84.5% of the times). Any child who had only one parent alive (whether mother or father), or a child who was a total orphan, still had the higher probability of being brought to the clinic by a female caregiver. The great gender disparity, which expressed a predominant female involvement, in caring for the HIV-infected persons had also been noted in other studies conducted at Maseno, Kenya (Makori, Onyango, Kakai, et al. 2011), and western Uganda (Kipp, Tindyebwa, Karamagi et al. 2006).

The study showed that of all the caregivers, the non-relative adults had the lowest prevalence of both depression and anxiety followed by siblings of the HIV-positive child. Biological parents, most of whom were HIV-positive themselves, did not have significantly different prevalence rates for either depression or anxiety compared to grandparents, step-parents, aunts or uncles. This result suggests that a positive HIV status may not be the most significant stressor for the caregivers in relation to the other stressors. A similar conclusion was found in another study conducted in Soweto, South Africa, that aimed at investigating the differences between a group of HIV-positive mothers and another group of mothers who were either HIV-negative or did not know their status (Kasese-Hara, Mayiseko, Modipa et al. 2008).

Caregivers aged 30-49 years formed the group that was most involved in taking children to the clinic. This group included most of the people in the reproductive age, a group that also visits the hospitals more often since they quite likely care for other young children. It is a common practice in many families for female caregivers to take the children to hospitals for any healthcare needs. This same age group was noted to have the highest prevalence of anxiety (33.1%) and the highest prevalence of depression (66.9%) compared to the other groups. This age group is comparable to the age of most caregivers in another study conducted in South Africa in which the majority of the people, particularly mothers of the children (who formed

85.2% of the study sample) were aged 24 – 34 years, while the mean age of their HIV-infected children was 18 months (Potterton, Stewart and Cooper 2007).

Caregivers who depended on casual work had the highest prevalence of both anxiety and depression compared to others. The researcher speculates that this could be due to the unpredictable availability of work and, subsequently, unstable income. Other studies have also shown that living with uncertainty and having poor family finances are among the most significant contributors to parental and family stress and hence are closely associated with development of anxiety and depression (DeMatteo, Wells, Goldie et al. 2002). Research done elsewhere has also shown that social support has the potential to buffer caregiver stress and facilitate caregiver coping (Hansell, Hughes, Caliandro et al. 1999).

Parents who had already disclosed the HIV-positive status to children had a slightly lower prevalence of depression. This result concurs with other studies that have suggested that parents who have disclosed the HIV-positive status to their children experience less depression (American Academy of Pediatrics 1999). Such parents have also been reported to feel an improvement in their wellbeing and in the relationship with their children (Tompkins, Henker, Whalen et al. 1999). Reasons for failure to disclose vary from one person to another and include caregivers' struggle with denial, fear that children will not maintain the secret regarding the infection and other concerns about the impact that disclosure may have on a child's emotional health. This becomes worse in an environment where parents are at a great risk of encountering stigma and discrimination.

The significant association between anxiety and the level of formal education pointed to the importance of education in helping caregivers to cope with the challenges associated with HIV infection. This finding is consistent with the results of another study that was conducted in South Africa, and which showed that caregivers with higher levels of education were more likely to experience decreased levels of parenting stress. These educated caregivers were probably better equipped to access health and social services available to them, and possibly be more financially secure, and therefore less vulnerable to the stresses of extreme poverty (Potterton, Stewart and Cooper 2007). Having a low level of education or no formal education compromises a person's

ability to get a good well-paying job and hence reduces the person's ability to overcome poverty. The helplessness that is associated with poverty becomes a compounding factor in the development of anxiety and depression.

The results showed a close relationship between the prevalence of anxiety and that of depression in that 98.8% of all the people who had anxiety also had depression. Other researchers have found similarly high rates of co-morbidity. One researcher in New York found that approximately 85% of patients with depression also experience significant symptoms of anxiety, while co-morbid depression occurred in up to 90% of patients with anxiety disorders (Gorman 1997). In Texas, a study by Hirschfeld established that more than 75% of patients diagnosed with depression in a primary care setting suffer from a current anxiety disorder (Hirschfeld 2001).

STUDY LIMITATIONS

1. Some of the older children were in school (some in boarding schools) during the study period and hence their caregivers did not participate.
2. The study was done in only one part of Nairobi and from only one clinic in that area. It also excluded people who care for children outside the age bracket of 2 – 18 years. Hence the results may not be generalized to represent the whole population of Nairobi.

CHAPTER 6

CONCLUSIONS AND RECOMMENDATIONS

6.1 CONCLUSIONS

There is a high prevalence of both anxiety and depression among the caregivers of HIV-positive children, a result reflected by various studies done in many parts of the world.

There is a significant association between the prevalence of anxiety and depression and various socio-demographic characteristics that include being female, having little or no formal education, and having a low or unreliable family income.

There is a high likelihood of co-morbidity between anxiety and depression.

6.2 RECOMMENDATIONS

- 1). There is need for concerted effort to support the caregivers of HIV-positive children, particularly those aged 30-49 years. These are expected to be the most productive people and yet are the most affected by both anxiety and depression. In particular, caregivers who are engaged in irregular, non-guaranteed casual labor need to be assisted to get into regular and stable sources of income. This can be implemented through provision of material help, direct financial assistance, formation of self-help groups, and other employment opportunities.
- 2). There needs to be better policies towards comprehensive care for HIV positive children that address the needs of their caregivers as well.

CHAPTER 7

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BUDGET

RESEARCH BUDGET IN KENYA SHILLINGS (KSH.)

1. Stationery	20,000
2. Computer services, printing and photocopying	10,000
3. Communication	10,000
4. Transport	10,000
5. Data analysis	20,000
6. Dissertation typing and binding	15,000
7. Miscellaneous	10,000
TOTAL	95,000

Funding was undertaken by the researcher.

CHAPTER 8

APPENDICES

APPENDIX 1: CONSENT FORM

(i) EXPLANATION FOR INFORMED CONSENT

My name is Dr. Alexander Wainaina. I am currently pursuing a Masters of Medicine Degree, specializing in Psychiatry, at the University of Nairobi. I am conducting a study on the prevalence of anxiety and depression among caregivers of HIV-positive children.

I am conducting the study as the principal investigator. My supervisors are Dr. Mary Kuria and Dr. Muthoni Mathai, both of whom are lecturers in the department of Psychiatry of the University of Nairobi.

Through this letter, I am requesting for your participation in this medical research. I also hereby inform you about the general principles that apply in medical research:

- a) Your participation in the study is entirely voluntary.
- b) Refusal to participate in the study does not lead to penalty or loss of benefits to which you or the child under your care are otherwise entitled to.
- c) You may at any time during the course of the study revoke your consent and withdraw from the study without any penalty or loss of benefits to which you or the child under your care are otherwise entitled to.
- d) Although there is no financial gain to you personally for participating in the study, it is hoped that the results of this study will be of benefit to future medical practice, and help in improving the welfare of people who take care of HIV-positive children.
- e) All information that you give is highly confidential. Your name will not appear in the study report or in any resulting publication. Your name only appears in the consent form which is guarded securely by the investigator. Any other identification is only through a serial number in order to maintain confidentiality.
- f) You have an opportunity to ask any questions concerning the study and your questions will be answered to your satisfaction.

There are no invasive procedures, such as drawing of blood and hence there is no significant risk to you. However, you will be expected to give any relevant information about yourself or the child under your care.

In this research, you will be asked questions in the form of questionnaires. The whole exercise will take about 20 to 30 minutes.

In case you have a question related to this study, you can contact me on telephone number 0713502169 or my supervisors, Dr. Mary Kuria and Dr. Muthoni Mathai at the Department of Psychiatry, University of Nairobi. Any concerns can also be forwarded to the Kenyatta National Hospital/ University of Nairobi Ethics and Research Committee on telephone number 726300-9 or through P.O. Box 20723, code 00202, KNH, Nairobi.

MAELEZO KUHUSU RIDHAA YA KUSHIRIKI KATIKA UTAFITI

Jina langu ni daktari Alexander Wainaina. Nasoma shahada ya uzamili ya magojwa ya akili katika Chuo Kikuu cha Nairobi. Nafanya utafiti unaojulikana kama “Ukubwa wa tatizo la wasiwasi mkubwa na sonono miongoni mwa watoa huduma au walezi wa watoto wanaoishi na virusu vya ukimwi.” Wasimamizi wangu ni Dr Mary Kuria na Dr Muthoni Mathai ambao wote ni wahadhiri katika kitengo cha magojwa ya akili, Chuo Kikuu cha Nairobi. Huu utafiti utafanywa na mimi mwenyewe chini ya wasimamizi wangu niliowataja hapo juu.

Kupitia barua hii, ningepomba ushiriki wako katika utafiti huu wa kitabibu. Pia ningependa kukuelezea kwa ufupi kuhusu utaratibu mzima unaotumika katika utafiti wa kitabibu:

- a. Kushiriki kwako ni kwa hiari.
- b. Kukataa kwako kushiriki hakutaathiri kwa namna yoyote zile huduma zako au za mtoto aliye chini ya uangalizi wako ambazo mnastahili kupewa.
- c. Unaweza kusitisha ridhaa yako ya kushiriki wakati wowote na kitendo hiki hakitaathiri kwa namna yoyote zile huduma zako au za mtoto aliye chini ya uangalizi wako ambazo mnastahili kupewa.
- d. Hakutakuwa na kupewa hela ama zawadi zozote zile katika utafiti huu ila matokeo yake yatasaidia katika kuboresha huduma za kiafya kwa watoa huduma au walezi wa watoto wanaoishi na virusu vya ukimwi.

- e. Habari zitakazopatikana katika utafiti huu zitabakia kuwa siri. Jina lako halitaandikwa popote katika ripoti itakayoandaliwa kufuatia utafiti huu, ila tu itakubidi kuandika jina lako katika fomu ya maridhiano ambayo itahifadhiwa tofauti na nyaraka nyingine za utafiti. Kwingineko, utatambulika tu kwa kutumia namba ya utafiti.
- f. Baada ya kuelezwa maelezo haya, usisite kuuliza maswali endapo utahitaji ufafanuzi wowote.

Hakutakuwa na vitendo kama vile utolewaji wa damu katika utafiti huu na kwa hivyo hakutakuwa na athari zozote kwako. Hata hivyo, utahitajika kutoa habari muhimu kukuhusu wewe mwenyewe au mtoto aliye chini ya matunzo yako.

Katika utafiti huu utaulizwa maswali kwa njia ya dodoso na zoezi zima litachukua kama dakika 20 mpaka 30.

Endapo utakuwa na maswali yoyote kuhusiana na utafiti huu unaweza kunipigia simu kupitia namba yangu ambayo ni 0713502169 au unaweza kuwasiliana na wasimamizi wangu, Dr. Mary Kuria na Dr. Muthoni Mathai, katika kitengo cha magonjwa ya akili, Chuo Kikuu cha Nairobi. Pia unaweza kuwasiliana na kamati ya maadili ya utafiti ya hospitali kuu ya Kenyatta ikishirikiana na Chuo Kikuu cha Nairobi (KNH/ UON Ethics and Research Committee) kupitia namba ya simu 726300-9 au sanduku la posta namba 20723 - 00202, KNH, Nairobi.

(ii) CONSENT FORM

I..... (Name of caregiver), caregiver (parent, relative or guardian) of..... (child's name), do hereby voluntarily give consent to participate in the research entitled THE PREVALENCE OF ANXIETY AND DEPRESSION AMONG CAREGIVERS OF HIV- POSITIVE CHILDREN, under the direction of Dr. Alexander Wainaina (Name of the investigator). The nature and purpose of the study have been explained to me satisfactorily.

Caregiver's signature or thumb print..... Date.....
Home address.....
Telephone.....
Study number.....
Witness (Dr Wainaina) Telephone: 0713502169

FOMU YA RIDHAA YA KUSHIRIKI KATIKA UTAFITI

Mimi, (jina la mtu anayemtunza mtoto), humtunza mtoto aitwaye (jina la mtoto). Uhusiano baina yangu na mtoto huyu ni kama ifuatavyo: mimi ni (i) mzazi, (ii) mtu wa familia moja naye, au (iii) mlezi.

Nimekubali kwa hiari yangu kushiriki katika utafiti unaoongozwa na daktari Alexander Wainaina, unaoitwa "THE PREVALENCE OF ANXIETY AND DEPRESSION AMONG CAREGIVERS OF HIV- POSITIVE CHILDREN." Nimeelezwa kuhusu lengo na utaratibu za utafiti huu kwa kiwango cha kulidhisha.

Sahihi au alama ya kidole gumba Tarehe.....
Anwani
Namba ya simu
Namba ya utafiti
Shahidi (Dr. Wainaina) Namba ya simu: 0713502169

APPENDIX 2: STUDY INSTRUMENTS.

(a) SOCIO-DEMOGRAPHIC QUESTIONNAIRE

- Date..... Caregiver’s study number.....
- Caregiver’s age (years)..... Gender (M/F).....
- Relationship to the HIV-positive child (parent, grandparent, step-parent, sibling, uncle, aunt, non-relative adult).....
- Caregiver’s level of education (none, primary, secondary, tertiary).....
- Caregiver’s residence.....
- Caregiver’s occupation.....
- How long has the caregiver lived with the child? (years and/or months).....
- Existence of the child’s parents (e.g. both parents alive, single mother, etc).....
- Occupation of parent(s).....
- HIV status of parents: Father positive/negative/unknown.
Motherpositive/negative/unknown.
- Number of siblings.....
- Number of siblings known to be HIV-positive.....
- Number of HIV-negative siblings.....
- Number of siblings with unknown HIV status.....
- Total number of household members (adults and children)
- Child’s age (years).....Child’s gender (M/F).....
- Is the child on ARVs (Y/N)?.....
- Child’s history of hospitalization: How many times?.....
How long was the last admission?.....
How long ago was the last admission in hospital (years and/or months)?.....
- Disclosure to the child about their HIV status (done or not yet done?).....
- Family monthly income:
- a) Below KSh 5,000
 - b) Ksh 5,001 – 10,000
 - c) KSh 10,001 – 15,000
 - d) Above KSh 15,000

MAMBO YANAYOMHUSU MTOA HUDUMA.

Tarehe..... Namba ya mtoa huduma wa mtoto.....

Umri wa mtoa huduma wa mtoto (miaka)..... Jinsia (Mume/mke).....

Aina ya mahusiano na mtoto aliyeathirika na virusi vya ukimwi (mzazi, nyanya/babu, mzazi wa kambo, ndugu wa kuzaliwa, mjomba, shangazi, hamna undugu wowote).

Kiwango cha elimu cha mtoa huduma (hajasoma kabisa, elimu ya msingi, elimu ya sekondari, elimu zaidi ya sekondari).

Makazi ya mtoa huduma..... Kazi ya mtoa huduma.....

Muda ambao mtoa huduma alioishi na huyu mtoto (miaka, miezi).....

Uwepo wa wazazi wa mtoto (wazazi wote wapo hai, wazazi wote wamefariki, baba pekee yupo hai, mama pekee yupo hai).

Kazi ya baba..... Kazi ya mama.....

Hali ya maambukizi ya baba (ameathirika, hajaathirika, haijulikani).

Hali ya maambukizi ya mama (ameathirika, hajaathirika, haijulikani).

Idadi ya ndugu.....

Idadi ya ndugu wanaojulikana kuwa na maambukizi ya virusi vya ukimwi.....

Idadi ya ndugu wasiokuwa na maambukizi ya virusi vya ukimwi.....

Idadi ya ndugu wasiojulikana kama wana maambukizi ya virusi vya ukimwi.....

Idadi ya watu katika kaya (watoto na watu wazima)

Umri wa mtoto Jinsia ya mtoto (wa kiume au kike).....

Je mtoto yuko kwenye dawa za kurefusha maisha(ARVs)? Ndio au hapana.....

Je mtoto amewahi kulazwa hospitalini? Ndio au hapana.....

Kama jibu ni ndio, je amelazwa mara ngapi?.....

Je, mara ya mwisho alilazwa kwa muda gani?

Je ni lini mara ya mwisho kulazwa?.....

Je mtoto ameshaambiwa kama anaishi na virusi vya ukimwi? Ndio au hapana.....

Kipato cha familia kwa mwezi

- a). Chini ya KSh 5,000
- b). Kati ya Ksh 5,001-10,000
- c). Kati ya Ksh 10,001-15,000
- d). Zaidi ya Ksh 15,000

(b) BECK ANXIETY INVENTORY (BAI).

Below is a list of common symptoms of anxiety. Please carefully read each item in the list. Indicate how much you have been bothered by that symptom during the past week, including today, by circling the number in the corresponding space in the column next to each symptom.

Zifutatizo ni baadhi ya dalili za kawaida zinazoandamana na wasiwasi mkubwa. Tafadhali soma kila dalili iliyotajwa kwa makini. Onyesha kiasi cha usumbufu ulioupata kutokana na kila dalili wakati wa wiki moja iliyopita pamoja na siku ya leo kwa kuweka alama ya mviringo/duara kuzingira nambari inayolingana na dalili iliyotajwa .

	Not at all Halifanyiki kamwe	Mildly but did not bother me much. Hufanyika kwa kiwango kidogo ambacho hakinitishi	Moderately – it was not pleasant at all. Hufanyika kwa kiwango ambacho hakupendezi kamwe.	Severely – it bothered me a lot. Hufanyika kwa kiwango ambacho hunisumbua sana.
Numbness or tingling Kufa ganzi ama kuisimka	0	1	2	3
Feeling hot Kuhisi joto	0	1	2	3
Wobbliness in legs Kutetemeka miguuni	0	1	2	3
Unable to relax Kushindwa kutulia	0	1	2	3
Fear of worst happening Hofu ya uangamizi	0	1	2	3
Dizzy or lightheaded	0	1	2	3

Kuhisi usingizi ama uepesi wa kichwa				
Heart pounding/racing Kupigapiga kwa moyo	0	1	2	3
Unsteady Kutokuwa na utulivu	0	1	2	3
Terrified or afraid Kushtuka au kuogopa	0	1	2	3
Nervous Kuwa na wasiwasi	0	1	2	3
Feeling of choking Kuhisi kama unasongwa ama kunyongwa	0	1	2	3
Hands trembling Kutikisika mikono	0	1	2	3
Shaky/unsteady Kutetemeka	0	1	2	3
Fear of losing control Hofu ya kupoteza uwezo	0	1	2	3
Difficulty in breathing Ugumu wa kupumua	0	1	2	3
Fear of dying Hofu ya kufa	0	1	2	3
Scared Kuogopa	0	1	2	3
Indigestion Shida ya chakula kusagika	0	1	2	3

Faint/lightheaded Kuhisi udhaifu/uepesi	0	1	2	3
Face flushed Kuloa jasho kwa uso	0	1	2	3
Hot/cold sweats Kutoa jasho baridi	0	1	2	3
COLUMN SUM JUMLA				

(c) BECK DEPRESSION INVENTORY (BDI).

Serial number (namba ya utafiti)

Date (tarehe).....

1.

0 - I do not feel sad.

1 - I feel sad

2 - I am sad all the time and I can't snap out of it.

3 - I am so sad and 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 the future is hopeless and that things cannot improve.

3.

0 - I do not feel like a failure.

1 - I feel I have failed more than the average person.

2 - As I look back on my life, all I can see is a lot of failures.

3 - I feel I am a complete failure as a person.

1.

0 – Sina huzuni

1 – Nina huzuni

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

3 – Nina huzuni sana mpaka siwezi kustahimili au kuvumilia.

2.

0 – Sijavunjika moyo hasa na siku za usoni.

1 – Nahisi nimevunjika moyo na siku za usoni

2 – Nahisi sinalo tarajia siku za usoni

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

3.

0 – Sijihisi kama nimeanguka maishani.

1 – Nahisi nimeanguka maishani zaidi ya mtu wa kawaida.

2 – Nikiangalia maisha yangu yaliyopita naona nimeanguka sana.

3 – Nahisi nimeanguka kabisa maishani.

4.
0 - I get as much satisfaction out of things as I used to.

1 - I don't enjoy things the way I used to.

2 - I don't get real satisfaction out of anything anymore.

3 - I am dissatisfied or bored with everything.

5.
0 - I don't feel particularly guilty

1 - I feel guilty a good part of the time.

2 - I feel quite guilty most of the time.

3 - I feel guilty all of the time.

6.
0 - I don't feel I am being punished.

1 - I feel I may be punished.

2 - I expect to be punished.

3 - I feel I am being punished.

7.
0 - I don't feel disappointed in myself.

1 - I am disappointed in myself.

2 - I am disgusted with myself.

3 - I hate myself.

4.
0 – Naridhika na mambo kama ilivyo kawaida yangu.

1 – Sifurahii mambo kama ilivyo kawaida yangu.

2 – Sitosheki tena kikamilifu na jambo lolote.

3 – Sitosheki wala sichangamshwi na chochote tena.

5.
0 – Sihisi 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 ninaadhibiwa.

1 – Nahisi kama naweza kuadhibiwa.

2 – Natarajia kuadhibiwa.

3 – Nahisi ninaadhibiwa.

7.
0 – Sihisi kama nimeikasirikia nafsi yangu.

1 – Nimeikasirikia nafsi yangu.

2 – Najidharau.

3 – Najichukia.

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 any thoughts of killing myself.

1 - I have thoughts of killing myself, but I would not carry them out.

2 - I would like to kill myself.

3 - I would kill myself if I had the chance.

10.
0 - I don't cry any more than usual.

1 - I cry more now than I used to.

2 - I cry all the time now.

3 - I used to be able to cry, but now I can't cry even though I want to.

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 linalotendeka.

9.
0 – Sina wazo lolote la kujiuwa.

1 – Nina wazo la kuijiuwa, lakini sitalitimiza wazo hilo.

2 – Ningetaka kujiuwa.

3 – Nitajiuwa 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 - I am no more irritated by things than I ever was.

1 - I am slightly more irritated now than usual.

2 - I am quite annoyed or irritated a good deal of the time.

3 - I feel irritated all the time.

12.

0 - I have not lost interest in other people.

1 - I am less interested in other people than I used to be.

2 - I have lost most of my interest in other people.

3 - I have lost all of my interest in other people.

13.

0 - I make decisions about as well as I ever could.

1 - I put off making decisions more than I used to.

2 - I have greater difficulty in making decisions more than I used to.

3 - I can't make decisions at all anymore.

11.

0 - Sikasirishwi kwa urahisi siku hizi zaidi ya ilivyo kawaida yangu.

1 - Nakasirishwa kwa urahisi zaidi ya ilivyokuwa kawaida yangu.

2 - Nahisi nimekasirishwa kwa urahisi wakati mwingi.

3 - Nahisi mimekasirishwa kwa urahisi wakati wote.

12.

0 - Sijapoteza hamu ya kujihusisha au kujumuika na watu.

1 - Hamu yangu ya kujihusisha na watu imepunguka zaidi ya ilivyokuwa.

2 - Nimepoteza sana hamu yangu ya kujihusisha na watu.

3 - Nimepoteza hamu yangu yote ya kujihusisha na watu.

13.

0 - Ninafanya uamuzi kuhusu jambo lolote kama kawaida.

1 - Ninahairisha kufanya uamuzi zaidi ya vile nilivyokuwa nikifanya.

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

3 - siwezi tena kufanya uamuzi wa jambo lolote lile.

14.
0 - I don't feel that I look any worse than I used to.

1 - I am worried that I am looking old or unattractive.

2 - I feel there are permanent changes in my appearance 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 wake up 1-2 hours earlier than usual and find it hard to get back to sleep.

3 - I wake up several hours earlier than I used to and cannot get back to sleep.

14.
0 – Sihisi kuwa naonekana vibaya zaidi ya vile nilivyokuwa.

1 – Nina wasiwasi kuwa naonekana zivutii.

2 – Ninahisi kuwa kuna mabadiliko yasioondoka kwenye umbo langu yanayofanya nisivutie.

3 – Ninaamini ya kuwa nina sura mbaya.

15.
0 – Naweza kufanya kazi kama vile ilivyokuwa hapo awali.

1 – Ni lazima nifanye bidii ndipo nianze kufanya jambo lolote.

2 – Inabidi nijilazimishe sana ili niweze kufanya jambo lolote.

3 – Siwezi kabisa kufanya kazi yoyote.

16.
0 – Ninalala kama kawaida yangu.
1 – Silali vyema kama nilivyokuwa 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 - 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.

17.

0 – Sichoki zaidi ya nilivyokuwa nikichoka hapo awali.

1 – Nachoka kwa urahisi zaidi ya kawaida yangu.

2 – Nachoshwa karibu na kila jambo ninalofanya.

3 – Nimechoka sana hata siwezi kufanya lolote.

18.

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

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

2 – hamu yangu ya chakula ni mbaya zaidi siku hizi.

3 – Sina tena hamu ya chakula hata kidogo.

19.

0 – Sijapunguza uzito wa mwili 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 - I am no more worried about my health than usual.

1 - I am worried about physical problems like aches, pains, upset stomach, or constipation.

2 - I am very worried about physical problems and it's hard to think of much else.

3 - I am so worried about my physical problems that I cannot think of anything else.

21.

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 have almost no interest in sex.

3 - I have lost interest in sex completely.

20.

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

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

2 – Nina wasiwasi sana kuhusu matatizo ya mwili mpaka inakuwa ni vigumu kuwaza jambo lingine lolote.

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

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