

**PREVALENCE OF DEPRESSION AMONG CAREGIVERS OF HIV INFECTED
CHILDREN AGED 10 YEARS AND BELOW, ON FOLLOW UP AT
COMPREHENSIVE CARE CLINIC AT KENYATTA NATIONAL HOSPITAL.**

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and Child Health, University of Nairobi.

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DECLARATION

This dissertation is my original work and has not been presented for the award of a degree in any other university.

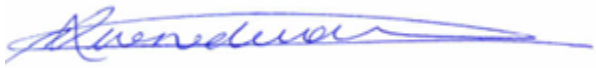
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1. The University of Nairobi
2. Kenyatta National Hospital

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LIST OF ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
AMA	American Medical Association
ART	Antiretroviral Therapy
BDI	Becks Depression Inventory
CCC	Comprehensive Care Centre
CD4	Cluster of Differentiation
CSED	Centre for Epidemiological Studies Depression scale
GHQ	General Health Questionnaire
HIV	Human Immunodeficiency Virus
KASF	Kenya AIDS Strategic Framework
KNH	Kenyatta National Hospital
MOH	Ministry of Health
MTCT	Mother to Child Transmission
NACC	National AIDS Control Council
PHQ	Patient Health Questionnaire
PLWHA	People Living with HIV/AIDS
PMTCT	Prevention of Mother to Child Transmission
SES	Socioeconomic status
SSA	Sub-Saharan Africa
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations Children's Fund
WHO	World Health Organization

OPERATIONAL DEFINITIONS

A **caregiver** is an individual who is most closely attached to a child and is responsible for the daily care and support of a child.(1)

Depression is a common and serious medical illness that negatively affects how one feels, thinks and acts. It causes a feeling of sadness and or loss of interest in activities once enjoyed, and impairs an individual from taking care of his or her responsibilities(2)

Adherence is defined as the extent to which patients take medications as prescribed by a healthcare provider.(3) In HIV treatment, adherence of less than 95% is associated with virological failure, risk of opportunistic infections and death(4).

HIV Viral load is the number of HIV viral particles per millilitre of blood. A low viral load indicates that treatment is effective. A high viral load indicates either that the medication is not being taken properly or there is viral resistance.(5)

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ABSTRACT

Background: Mental health morbidities such as depression are well described consequences associated with chronic illnesses and are exacerbated when offspring are suffering from chronic illnesses such as HIV. Caregivers own health and quality of care is impacted over time in such situations.

Objectives

The primary objective was to determine the prevalence and factors associated with depression among caregivers of HIV infected children using the PHQ-9.

Study Design: Descriptive cross-sectional study

Study methods

Study participants were recruited from the Comprehensive Care Clinic, where HIV infected patients are followed up, at Kenyatta National Hospital(KNH). KNH is Kenya's largest referral hospital. Depression was assessed using the PHQ-9 questionnaire. Pill count record was used to assess for ART adherence among children. Children's viral load and clinic attendance were abstracted from the electronic records.

Results

A total of 116 caregivers-child dyads were enrolled. The prevalence of depression among caregivers of HIV infected children was 54%, of whom 62% were mildly depressed, 35% moderately depressed and 3% moderately-severely depressed. None of the caregivers had severe depression. PHQ-9 scores ≥ 10 was associated with 31 times increased likelihood of having children who were not virally suppressed AOR 31(6.5,150.9) $p=0.000$, additionally, it was associated with lower likelihood of achieving good ART adherence among children AOR 0.008(0.02,0.29) $p=0.000$. Being a married caregiver was associated with a lower likelihood of being depressed AOR 0.13(0.03, 0.59) ($p=0.009$) whereas being HIV-infected was associated with a higher likelihood of being depressed AOR17.1(1.2,24.9) $P=0.03$. Severity of depression was significantly associated with poorer outcomes.

Conclusions

There is a high prevalence of depression among the caregivers of HIV infected children. Caregivers' depression is significantly associated with children's level of adherence and viral suppression.

Recommendations

Assessment of caregivers' depression should be done routinely

CHAPTER 1: INTRODUCTION

Human Immunodeficiency Virus (HIV) still stands as a huge public health concern in Sub-Saharan Africa (SSA), accounting for more than 70% of the global burden of infections. In 2017, there were 36.9 million people living with HIV in the world, among whom 1.8 million were children below 15 years of age(6). There has been immense scale up of global response to HIV in recent years through partnerships with multilateral institutions such as Joint United Nations Programme on HIV/AIDS (UNAIDS), World Health Organization (WHO), national health programs, and donors, which has led to an increase in the number of the HIV infected people on antiretroviral therapy (ART) (6). For instance, the ‘treat all’ policy introduced by WHO in 2015 (7) has led to significant reduction in HIV incidence (8). Among HIV infected children, ART use has also led to significant decline of AIDS related deaths and seen more than 2 million HIV infections averted in children due to Prevention of Mother To Child Transmission of HIV (PMTCT) measures. However, despite the notable progress in reducing HIV incidence, HIV infected children remains significantly disadvantaged. They still face inequities in access to care, with lower adherence rates and consistently low viral suppression rates(9). UNAIDS estimate reports indicated that only 43% of the HIV infected children had access to ART globally in 2017 (6).

Children, unlike adults rely on their caregivers for HIV care(10). HIV, unlike other chronic illnesses, presents additional challenges in that the care-giver often is infected and has to deal with their own ill health and that of their child. The strain of caregiving may lead to psychosocial, physical, mental and economic burden on the caregivers, which may predispose them to mental health disorders such burnout, stress, anxiety, and depression (11). Caregiver depression has been linked with poor outcomes among HIV infected children(12). This study aims to determine the prevalence of depression among caregivers of HIV infected children, its association with ART adherence, viral suppression and clinic attendance among the children; and to determine the caregiver factors associated with depression.

CHAPTER 2: LITERATURE REVIEW

2.1 Epidemiology of paediatric HIV

According to Kenya HIV estimates report of 2018, there were approximately 105, 200 children aged 0-14 years, living with HIV in Kenya in 2107(13). Kenya has continued to see a sharp decline in HIV incidence. The report showed that infections among children aged 0 to 14 years have declined by 41%, from 13,500 in 2010 to 8,000 in 2017. However, the morbidity and mortality associated with HIV among children is still unacceptably high, with approximately 4,300 AIDS related deaths reported in Kenya, in 2017(13).

Kenyan guidelines recommend 6 monthly viral loads monitoring for HIV infected children, via the use of DNA PCR, and shorter durations in special circumstances such as after regimen modification. A viral load of less than 1000 copies/ml is considered normal. On the other hand, it is recommended that adherence should be assessed during every visit and should be done by a trained provider. An adherence level of 95% is recommended to achieve viral suppression. Recommended methods of adherence include use of Morisky Medication Adherence Scale-4 (MMAS-4) as well as Pill count.

2.1.1 Caregiving in paediatric HIV

HIV/AIDS care refers to care for people living with HIV, including children and their families(14). A caregiver is someone who supports and provides assistance to a child, in need physically, emotionally, psychosocially and financially(15). Mothers constitute the majority of caregivers of the HIV infected children (16). However, a caregiver is not always a parent or a blood relation. In the event of illness, death of biological parents or abandonment, relatives, mainly grandmothers take up the role of caregiving (17). In most cultures, the role of caregiving of a child is primarily the responsibility of women(18), with very few men involved in caregiving due to the nature of division of labour in most societies where the role of

caregiving and home chores are left to women (19). HIV infected caregivers are faced with the challenges of dealing with their own ill health and that of their children, guilt for infecting their children and constant worry over their illness.

Often, grandmothers have been placed with an enormous caregiving burden of HIV infected orphans. A general household survey done in 2003 in South Africa showed that 60% of HIV infected orphans were being raised by their grandmothers(20). Studies have shown that due to the challenges of caregiving, the old caregivers are predisposed to physical, financial, and psychological strain and risk of depression (21) than their non-caregiving peers. (14) This also predisposes the HIV infected children to poverty, and poor living conditions(17). It is also likely to affect adherence to ART.

Caregivers' role in paediatric HIV management is enormous with caregiver's factors such age, gender, relationship with the child, HIV status, and marital status among others, reported in studies to influence a child's adherence to ART. A study done in Kenya showed that caregivers played a huge role in determining a child's time of ART initiation, treatment outcomes, and loss to follow up (10). Another study in South Africa showed that caregiver's psychological distress, income and biological relation influenced the level of adherence among children under their care (22). Martin et. al, in a study on 'Patient, caregiver and regimen characteristics associated with adherence to Highly Active antiretroviral Therapy among HIV-infected children and adolescents' showed that loss to follow up was influenced by the caregivers health, financial and social wellbeing(23). A study in Ethiopia showed that age and marital status of the caregiver influenced adherence , with better adherence noted among children whose caregivers were married and those who were younger(24). Another study done in Uganda showed that the relationship of the caregiver with the child affected paediatric HIV management especially adherence, with better adherence noted among children under the care of their biological mothers(25).

2.1.2 Prevalence of depression among caregivers of HIV infected children

Depression is defined as a common and serious medical illness that negatively affects how one feels, thinks and acts. It causes feelings of sadness and or loss in interest in activities once enjoyed(26). Depression in the general population is increasingly becoming common globally. A meta-analysis on prevalence of depression in community from 30 countries between 1994 and 2014 showed that aggregate point prevalence of depression was 12.9%, with a 1 year prevalence at 7.2%(27). Another study done in South Africa showed a point prevalence of depression 9.8% for lifetime, with a higher prevalence in females than in males and among people of low socio economic status (28).

Studies have shown that caregivers of young HIV infected children experience extremely high parental stress(17). Unlike the case with most other chronic illnesses, most caregivers of HIV infected children are also infected with HIV and therefore have to deal with their own illness in addition to that of their child/children (17). In addition to the health challenges, they are faced with other numerous challenges that include; financial struggles, isolation, shame, anger, worry, emotional pain, stigma, fear of disclosure, sero-discordancy, disrupted families, rejection by family and friends, uncertainty, and fear of the death of the child/self/other sick family members, and lack of social support (17). Because of this, they are predisposed to caregiver burnout, psychological distress, anxiety and depression. Depression is one of the most common mental illness among both HIV infected people(29) and caregivers of patients with chronic illnesses including HIV.(25).

In Kenya, a cross-sectional study on prevalence of anxiety and depression using Becks Depression Inventory among caregivers of HIV positive children receiving comprehensive care at Lea Toto Clinic in Kibera, Nairobi showed that 147/228 (64.5%) caregivers of HIV positive children had depression. Anxiety levels among caregivers were lower at 67/228(29.4%). The study found that depression was significantly associated with a caregivers' 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 ($p=0.004$) (30). A randomized control trial done in rural Uganda by Itziar et al in 2016 among 288 female caregivers living with HIV found that, 61% of the female caregivers of HIV infected children reported depression using the standard Hopkins Symptom Checklist (HSC). Factors significantly associated with depression were lower wealth ($p=0.01$) and reduced family support ($p=0.01$) (31). Another study in Ghana showed that 28% of the caregivers had mild to severe depression. Caregiver depression was associated with being HIV positive ($P = 0.04$), financial problems ($P = 0.02$), lack of social support, ($P = 0.01$), and HIV stigma ($P \leq 0.001$) (32). Lv Y. et al evaluated symptoms of depression among caregivers of children in HIV affected families in rural China using ‘The Centre for Epidemiological Studies’ scale (CES-D) and found a mean score of 17.84 for men and 20.44 for women with a mean score of 19.18 for the entire sample. The CES-D scores of 16 was used as the cut-off for possible clinical depression. The study found that financial challenges, lower education, and having a HIV infected family member(s) to be significantly associated with depression (33). Table 2.1 below provides a summary of these four studies.

This study will look at the prevalence of depression among the caregivers of HIV infected children and caregiver characteristics associated with depression. Some of the caregivers’ factors that study will look into include; caregiver’s age, gender, marital status, HIV status, disclosure, sero-discordancy, social support, stigma, education, financial status, relationship with child, duration of caregiving and number of children under their care.

2.1.3 Effect of caregiver depression on adherence

Adherence is defined as the extent to which patients take medications as prescribed by a healthcare provider (34). A high level of adherence of at least 95% is required for ART to be effective (4) while non-adherence may lead to treatment failure. The main factors affecting adherence among HIV infected children include child’s characteristics, type of regimen, and caregiver characteristics. Some of the caregivers’ characteristics that have been associated with non-adherence among HIV infected children include; caregiver forgetfulness, biologic

relationship to the child, caregiver permanence, caregiver religion, caregiver understanding of HIV and use of ART and the caregiver psychosocial well-being. A study done by Mellins CA et al, on the role of psychosocial and family factors in adherence to ART among infected children showed higher caregiver stress ($P < 0.002$), lower caregiver quality of life ($P < 0.003$) and worse caregiver cognitive functioning ($P = 0.033$) to be strongly associated with non-adherence (35). Jaspan et al demonstrated that caregiver depression was associated with poorer paediatric adherence(25)

2.1.4 Screening for depression

Use of screening tools is a quick and reliable option in the initial assessment of depression or as a treatment monitor. An initial screen must be followed by a clinical interview to make the diagnosis of depression. Using validated tools for screening and diagnosis of depression is essential in providing appropriate care. One of the most widely used validated tools for screening and diagnosis of depression is the Patient Health Questionnaire-9 (PHQ). The PHQ-9 is a tool used for screening, diagnosing and monitoring the severity of depression. It is a self-administered version of the PRIME-MD diagnostic instrument for common mental disorders. The questions are based on the DSM-IV criteria for depression over the previous 2 weeks. It scores each of the DSM IV criteria as “0” (not at all) to “3” (nearly every day) It has nine items with response options ranging from 0-3 for each item as below;

Not at all - scored 0

Several days - scored 1

More than half the days- scored 2

Nearly every day- scored 3

PHQ-9 is brief, reliable and easy to administer. PHQ-9 scores can be interpreted in a binary or multilevel categorical fashion whereby in the binary fashion any score greater than 4 indicate depression and no depression for scores below 4. Multilevel categorical fashion has the following categories; (0-4) mild (5-9) moderate (10-14) moderately severe (15-19), and

severe (over 20). While the PHQ-9 was developed to be self-administered, interviewer-administration has yielded similar results(36)

Interpretation

Provisional Diagnosis and Proposed Treatment Actions		
PHQ-9 Score	Depression Severity	Proposed Treatment Actions
0 – 4	None-minimal	None
5 – 9	Mild	Watchful waiting; repeat PHQ-9 at follow-up
10 – 14	Moderate	Treatment plan, considering counseling, follow-up and/or pharmacotherapy
15 – 19	Moderately Severe	Active treatment with pharmacotherapy and/or psychotherapy
20 – 27	Severe	Immediate initiation of pharmacotherapy and, if severe impairment or poor response to therapy, expedited referral to a mental health specialist for psychotherapy and/or collaborative management

The diagnostic validity of PHQ-9 tool among Africans has been established by a number of studies done in Africa. A study done in Cameroon to validate the use of the PHQ-9 in screening for depression among HIV infected individuals showed that PHQ-9 had high specificity but a low sensitivity in detecting depression(36). Another study done to assess Validity of the Patient Health Questionnaire-9 for Depression Screening and Diagnosis in East Africa found that the PHQ-9 is a reliable and valid instrument for diagnose major depressive disorders among adult Ethiopians. PHQ-9 threshold score of 10 offered optimal discriminatory power with respect to diagnosis of depression via the clinical interview with a sensitivity of 86% and a specificity of 67%(37).

Ministry of health, Kenya recommends basic screening of depression among HIV infected adults before initiating ART and annually thereafter. It recommends use of PHQ-2 for initial screening, If the PHQ-2 is positive for depression, the PHQ-9 should be administered. In addition, all patients with a detectable viral load after 6 or more months on ART (whether or not they had achieved viral suppression in the past), should undergo a more thorough screening for depression using the PHQ-9 screening tool, with management guided by the

PHQ-9 score(38). Screening of depression among caregivers of HIV infected children at the Kenyatta National Hospital CCC is not routinely been done.

Table2.1: Prevalence of depression among caregivers of HIV infected children, and factors associated with depression

Study Title	Study Design & population	Tools used & cut offs for depression	Outcomes
The prevalence of anxiety & depression among caregivers of HIV-positive children at Lea Toto Clinic, Kibera, Nairobi. A.M.W, 2012 (30)	descriptive cross sectional study, 228 caregivers of HIV infected children >2 years of age	Becks Depression Inventory	64.5% had depression. Factors with significant association with depression were; Gender (p=0.003), occupation (p=0.027), education(p=0.001) Family monthly income p=0.041
Socio-demographic correlates of depression and anxiety among female caregivers living with HIV in rural Uganda Itziar et al.(2016)(31)	Secondary analysis of data from a RCT testing meditational intervention for sensitizing caregiver. 228 HIV infected caregivers of children aged 2-5 years	Hopkins Symptom Checklist	61% Had probable depression or anxiety. Mean depression score was 2.0, while mean anxiety score was 1.8 Hopkins Symptom Checklist Factors associated with depression; single/divorced p=0.004, poverty p=0.001
Prevalence and correlates of depression among caregivers of children with HIV in Ghana. Ofori et al. 2016(32)	Secondary analysis of data from a HIV disclosure interventional trial. 446 caregivers of HIV infected children		28% of caregivers had depression Depression was associated with; positive HIV status (p=0.04),financial challenges (p=0.02),lack of social support(p=0.01), low HIV knowledge(p=0.01), stigma(p=/ $<$ 0.001)
Depression symptoms among caregivers of children in HIV-affected families in rural China. Lv Y et al. 2010 (33)	Cross-sectional study; 160 caregivers	CSED tool	Women CSED score=20.44, men=17.84 Mean score=19.18; higher scores noted among caregivers with low education and low socio-economic status

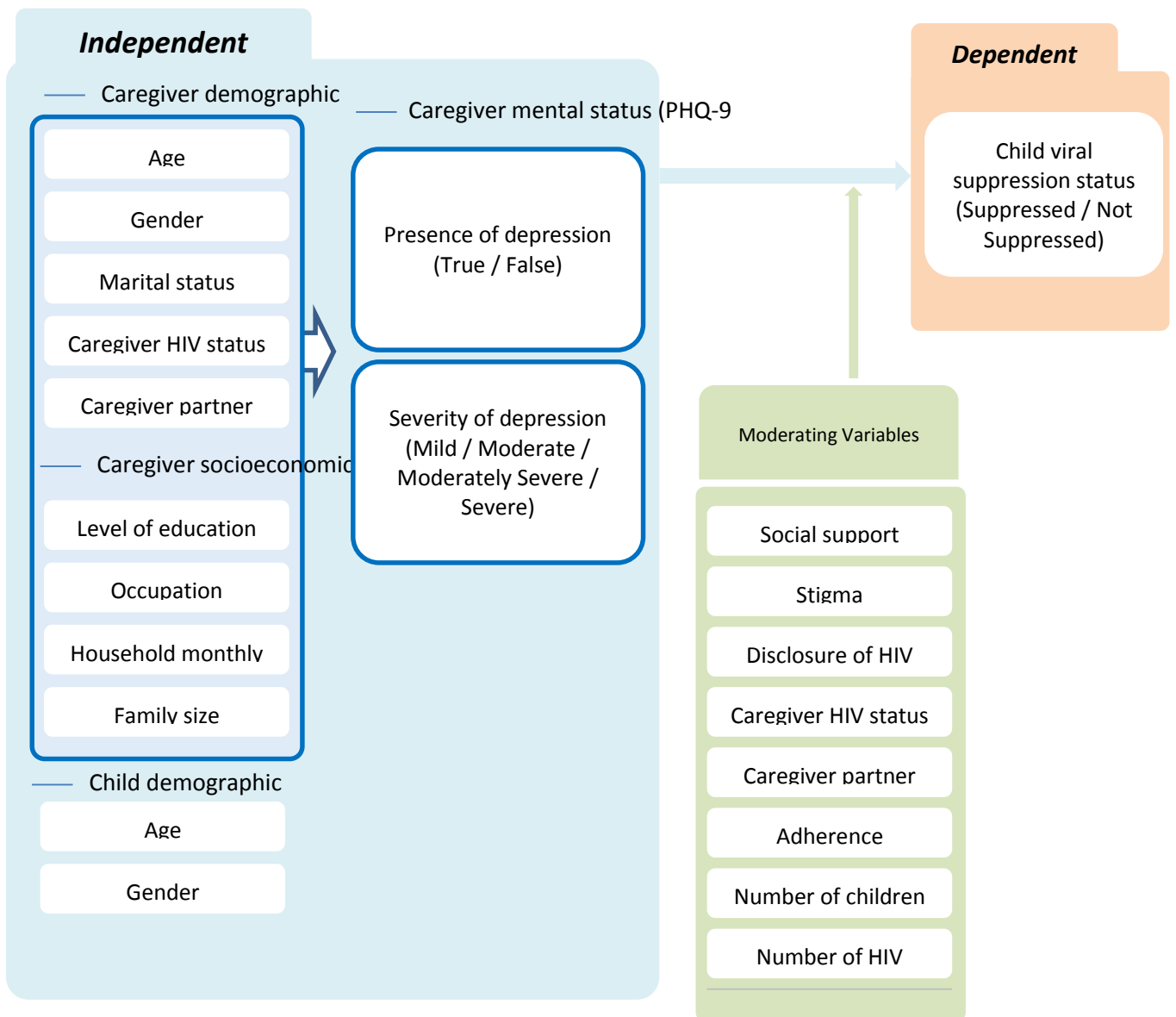


Figure 1.2 Conceptual Framework

The figure 1.2 above demonstrates a conceptual framework outlining the likely relationship between caregiver factors which are the independent variables, moderating factors which include Social support, stigma, disclosure to child, caregivers’ HIV status, partners’ HIV status, adherence counselling, number of HIV infected children, duration of caregiving and the no of children living in the household. Dependent factor is the caregivers’ depression, which is likely to have an association with children’s outcomes in terms of adherence to ART, viral suppression and clinic attendance.

2.2 STUDY JUSTIFICATION AND UTILITY

HIV still remains a major public health concern in sub-Saharan Africa with an estimated 8000 new infections in children yearly. Despite the significant success in reducing the number of new HIV infections among children, ART coverage among HIV infected children remains low. In addition, HIV related illnesses are still among the leading causes of infant mortality in Kenya. In order to improve paediatric HIV management, joint efforts are necessary from all the stakeholders, particularly the caregivers as they spend most of the time with the children. Unfortunately, the caregivers are faced with the challenges of caregiving which affect their psychological well-being and compromise care. Mental well-being of the caregivers is critical in achieving successful treatment outcomes. Currently, mental health status is not routinely assessed during HIV care of children. It is important to make efforts to improve caregiver's mental health in order for them to provide proper care without themselves experiencing negative health outcomes as a result.

This study aims to develop an understanding of the psychosocial challenges experienced by caregivers caring for a child infected with HIV. The study also aims to determine the association between caregivers' depression and the wellness of a HIV infected child. Results from this study may justify routine screening of caregivers for depression during enrolment at CCC and in subsequent visits as part of paediatric HIV care, should we find a high burden of depression among caregivers, which is not currently done. It will also guide on suitable interventions that should be instituted targeting the caregiver factors we identify and subsequently improve care of the HIV infected children in order to achieve the global targets. Focus on the wellbeing of the caregivers will likely improve retention to follow up, adherence to ART and improve quality of paediatric HIV care in Kenya.

2.3 RESEARCH QUESTIONS

1. What is the prevalence of depression among caregivers of HIV infected children aged 10 years and below who are on follow up at the Comprehensive Care Clinic in Kenyatta National Hospital?
2. Is there an association between caregivers' depression and the degree of viral suppression, adherence of ART and clinic attendance among their children?
3. What are the factors associated with depression among caregivers of HIV infected children on follow up at CCC, KNH?

2.4 STUDY OBJECTIVES

2.4.1 Primary objective

1. To determine the prevalence of depression among primary caregivers of HIV infected children using the Patient Health Questionnaire-9 at the comprehensive care clinic in Kenyatta National Hospital.

2.4.2 Secondary objectives

1. To determine the association between caregiver depression and degree of viral suppression, adherence to Antiretroviral Therapy and clinic attendance among their children on follow up at the Comprehensive Care Clinic in Kenyatta National Hospital
2. To describe psychosocial and demographic factors associated with depression among caregivers.

CHAPTER 3: METHODOLOGY

3.1 Study design and population

We conducted a descriptive cross-sectional study at the Kenyatta National Hospital's Comprehensive Care Clinic, between January and March 2020. The study population was the caregivers of HIV infected children and their children on follow up at the clinic.

Inclusion criteria

We included caregivers whose children were aged ≤ 10 years who had been on ARV for ≥ 6 months. The caregivers had to have been the primary caregiver of the child for a period of 6 months or more prior to the study

Sample size determination

We calculated the sample size using Fischer's formula whereby we estimated that the proportion of caregivers with depression would be 65%(30) using a precision of 0.005. Consecutive sampling was used to recruit participants until the desired sample size was achieved.

3.2 Case definitions

Depression; a caregiver was considered depressed if their PHQ-9 scores are above 4. Severity of depression will be based on the PHQ-9 scores as follows: 0-4 normal, 5-9 mild depression, 10-14 moderate depression, 15-19 moderately severe, 20-27 severe.

In assessing association between caregiver depression and children outcome and factors associated with caregivers' depression, PHQ-9 scores of 10 above versus those below 10 will be used as studies have shown that PHQ-9 scores of ≥ 10 had a sensitivity of 88% and a specificity of 88% for major depression(40)

Viral load; viral load above 1000copies/ml while a low viral load is viral loads less than 1000 copies/ml

Adherence; good adherence was defined as an adherence of more than or equal to 95% using pill count method over a period of 3 months.

Clinic attendance was defined as any missed clinic visits in the period 3 months prior to the study.

Quality assurance

For quality assurance in the study, the following measures were undertaken:

1. The questionnaires were pretested to determine the sensitivity of the questions in detecting important differences in the study's variables.
2. There was one research assistant with a certified diploma in clinical psychology and previous experience in research. He had 1 week training on how to administer the semi structured questionnaire and how to tabulate and interpret the PHQ-9 scores. The principal investigator worked side by side with the research assistant to administer sociodemographic questionnaires and doing data entry. The research assistant was issued with a copy of the study procedure protocols to ensure uniformity in data collection.
3. The Principal Investigator assessed the collected data on a daily basis and oversaw data entry.

Ethical Considerations

1. Ethical approval was sought from the KNH/UoN research and ethics committee. Data collection and analysis did not commence until ethical approval.
2. Permission was sought from KNH in order to conduct the study at the Comprehensive Care Clinic. A written informed consent was obtained from the study participants before enrolment. The study was explained in details to the parents or guardians in either English or Swahili. Caregivers were informed that information including their child's age, ART regimen, CD4 counts, viral load, WHO stage, clinic attendance was

abstracted from their children's files. They were assured of continued same standard of care even if they declined to participate in the study.

3. Consenting participants were also informed that they could opt out of the study at any point without being disadvantaged in any way.
4. The participants were informed that they would not have any monetary benefit for participating in the study.
5. Participants who were found to be depressed were linked to the clinical psychologists and psychiatrists within KNH for management and follow up.
6. To ensure confidentiality, study participants were given unique identification codes and no personal identification data was recorded. There was also an assurance that once the study was published, there will not be any direct and identifying link between the study participants and the results.

Data management and analysis

Study data was entered into a customized password protected SPSS software after which it was exported to STATA 13.0 software for cleaning, verification and analysis. Demographic data was presented as medians and interquartile range for continuous variables and as frequencies and percentages in tables for categorical variables. Prevalence of Depression among caregivers was calculated by expressing the total number of caregivers who had a PHQ score >4 . Severity of depression based on the PHQ-9 scores was classified as mild, moderate, moderately severe or severe, and presented as proportions in form of a bar graph. Binary logistic regression (odds ratio (95%CI) and p value <0.05) was used to determine the association between dependent and each independent variable. Factors associated with depression among caregivers (PHQ score ≥ 10) were analysed using binary logistic regression (odds ratio (95%CI). Significant associations were defined by p value <0.05 .

CHAPTER 4: RESULTS

The study was carried out over the 4th quarter of 2019 and the first quarter of 2020. Data collection was conducted between 6th January 2020 and 28th February, 2020. In this period, 123 caregivers-child dyads who visited the Kenyatta National Hospital, Comprehensive Care Clinic were approached to participate in the study. However, 4 declined to participate in the study. 119 caregivers were enrolled and interviewed. Out of these, 2 of them had children who did not have recent viral loads (done within 6 months prior to the study period). Additionally; one child was excluded from analysis as the child was from a children home. These caregivers-child dyads were excluded in the analysis.

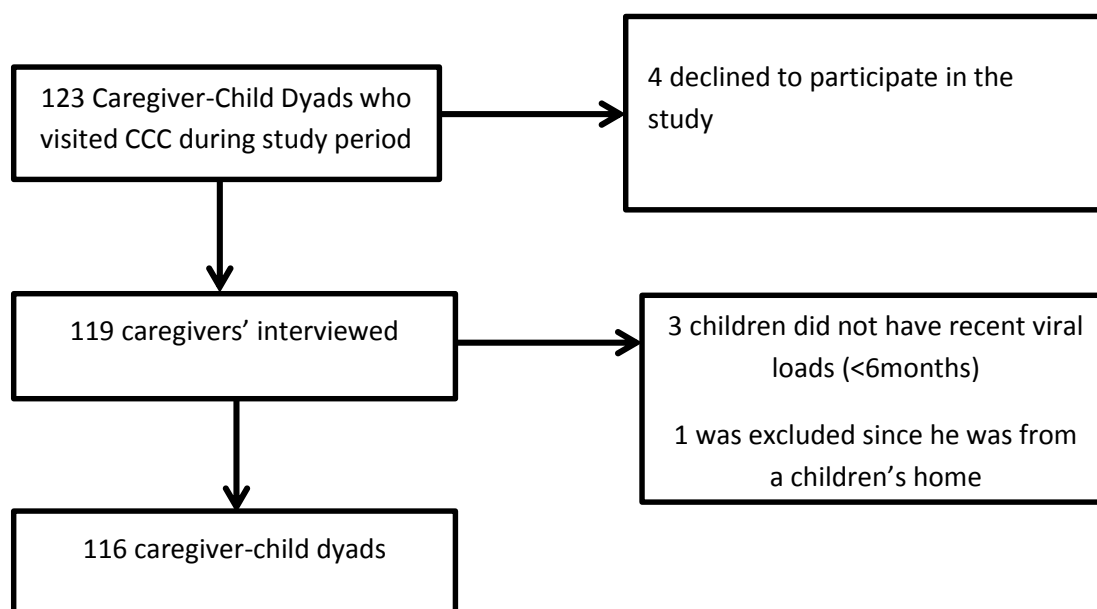


Figure 4.1 flow chart of the study population

4.1 Caregivers and child characteristics

Sociodemographic characteristics

Of all the caregivers, 109 (94%) were females while 7(6%) were males. Almost two thirds of them 77(65.8%) were aged 31-45 years. The Median age was 35(IQR 31-42) years. The youngest caregiver was 19 years old while the oldest was 63 years old. Majority of the caregivers were married 78(66.2%) and 52(44.4%) had attained secondary level education.

With regards to their employment, majority of the caregivers were either casual labourers 38(34.2%) or self- employed 38(34.2%), 26(23.4%) of the caregivers were unemployed and 9(8.1%) had formal employment.

Among the children recruited in the study, almost half 57(48.7%) were between ages 1-5 years with a median age of 5 years and an IQR (3-7 years). The youngest child was 6 months old while the oldest was 10 years. 65(55.6%) of them were male while 52(44.4%) were female. Majority of the children had a biological parent 95(81.2%) as the primary caregiver. Children with viral load less than 1000copies/ml were 75(64.1%) while those with a viral load of more than 1000 copies/ml were 42 (35.9%). Majority of the children 95 (81.2%) were adherent to ART (had attained the recommended % pill count of 95%) and 113(96.58%) had not missed any clinic visits. Majority of them were on a first line ART regimen with a median duration of treatment of 4 years and an IQR (1.25-6 years) with the least duration being 6 months and the longest duration being 10 years. Table 4.1 and 4.2 below summarizes the socio-demographic characteristics of the caregivers and children who participated in the study.

Table 4.1 caregivers demographic characteristics

Variable	Characteristic	Frequency	Percent
Age	Below 30 Years	28	24.4
	31-45 Years	76	65.5
	Above 45 Years	12	10.6
Gender	Male	7	6.0
	Female	109	93.8
Marital Status	Single	30	26.1
	Married	76	66.1
	Widowed	10	7.8
Education Level	Primary	38	32.5
	Secondary	52	44.4
	Tertiary	27	23.1
Occupation	None	26	23.4
	Casual labourer	38	34.2
	Self-employed	38	34.2
	Formal employment	9	8.1

Table 4.2 Children characteristics

Variable	Characteristic	Freq.	Percent
Age(in years)	≤1	11	9.4
	>1-5	57	48.7
	>5	48	41.9
Gender	Male	65	55.6
	Female	51	44.4
Primary Caregiver	Parent	95	81.2
	Grand parent	9	7.7
	Sibling	2	1.7
	Aunt/uncle	7	6
	Step parent	3	2.6
Viral load within previous 6 months	<1000 copies	75	64
	>1000 copies	41	36
Current WHO Staging	1	106	91.5
	2	10	8.6
ART Adherence by pill count method over 3 months	<95%	22	18.8
	>95%	94	81.
Number of missed clinics in the past three months	None	112	96.6
	One	4	3.4
ART regimen	1st line	108	93.0
	2nd line	8	7
Duration of ART use (in years)	<1	28	24.3
	1-5	50	44.3
	>5	36	31.3

Caregiver psychosocial characteristics

Majority of the caregivers at 96(82%) reported to be HIV infected, with an equal number of the caregivers 96(82%) reporting of HIV related stigma. Majority of caregivers had partners who were HIV infected 50(57.5%) while 7(8%) of the caregivers did not know their partners' status. Only 37(31.6%) caregivers had disclosed the HIV status of their children to them. Of these, only 27(72.97%) had completely disclosed. The most commonly cited reason for non-disclosure was that the children were still too young to understand. However, majority of the children in the study were below age 6 years which is the most common age in which disclosure begins. Most of the caregivers 60(51.3%) reported that they had been caregiving

for about five years with 57(50%) citing lack of social support in providing care to their HIV infected children. Only 16(14%) reported getting full social support. Table 4.3 below demonstrates the psychosocial characteristics of the caregivers in the study.

Table 4.3 psychosocial characteristics of the caregiver

Variable	Characteristic	Frequency	Per cent
HIV status of the caregiver	Infected	96	82.1
	Not infected	21	18.0
Disclosure of the caregiver's HIV status	Yes	38	40
	No	57	60
Stigma	No	21	17.9
	Yes	96	82.1
Duration of caregiving (in years)	<1	19	16.2
	1-5	60	51.3
	>5	38	32.5
Social support for care	Partially	41	36.0
	Full support	16	14.0
	None	57	50
Partner's HIV status	Infected	50	57.5
	Not infected	30	34.5
	Not known	7	8.0

4.2 Prevalence of depression among caregivers

The results of the study showed that majority of the caregivers at 63(54%) had depression based on the PHQ-9 scores of more than 4 and this was statistically significant ($p=0.04$). Among them, 60(95.2%) were female, while 3(4.8%) were male. In view of the severity of depression among the caregivers, 39(62%) had mild depression, 22(35%) had moderate depression and 2(3%) had moderate severe depression. No caregiver had severe depression. The difference in the severity of depression was statistically significant($p=0.000$).

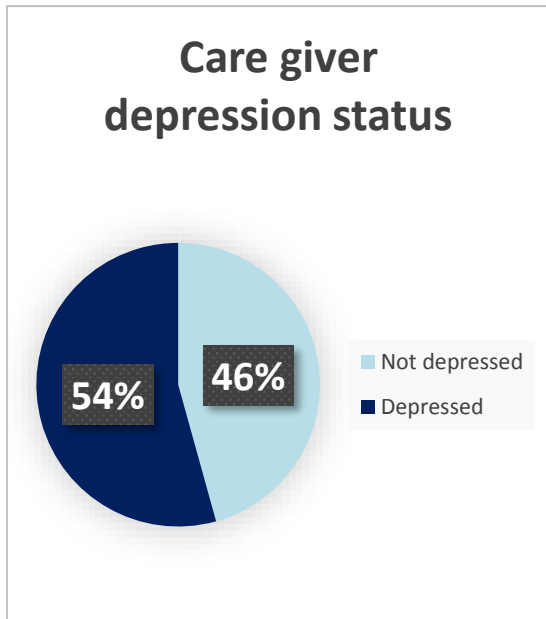


Figure 4.3: prevalence of caregivers depression

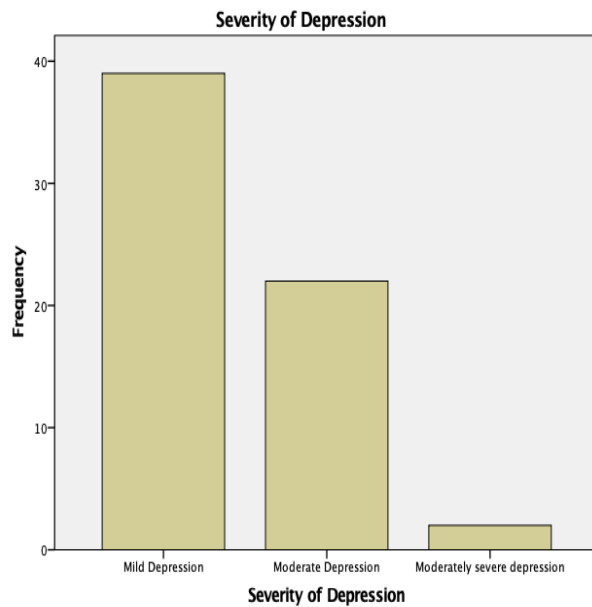


Figure 4.2: Severity of caregivers depression

Each of the 9 questions on the PHQ-9 was evaluated on a 4-point rating scale, ranging from 0(not at all) to 3(nearly every day) summing up to a total PHQ-9 per patient.

The questions on PHQ-9 with highest responses were; question 6- feeling bad about yourself, or that you are a failure, or have let yourself or your family down with a total score of 128, followed by question 2- feeling down, depressed and hopeless with a total score of 123 and question 4- feeling tired or having little energy with a total score of 89 points. These findings are demonstrated on figure 4.4 below. In regards to question 9 which assess for suicidality, 43% responded 'not at all' 38% "several days' while 19% responded to 'more than half the days'. None of the caregivers responded to 'nearly every day. These findings are demonstrated on figure 4.5 below.

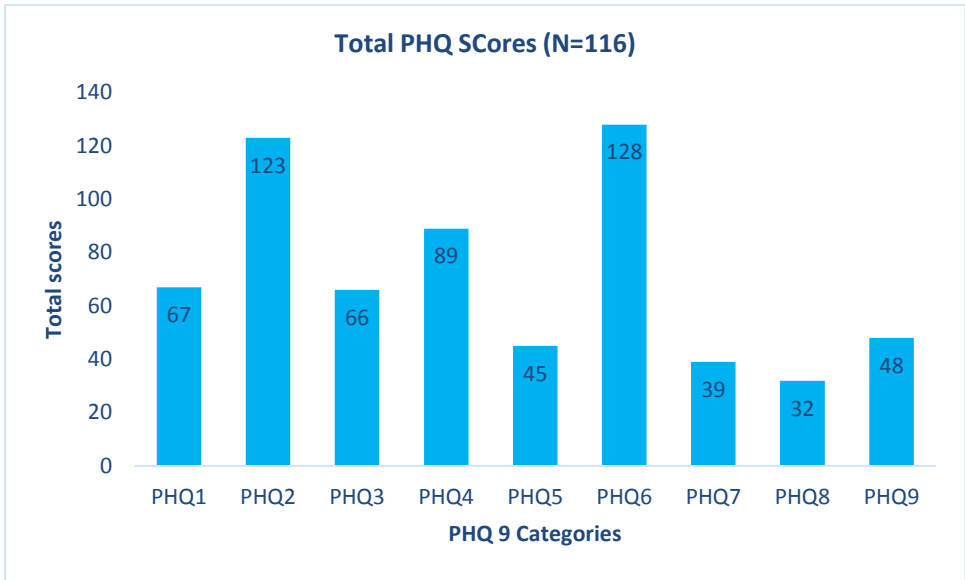


Figure 4.4 total scores of the responses in PHQ-9 among the depressed caregivers

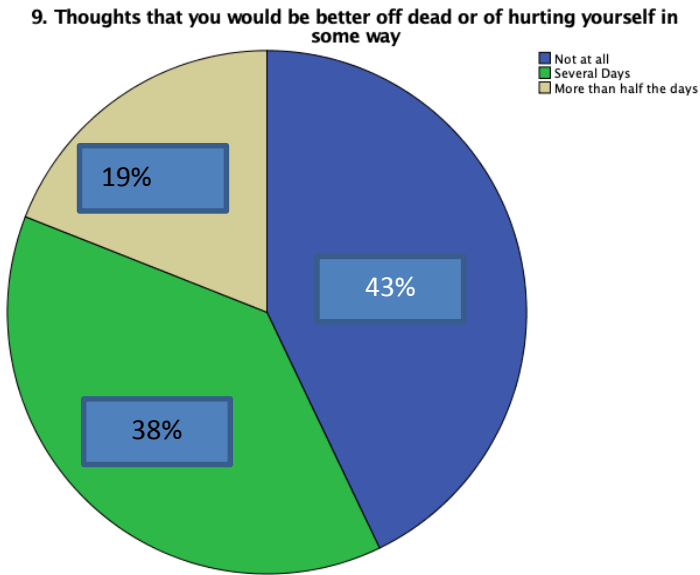


Figure4.5 response to question 9 on the PHQ-9 questionnaire

4.3 Association between caregiver depression and child viremia, ART adherence and clinic attendance

Majority of the children 94 (81%) had achieved good adherence of >95% in the period 3 months prior to the study as demonstrated using the pill count percentage method. Only 22(19%) had a poor adherence. 74(64%) of the children had viral loads below 1000copies/l with 41 of these having undetectable viral loads. On the other hand, 42(36%) of the children had viral loads above 1000copies/l. (see figure 4.6 (a) and (b) below). Among children below age 1 year, 5 had viral loads below 1000, while 6 had viral loads above 1000copies/ml. There was 100 % clinic attendance in the three-month period prior to the study among majority of the children 112(96.6%) with only 4(3.4%) children reporting 1 missed visit in that period

N=116

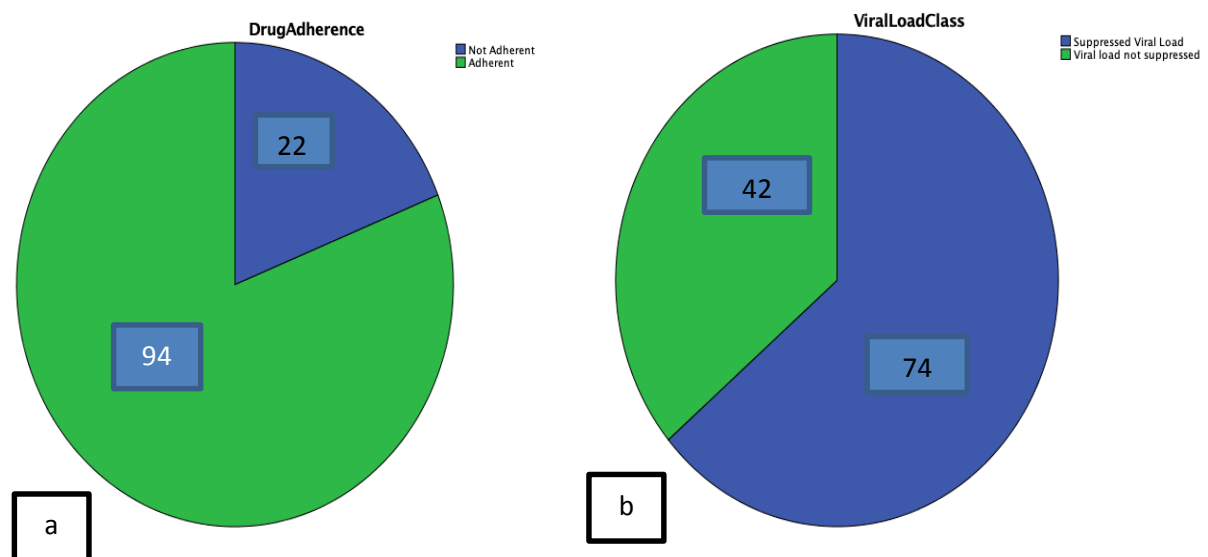


Figure 4.6 Adherence and viral suppression among HIV infected children

Using binary logistic model, the results of crude association showed that a PHQ ≥ 10 among caregivers was associated with 92% lower likelihood of achieving good adherence AOR 0.08(CI 0.02-0.29) (p=0.00).

In addition, the severity of caregiver depression was also significantly associated with increased likelihood of poor adherence to ART among children. This is graphically demonstrated on figure 4.7 below.

Table 4.4 Association between caregiver depression and ART adherence among HIV infected children

Characteristics	Adherence <95% N=22	Adherence ≥95% N=94	COR (95% CI)	P value	AOR	P value
Depression status						
PHQ <10	9(40.9%)	83 (88.3%)	1 (Reference)		1 (Reference)	
PHQ ≥10	13(59.1%)	11(11.7%)	0.09(0.03,0.26)	0.000	0.08(0.02,0.29)	0.000

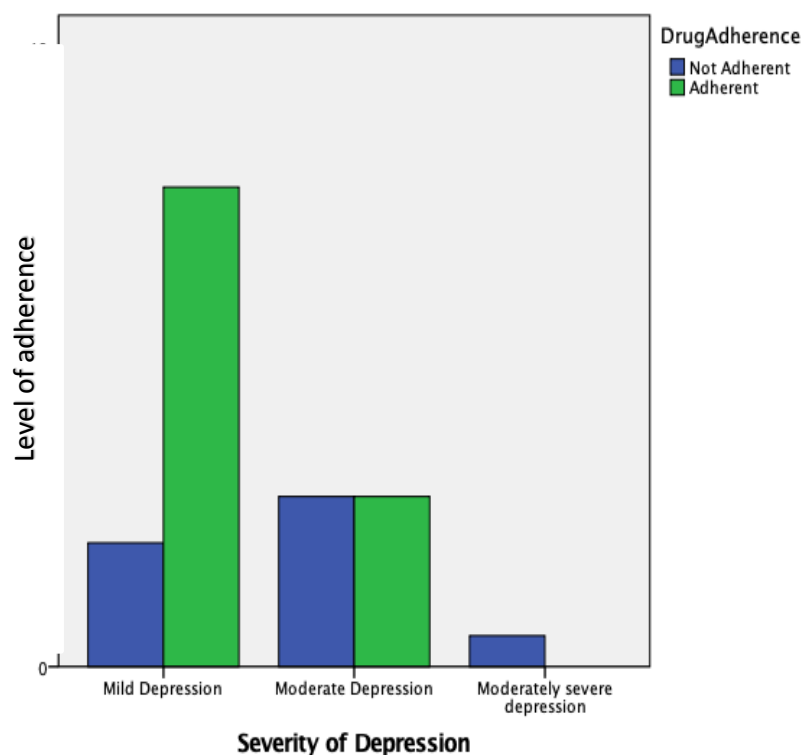


Figure 4.7 Association between severity of caregivers depression and ART adherence among children

Similarly, the model showed that depression among caregivers was associated with poor viral suppression among children. PHQ ≥ 10 among caregivers was associated with 31 times higher likelihood of having a child who was not virally suppressed. AOR 31.2(CI 6.5- 150.9) p=0.000. This is demonstrated on table 4.5 below.

Table 4.5 Association between caregiver depression and viral suppression among HIV infected children

Characteristic	Viral load < 1000 N=74	Viral load ≥ 1000 N=42	COR	P value	AOR	P value
Depression status						
PHQ <10	72(97.3%)	20(47.6%)	1 (Reference)		1 (Reference)	
PHQ ≥ 10	2 (2.7%)	22(52.4%)	39.6(8.6-182.7)	0.000	31.2(6.5,150.9)	0.000

On further analysis, we found that the severity of depression among caregivers was also associated with an increased likelihood of poor viral suppression among HIV infected (figure 4.8). We did an analysis excluding children below the age of 1 year since most children below age 1 year are not virally suppressed and we still found a significant association between caregiver depression and viral suppression among HIV infected children (P=0.000) this is demonstrated on figure 4.9

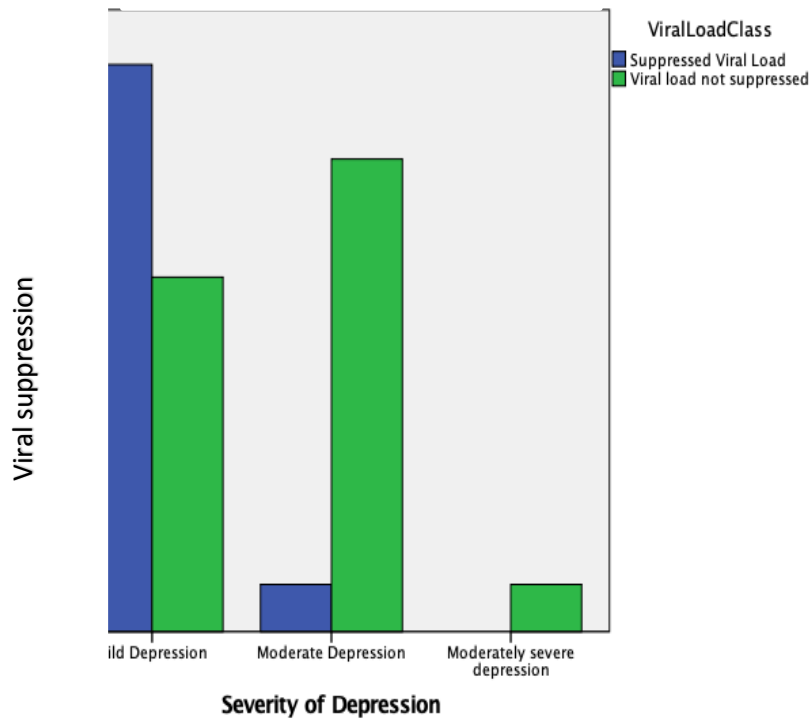


Figure 4.8 association between severity of caregiver depression and viral suppression among all HIV infected children

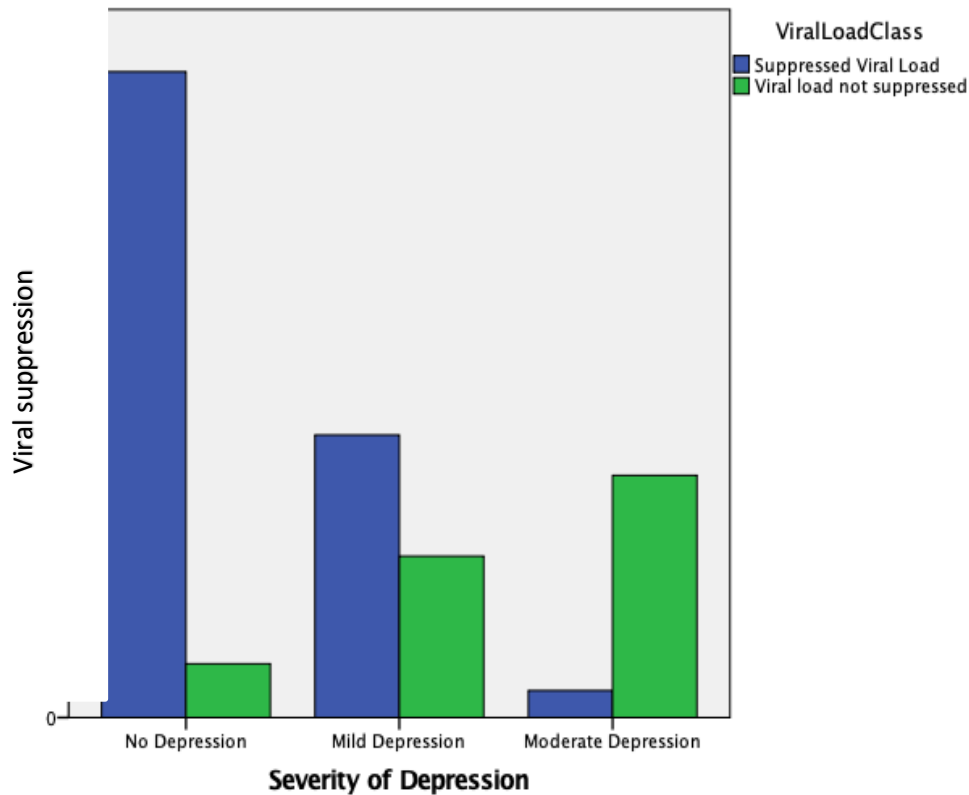


Figure 4.9 Association between severity of caregiver and viral suppression among HIV infected children above age 1 year

Association between caregiver psychosocial characteristics and adherence and viral suppression among HIV infected children.

We did a sub analysis to determine association between caregivers’ psychosocial factors and adherence, and viral suppression. The multivariate analysis showed no significant association between caregivers’ psychosocial characteristics and adherence or viral suppression among children. These findings are demonstrated on table 4.6 below and 4.7 below.

Table 4.6 Association between caregivers psychosocial characteristics and viral suppression

Characteristic	Viral load < 1000 N=74	Viral load ≥ 1000 N=42	Crude OR	P value	Multivariable OR	P value
HIV status of the caregiver						
Not Infected	17 (23%)	3 (7.1%)	1 (Reference)		1 (Reference)	
HIV infected	57 (77%)	39 (93%)	0.24 (0.07, 0.88)	0.03	1.85 (0.52, 6.56)	0.34
Disclosure of the caregiver’s HIV status						
No	36 (64.3%)	21 (53.8%)	1 (Reference)		-	-
Yes	20 (35.7%)	18(46.2%)	1.54 (0.67, 3.6)	0.31	-	-
Stigma						
No	18 (24%)	3 (7.1%)	1 (Reference)		1 (Reference)	
Yes	57 (76%)	39(92.9%)	4.1 (1.13, 14.9)	0.03	8.9 (0.06,1396.1)	0.39
Duration of care in years						
< 1	12 (16%)	7 (16.7%)	1 (Reference)		1(Reference)	
1-5	35 (46.7%)	25(49.5%)	1.2 (0.42, 3.54)	0.71	0.35(0.05,2.32)	0.28
>5	28 (37.3%)	10(23.8%)	0.6 (0.19, 1.9)	0.41	0.58(0.07,4.48)	0.60
Social support for care						
None	38 (50.7%)	19(45.2%)	1 (Reference)		1 (Reference)	
Partially	22 (29.3%)	19(45.2%)	1.7 (0.78, 3.94)	0.19	1.52 (0.44, 5.23)	0.51
Full support	13 (13.3%)	3 (9.6%)	0.46 (0.12, 1.82)	0.27	0.65 (0.09, 4.82)	0.670
Partner's HIV status						
Infected	37 (62.7%)	13(61.9%)	1 (Reference)		-	-
Not infected	22 (37.3%)	8 (38.1%)	1.03 (0.37,2.9)	0.95	-	-

Table 4.7 Association between caregivers' psychosocial factors and children's level of adherence

Characteristics	Adherence <95% N=22	Adherence ≥95% N=94	Crude OR (95% CI)	P value	Multivariable OR (95% CI)	P Value
HIV status of the caregiver						
Infected	20 (90.9%)	76 (80%)	1 (Reference)		1(Reference)	
Not infected	1 (9.1%)	19 (20%)	2.5 (0.54, 11.64)	0.24	0.42(0.01,17.4)	0.65
Disclosure of the caregiver's HIV status						
No	13 (65%)	44 (58.7%)	1 (Reference)		-	-
Yes	7 (35%)	31 (41.3%)	1.31 (0.47, 3.7)	0.61	-	-
Stigma						
No	16 (72.7%)	29 (30.5%)	1 (Reference)		1(Reference)	
Yes	6 (27.3%)	66 (69.5%)	0.75 (0.26, 2.17)	0.60	1.33(0.03,49.6)	0.87
Duration of care in years						
< 1	6 (27.2%)	13 (13.7%)	1 (Reference)		1(Reference)	
1-5	11 (50%)	49 (51.6%)	2.06 (0.64, 6.6)	0.23	6(1.24,28.9)	0.02
>5	5 (22.7%)	33 (34.7%)	3.05 (0.79, 11.74)	0.11	1.98(0.34, 11.6)	0.445
Social support for care						
None	12 (57.1%)	45 (48.4%)	1 (Reference)		1(Reference)	
Partially	8 (38.1%)	33 (35.5%)	1.1 (0.4, 2.99)	0.85	11.46(0.4,5.34)	0.56
Full support	1(4.8%)	15 (16.1%)	4 (4.8, 33.4)	0.20	3.9(0.25,60.4)	0.33
Partner's HIV status						
Infected	9 (90%)	41 (58.6%)	1 (Reference)		-	-
Not infected	1 (10%)	29 (41.4%)	6.3 (0.76, 53.0)	0.09	-	-

4.4 Factors associated with caregivers' depression

We used logistic regression to analyze the association between caregivers' factors and depression. In multivariable analysis, marital status and caregiver's HIV status were significantly associated with depression. Caregivers who were married had 87% lower odds of being depressed compared to those who were single AOR 0.13(CI 0.03 - 0.59) ($p=0.009$). Additionally, caregivers who were HIV positive were 17 times more likely to be depressed compared to those who were HIV negative, AOR17.08 (95%CI 1.2-24.49, $p=0.037$). A longer duration of care was a protective factor for depression. For every additional year in care, there was a 31% reduced likelihood of depression AOR=0.69(95%CI: 0.53-0.90 $p=0.005$)

These findings are demonstrated on table 4.8 below.

Table4.8 Logistic regression model of factors associated with depression among caregivers

Characteristic	PHQ-9 <10 N= 92	PHQ-9 >10 24	COR	P value	AOR	P Value
Age						
Below 30 years	21(22.8%)	7(29.2%)	1(Ref)		1(Ref)	
31-45 years	60(65.2%)	16(66.7%)	0.8(0.29, 2.21)	0.667	1.45(0.33, 6.37)	0.626
Above 45 years	11(12%)	1(4.1%)	0.28(0.03, 2.5)	0.251	1.43(0.08, 25.63)	0.806
Gender						
Male	6(6.5%)	1(4.2%)	1(Ref)		1(Ref)	
Female	86(93.5%)	23(95.8%)	1.60(0.18, 14.0)	0.669	1.52(0.10, 22.88)	0.760
Marital status						
Single	19 (20.7%)	11(45.8%)	1(Ref)		1(Ref)	
Married	66(71.7%)	12(50%)	0.26(0.11, 0.71)	0.008	0.13(0.03, 0.59)	0.009
Other	7(7.6%)	5(4.2%)	0.49(0.09, 2.80)	0.426	0.45(0.05,4.1)	0.485
Education						
Primary	31(33.7%)	7(29.2%)	1(Ref)		1(Ref)	
Secondary	40(43.5%)	12(50%)	1.33(0.47, 3.77)	0.594	0.75 (0.16, 3.52)	0.715
Tertiary	21(22.8%)	5(20.8%)	1.05(0.29, 3.77)	0.935	0.40(0.06, 2.48)	0.326
Occupation						
None	16(18.4%)	10(43.5%)	1(Ref)		-	-
Formal employment	7(8%)	1(4.3%)	0.22(0.02,2.15)	0.196	-	-
Other	64(73.6%)	12(52.2%)	0.3(0.11,0.82)	0.190		

Primary care giver						
Biological Parent	72(78.3%)	23(95.8%)	1(Ref)		-	-
Non biological parent	20(21.7%)	1(4.2%)	0.16(0.02,1.23)	0.078	-	-
Caregiver's HIV status						
Not infected	19(20.7%)	1(4.2%)	1(Ref)		1(Ref)	
Infected	73(79.3%)	23(95.8%)	5.98(0.76,47.2)	0.089	17.08(1.2,24.49)	0.037
Caregiver disclosure of HIV status						
Yes	28(38.9%)	10(43.5%)	1(Ref)		-	-
No	44(61.1%)	13(56.55%)	0.83(0.32,2.14)	0.696	-	-
Social support						
None	46(51.1%)	11(47.8%)	1(Ref)		1(Ref)	
Partial	31(34.4%)	10(43.5%)	1.35(0.51, 3.56)	0.545	1.55(0.49, 4.93)	0.717
Full support	13(14.5%)	2(8.7%)	0.64(0.13,3.28)	0.595	0.09(0.01, 0.59)	0.950
Discordance						
No	77(83.7%)	22(91.7%)	1(Ref)		1(Ref)	
Yes	15(16.3%)	2(8.3%)	0.47(0.09,2.19)	0.335	0.13(0.01, 1.33)	0.086
Disclosure to the child						
No	11(25%)	2(50%)	1(Ref)		-	-
Yes	33(75%)	2(50%)	0.33(0.04,2.66)	0.299	-	-
Duration of care(in years)			0.83(0.69, 0.99)	0.046	0.69(0.53,0.90)	0.005
No of children			1.41(0.9, 2.22)	0.130	1.72(0.33,8.93)	0,520
No of HIV children			1.56(0.43, 5.64)	0.497	1.73(0.91,3.27)	0.092

CHAPTER 5: DISCUSSION

The key finding from this study is that one in every two caregivers of children living with HIV is depressed. Most of them were identified with mild depressive symptoms on our screening using PHQ. Majority of the caregivers were female, married and middle aged, with at least secondary level of education. Most of them were HIV infected. Being single and HIV infected were significantly associated with caregivers' depression, on the other hand, a longer duration of being a caregiver was associated with reduced likelihood of being depressed. Majority of the children in the study were below the age of 6 years, had good adherence to ART and were virally suppressed. Caregivers depression significantly affected the ART adherence and viral suppression among children.

Among the depressed caregivers, majority reported mild depression as per the PHQ-9 screening tool, with approximately only 38%(n=63) of the depressed caregivers having moderate to moderately severe depression. This is significant because it implies that with early screening and proper interventions, we can prevent progression into severe depression among the caregivers of HIV infected children. PHQ-9 is validated tool for use in screening and diagnosing depression among African adult population, including those infected with HIV(36). *Majority of them reported high burden in questions 6 (feeling bad about yourself, or that you are a failure, or have let yourself or your family down), followed by question 2 (feeling down, depressed and hopeless) and question 4 (feeling tired or having little energy).* Majority of the depressed caregivers were female, which may have been as a result of a higher majority of the caregivers in the study being female. However, studies have shown a higher prevalence of depression among women than men. The high prevalence of depression in this study is similar to findings from a study published by Itziar et al in done in Uganda, where 61% of the female caregivers of children living with HIV had mild to severe depression based on the Standard Hopkins Symptoms Checklist (HSC), with low SES and lack of social support stated as factors that were significantly associated with depression(31). In Kenya, a study done by

Wainana et al showed a high prevalence of depression at 64 % (n=228) among caregivers of HIV infected children at Lea Toto, Kibera. This similarity in prevalence is likely due the common challenges faced by caregivers of HIV infected children. In the above mentioned studies, most of the caregivers were HIV infected, female and from low socioeconomic status, similar to this study. HIV infected individuals face unique challenges in dealing with their individual health and that of their children which can be burdensome. Studies have shown that HIV infected people are three times more likely to be depressed than the general population(23). Consequently, depression impacts negatively on self-care needed in optimal management of HIV, quality of life and outcomes of people living with HIV. This in turn affects the quality of caregiving.

The second important finding was that caregivers' depression was associated with significantly reduced likelihood of achieving good adherence to ART and viral suppression. Among caregivers with moderate to moderately severe depression (PHQ-9 score ≥ 10), there was 31 times higher likelihood of their children not achieving viral suppression in comparison to children of caregivers who had PHQ-9 scores < 10 . Similarly, caregivers' depression was significantly associated with poor adherence to ART among children. Compared to children of caregivers who had PHQ-9 scores < 10 , those with moderate to moderately severe depression (PHQ-9 score ≥ 10) had 92% less likelihood of achieving a $\geq 95\%$ adherence to ART. Additionally, severity of caregivers' depression was associated with poorer outcomes in terms of viral suppression and adherence among HIV infected children. There was no association between caregivers' depression and missed clinic visits. These findings are similar to findings by Jaspan et al that showed that caregiver's depression was associated with poor ART adherence among their HIV infected children(23). Caregivers play a huge role in determining a child's adherence to ART as most children; particularly those below the age of 10 years rely on their caregivers for care(39).

Thirdly, the results of the study showed that factors that were significantly associated with caregiver depression included, being a single caregiver and being HIV infected, a finding that is consistent with a study done by Lentoer et al in south Africa. A longer duration of providing care was a protective factor. This could be explained by the fact that caregivers develop resilience and coping mechanisms which may be helpful in reducing the psychosocial burden.

Notably, a high majority of the children were virally suppressed and adherent to ART. High incidence of HIV stigma was noted among study participants indicating need to put more measures to curb HIV related stigma. In addition, most caregivers reported lack of social support from friends and family, which mainly was as a result of HIV associated stigma.

Although we found a high prevalence of depression among our study participants, several of the risk factors identified are modifiable and amenable to interventions that are locally available and affordable. In addition, majority of the caregivers suffer from mild depression which if detected and managed early will result to both good outcomes among the caregivers and children. With routine screening, it is possible to pick early stages of depression.

STUDY STRENGTHS

The PHQ-9 tool was easy to administer and well understood by the study participants.

Secondly, most of the children had viral loads and other clinical information available in the electronic medical records which made the collection of data and analysing efficient.

STUDY LIMITATIONS

The major limitation of this study was that it was cross-sectional study, meaning that exposure and outcome were measured at the same time therefore causal relationship could not be ascertained. Secondly, more females than male caregivers were interviewed which could have influenced the prevalence of depression as studies show that females are more likely to suffer from depression than males(41). Thirdly, the study relied on self-reported information from caregivers and there was no way to ascertain the accuracy of the information.

CHAPTER 6: CONCLUSIONS AND RECOMMENDATIONS

CONCLUSIONS

There is a high prevalence of depression among the caregivers of HIV infected children on follow up at the CCC in KNH. A third of the depressed caregivers had moderate to severe depression. Caregivers' depression is significantly associated with both poor children's adherence to ART and viral suppression. Finally, factors that are significantly associated with caregivers' depression included being a single caregiver and being HIV infected. A longer duration of providing care was protective of depression.

RECOMMENDATIONS

Assessment of depression should be done routinely using the PHQ-9 tool especially among caregivers of children with poor adherence and high viral loads, and those with the risk factors identified in the study which included, being a single caregiver, lack of social support, and those caring for more than three children. Secondly, to maximize positive outcomes, psychosocial support interventions should be coordinated with clinical care, and reach children and caregivers where they are such as in their communities, churches, and schools.

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CHAPTER 8

APPENDIX 1

CONSENT FORM FOR PARTICIPATION IN THE STUDY

Study title: prevalence of depression among caregivers of HIV infected children at CCC, Kenyatta National Hospital

Name of researcher: Dr Agatha Kihiu

I am a postgraduate student at the **University of Nairobi** pursuing a **Master of Medicine degree in Pediatrics and Child Health**.

I am conducting a study on the prevalence of depression among caregivers of HIV infected children at CCC, KNH. The purpose of this consent form is to give you the information you will need to help you decide whether or not you should participate in the study.

Depression is a major issue in people infected and affected by HIV and it affects both the caregiver and the people under their care. Your participation in this study will help me determine the percentage of caregivers of HIV infected children with depression. You will be requested to provide some information about yourself and in relation to caregiving of your child. We shall extract your child's details from the medical records/file. These includes their age, gender, when they were started on ART, WHO stage at diagnosis, current WHO stage, current vital load and Cd4 counts. The results of this study will help us to reorganize and plan our services so that we are able to provide the needed support to the caregiver as part of management and follow up of the HIV infected children.

If you agree to participate in the study, I shall ask questions such as your age, your income, your level of education. If there are any questions you do not want to answer, you can skip them. To protect your privacy, I shall not include your name. You have the right to refuse the interview or any questions asked during the interview.

Kindly understand the following:

Participation is voluntary.

Confidentiality shall be maintained at all times. We shall use a code number to identify you in a password-protected computer database and will keep all of our paper records in a locked file cabinet.

Refusal of any participation in the study will not attract any penalties. You and your child shall continue to receive treatment as required.

Risks: there are no risks in participating in this study. The participants will just be taken through a questionnaire guided interview.

Benefits: Any caregiver found to have depressive symptoms will be linked to care for further management. There is no monetary compensation for participating in this study.

If you have further questions or concerns about your participation in this study, please call or send a text message to the study staff on **0724799494**. For more information about your rights as a research participant, you may contact the Secretary/Chairperson, Kenyatta National Hospital-University of Nairobi Ethics and Research Committee Telephone No. **2726300 Ext. 44102** email **uonknh_erc@uonbi.ac.ke**.

Your decision to participate in this research is voluntary. You are free to decline or withdraw participation in the study at any time without injustice or loss of benefits (Just inform the study staff and your participation in the study shall be stopped). You do not have to give reasons for withdrawing if you do not wish to do so. Withdrawal from the study will not affect the services you and your child is otherwise entitled to in this health facility or other health facilities.

CONSENT FORM

The aim of this document is to seek your permission to participate in this study.

Participant statement

I have read this consent form or had the information read to me. I have had the chance to discuss this research study with a study counselor. I have had my questions answered by him or her in a language that I understand. The risks and benefits have been explained to me. I understand that I shall be given a copy of this consent form after signing it. I understand that my participation and that of my child in this study is voluntary and that I may choose to withdraw at any time. I understand that all efforts shall be made to keep information regarding me and my child's personal identity confidential. By signing this consent form, I have not given up my child's legal rights as a participant in this research study.

I voluntarily agree to participate in this research study: Yes No

I agree to provide contact information for follow-up: Yes No

Participant signature /Thumb stamp: _____ Date _____

Researcher's statement

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has knowingly given his/her consent.

Printed Name: _____ Date: _____

Signature: _____

Role in the study: _____

Witness Printed Name _____

Signature: _____ Date; _____

**IDHINI YA KUSHIRIKISHWA KATIKA UTAFITI
KIWANGO CHA HUZUNI KATI YA WALEZI WA WATOTO
WALIOAMBUKIZWA VIRUSI VYA UKIMWI AMBAO WANAPATA HUDUMA
KWENYE KLINIKI YA CCC KATIKA HOSPITALI YA KITAIFA YA KENYATTA.**

Jina la mtafiti: Dr Agatha Kihiu

Mimi ni mwanafunzi wa Uzamili katika Chuo Kikuu cha Nairobi ninayesomea shahada ya afya na magonjwa ya watoto.

Ili kuhitimu shahada hii, ninafanya utafiti juu kiwango cha huzuni kati ya walezi wa watoto walioambukizwa na virusi vya ukimwi ambao wanapata huduma kwenye kliniki ya CCC katika hospitali ya kitaifa ya Kenyatta.

Ushiriki wako katika utafiti huu utanisaidia kudhibitisha kiwango cha huzuni kati ya walezi wa watoto walioambukizwa na virusi. Kusudi kuu ya kukupa habari hizi ni kukuwezesha kuamua iwapo utakubali kushiriki kwenye utafiti huu.

Iwapo utakubali kuhusishwa kwenye utafiti huu, nitakuuliza maswali kukuhusu kama vile umri wako, kiwango cha elimu kati ya maswali mengine.

Tafadhali elewa yafuatayo: -

1. Ushiriki ni kwa hiari. Nitaitunza siri yako. majibu yako katika kijikaratasi cha maswali yatahifadhiwa kwenye kompyuta iliyo na neno siri na kufungiwa kwa kabati iliyo na kufuli.
2. Kukataa kushiriki katika utafiti hautavutia adhabu yoyote. Wewe pamoja na mtoto wako mtaendelea kupokea matibabu inayo stahili. Hakuna hatari inayotarajiwa kwa kushiriki katika utafiti huu.
3. Mshiriki yeyote atakayepatikana na huzuni atahusishwa na mtaalamu wa saikologia na madaktari ili kupata matibabu.
4. Hakuna fidia ya fedha kwa ajili ya kushiriki katika utafiti huu.

Uko na uhuru wa kukataa kuhusishwa katika utafiti huu wakati wowote kupitia **nambari 0724799494**. Utakapobadilisha nia ya uhusisho unaweza andika barua pepe au kupiga simu kwa kamati ya maadili ya hospitali kuu ya Kenyatta kwa **nambari 2726300 Ext. 44102** ama barua pepe: uonknh_erc@uonbi.ac.ke.

Kauli ya mshiriki

Nimeisoma fomu hii ya idhini na kuelewa inavyoagiza. Nimejadiliana na mshauri wa utafiti barabara na maswali yangu yamejibiwa kwa ugha ninayoielewa. Nimeelezwa hatari na faida za ushirikisho kwa utafiti huu. Ninaelewa kuwa nitapewa nakalaya idhini hii nitakapoisahihisha. Ninaelewa kuwa siri zangu zitatumzwa vyema. Ninaelewa kuwa ushirika

wangu katika utafiti huu ni kwa hiari na ninaweza kukataa kuhusishwa kwa utafiti wakati wowote.

Nimekubali kwa hiari kushiki kwa utafiti huu: Ndio ____ La ____

Nimekubali kumpa mtafiti nambari ya simu: Ndio ____ La ____

Sahihi ya mshiriki _____ Tarehe _____

Kauli ya mtafiti

Mimi niliyesahihisha idhini hii nimeeleza mzazi barabara maelezo muhimu kuhusu utafiti huu na ninaamini kuwa ameelewa na kukubali kushirikishwa katika utafiti huu.

Jina la mtafiti _____ Tarehe _____

Sahihi _____

Jina la shahidi _____ Tarehe _____

Sahihi ya shahidi _____

APPENDIX 2:

QUESTIONNAIRES

STUDY TITLE: DEPRESSION AMONG CAREGIVERS OF HIV INFECTED CHILDREN
AGED 10 YEARS AND BELOW AT CCC, KNH

RESEARCHER: DR AGATHA W. KIHU

(Tick where appropriate)

SERIAL NO..... **Date of Interview**/...../.....

Part 1: Caregiver's details

1. Age
2. Gender:
 - a) Male
 - b) Female
3. Marital status:
 - a) Single
 - b) Married
 - c) Other (specify).....
3. Level of education
 - a) None
 - b) Primary
 - c) Secondary
 - d) Tertiary
4. Occupation
 - a) None
 - b) Casual laborer
 - c) Self-employed
 - d) Formal employment

Part 2: Household characteristics

1. What is your main source of drinking water?
 - a) Piped water
 - b) Borehole
 - c) Dug well
 - d) Rain water
 - e) Surface water (river, dam/lake/pond)
2. What kind of toilet facility do members of your household usually use?
 - a) Flush toilets

- b) Pit latrine
- c) Bucket toilet
- d) No facility/bush/field

3. Does your household have the following?

a) Electricity? Yes

No

b) A TV set? Yes

No

c) Phone? Yes

No

3. What type of fuel does your household use mainly for cooking?

- a) Electricity
- b) Gas
- c) Kerosene
- d) Charcoal
- e) Wood

4. Does your household own the structure your house sits on?

- a) Owns
- b) Pays rent/lease
- c) No rent (with consent of owner)
- d) No rent (squatting)

5. Does your household receive any cash or social assistance from the government?

a) Yes

b) No

For what reason does the household receive a cash transfer or social assistance?

- a) Orphaned children 18 years or younger.
- b) Elderly person(s)
- c) Person with severe disability
- d) Urban food subsidy
- e) Health voucher
- f) Other (specify)

12) How many people are currently living in your household, including you?.....

How many of these are children?

- a) 0-5years
- b) 6-10
- c) Above 12

Part 3: Caregiving of a HIV infected child

1. What is your relation to the child?

- a) Parent
- b) Grandparent
- c) Sibling
- d) Aunt/uncle
- f) Adoptive parent

2. How long have you been giving care to the child?

3. Have you disclosed to the child about their HIV status?

- a) Yes
- b) No

If yes, a) Partial disclosure

b) Complete disclosure

If not, what is your reason for not disclosing?

4. Who administers ARV's to the child?

- a) Myself
- b) The child
- c) Other family member (specify).....
- d) Different members of the family.

5. What is your HIV status?

- a) Infected
- b) Not infected
- c) Unknown

5. If answer (a), have you disclosed to any friend/family?

- a) Yes
- b) No

What is your reason for non- disclosure?.....

6. What is your partners HIV status?

- a) Infected
- b) Not infected
- c) I don't know

7. How many member(s) of your household living with HIV?

How many of these are children?

- a) 0-5years
- b) 6-10
- c) Above 12

8. Have you received adherence counseling before?

- a) Yes
- b) No

9. Have you missed any doses of your ARVs over the last 1 week? Yes/no

What was your reason for missing your dose(s).....

10. Do you feel like you have the support of your family and friend as regards your/your child's or your condition?

- a) Partially
- b) Full support
- c) None

Part 4: HIV stigma

- a) some people act as though it's my fault I have HIV
- b) I have stopped socializing with some people because of their reaction to my status
- c) I have lost friends because of my status
- d) No one knows I have HIV
- e) I regret having told some people that I have HIV
- f) People I cared about stopped associating with me when they learnt about my status
- g) People who know my HIV status ignore my opinion
- h) People seem afraid of me once they learn I have HIV
- i) When people learn you have HIV they look for flaws in your character
- j) Peoples attitude make me feel worse about myself
- k) People with HIV are treated like outcasts
- l) Most people believe that a person who has HIV is dirty

Part 5: Child's details

- a) Age
- b) Gender
- c) ART regimen
- d) Duration of time on ART
- e) Most recent Viral Load Count
- f) WHO stage at initiation of treatment
- g) Current WHO stage
- h) Percentage pill count

PATIENT HEALTH QUESTIONNAIRE (PHQ-9)

NAME:

DATE:

Over the last 2 weeks, how often have you been bothered by any of the following problems?
(use "✓" to indicate your answer)

	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed. Or the opposite being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead, or of hurting yourself	0	1	2	3

add columns

+

+

(Healthcare professional: For interpretation of TOTAL, please refer to accompanying scoring card). **TOTAL:**

10. If you checked off *any problems*, how *difficult* have these problems made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all
Somewhat difficult
Very difficult
Extremely difficult

APPENDIX 3: KNH Ethical Approval Letter



UNIVERSITY OF NAIROBI
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Ref: KNH-ERC/A/384

16th October, 2019

Dr. Agatha Wangari Kihiu
Reg. No. H58/7132/2017
Dept. of Paediatrics and Child Health
School of Medicine
College of Health Sciences
University of Nairobi



Dear Dr. Kihiu,

RESEARCH PROPOSAL: PREVALENCE OF DEPRESSION AMONG CAREGIVERS OF HIV INFECTED CHILDREN AGED 10 YEARS AND BELOW ON FOLLOW UP AT COMPREHENSIVE CARE CLINIC AT KENYATTA NATIONAL HOSPITAL (P521/06/2019)

This is to inform you that the KNH- UoN Ethics & Research Committee (KNH- UoN ERC) has reviewed and approved your above research proposal. The approval period is 16th October 2019 – 15th October 2020.

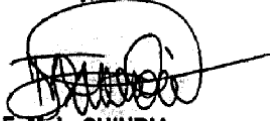
This approval is subject to compliance with the following requirements:

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

Protect to discover

For more details consult the KNH- UoN ERC website <http://www.erc.uonbi.ac.ke>

Yours sincerely,



PROF. M. L. CHINDIA
SECRETARY, KNH-UoN ERC

c.c. The Principal, College of Health Sciences, UoN
The Director, CS, KNH
The Chairperson, KNH- UoN ERC
The Assistant Director, Health Information, KNH
The Dean, School of Medicine, UoN
The Chair, Dept. of Paediatrics and Child Health, UoN
Supervisors: Dr. Beatrice Mutai (Dept. of Paediatrics and Child Health, UoN),
Prof. Ruth Nduati (Dept. of Paediatrics and Child Health, UoN),
Dr. Manasi Kumar (Dept. of Psychiatry, UoN)

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