PSYCHIATRIC MORBIDITY AND CARE AMONG CHILDREN AND ADOLESCENTS WITH HIV INFECTION AT MOI TEACHING AND REFERRAL HOSPITAL ELDORET, KENYA

BY

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MOI UNIVERSITY

DECLARATION

I declare that this research thesis is my original work and has not been presented in any other university/institution for consideration for any certification. This research has been complemented by referenced sources duly acknowledged. Where text, data, graphics, pictures or tables have been borrowed from other sources, including the internet, these are specifically accredited and references cited using current American Psychologist Association (APA) system and in accordance with anti-plagiarism regulations.

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LIST OF ABBREVIATIONS/ACRONYMS

AIDS	Acquired Immunodeficiency Disease Syndrome
AMPATH	Academic Model Providing Access to Healthcare
ARV	Antiretroviral Drug
ASD	Autism Spectrum Disorder
CALHIV	Children and Adolescents Living with HIV
CDI	Child Depression Inventory
CNS	Central Nervous System
CPRS	Conner's Parent Rating Scale
DSM-5	Diagnostic Statistical Manual Fifth Edition
DSM-IV	Diagnostic Statistical Manual Fourth Edition
HAART	Highly Active Antiretroviral Drugs
HIV	Human Immunodeficiency Virus
MINI Kid	Mini International Neuropsychiatric Interview for Children and Adolescents
MTRH	Moi Teaching and Referral Hospital
PHEU	Perinatally exposed to HIV but uninfected
PHIV-	Perinatally exposed to HIV who is HIV negative
PHIV+	Perinatally exposed to HIV who is HIV positive
PLWH	People living with HIV/AIDS
UNAIDS	United Nations Program on HIV and AIDS
UNICEF	United Nations Children's Fund
USA/US	United States of America
WHO	World Health Organization

KEY DEFINITIONS

Psychiatric morbidity - A term of art for mental illness. This term has been used synonymously with psychiatric disorder and mental disorder in this study**.**

According to DSM-5, **a mental disorder** is a syndrome characterized by clinically significant disturbance in an individual's cognition, emotion regulation, or behaviour that reflects a dysfunction in the psychological, biological, or developmental processes underlying mental functioning. Mental disorders are usually associated with significant distress in social, occupational, or other important activities (American Psychiatric Association 2013).

Examples include: Autism spectrum disorder, Attention-Deficit/Hyperactivity Disorder, Schizophrenia, Bipolar and related disorders, Major Depressive disorder, Anxiety disorders among others.

Anxiety disorders are characterized by excessive and persistent fear, worry, anxiety and related behavioral disturbances. Fear involves an emotional response to a threat, whether that threat is real or perceived. Anxiety is anticipation of future threat. Types of Anxiety disorders according to DSM-5 include: Separation anxiety disorder, Selective mutism, Specific phobia, Social anxiety disorder, Panic disorder, Agoraphobia and Generalised anxiety disorder (American Psychiatric Association 2013).

Attention deficit hyperactivity disorder is characterized by developmentally inappropriate, persistent problems in inattention and/or impulsivity that significantly interfere with functioning or development (American Psychiatric Association 2013)

Autism spectrum disorder is defined by core impairments in social communication behaviours and the presence of repetitive and stereotyped behaviours (American Psychiatric Association 2013).

Bipolar disorders are characterized by shifts in mood as well as changes in activity and energy levels. The disorder often involves experiencing shifts between elevated moods and periods of depression. Such elevated moods can be pronounced and are referred to either as mania or hypomania (https://www.verywellmind.com/a-list-of-psychological-disorders-2794776).

For a diagnosis of bipolar I disorder, it is necessary to meet the criteria for a manic episode. For a diagnosis of bipolar II disorder, it is necessary to meet the criteria for a current or past hypomanic episode and for a current or past major depressive episode (American Psychiatric Association 2013).

Major Depressive disorder is characterized by discrete episodes of at least 2 weeks duration (although most episodes last considerably longer) involving clear-cut changes in mood, cognition, and neurovegetative functions. At least one of the symptoms is either depressed mood or loss of interest or pleasure (American Psychiatric Association 2013).

Suicidality is a term used to describe suicidal ideation (serious thoughts about taking one's own life), suicide plans and suicide attempts.

(https://www1.health.gov.au/internet/publications/publishing.nsf/Content/mental-pubs-m-mhaust2-toc~mental-pubs-m-mhaust2-hig~mental-pubs-m-mhaust2-hig-sui).

Orphan - UNICEF and global partners define an orphan as a child under 18 years of age who has lost one or both parents to any cause of death (https://www.unicef.org/media/orphans).

Foster care - A system in which a minor (usually an orphan or an abandoned child) has been placed into a group home (treatment centre or charitable children's Institutions), or private home of a state-certified caregiver, referred to as a "foster

parent". The placement of the child is normally arranged through the government or a social service agency (https://en.wikipedia.org/wiki/Foster_care).

Model of Mental Health Care - Is a term that defines the way mental health services are delivered. It outlines the best practice care and services for a person, population group or patient cohort. It aims to ensure people get the right care, at the right time, by the right team and in the right place (Framework, n.d.).

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ABSTRACT

Background: Psychiatric disorders and Human Immunodeficiency Virus (HIV) have been closely interlinked with a causal relationship having been demonstrated. Among children, mental disorders are a significant public health concern due to the rising prevalence. The effects of HIV and mental disorders are pervasive and have far reaching implications that impact on communities not only psychologically but also economically and socially**.** However, little is known about the prevalence of mental disorders among children/adolescents with HIV-infection and no studies have been done on the integration of mental health services in HIV programs in our setting. This will be the first study in our setting to give a baseline of prevalence of psychiatric disorders among children and adolescents living with HIV while assessing the integration of mental health services in the HIV program.

Objective: This study investigated the prevalence, patterns and factors associated with psychiatric morbidity, while assessing models of mental health care of HIV-infected children and adolescents between 6 and 17 years of age at Moi Teaching and Referral Hospital (MTRH).

Methods: This was a descriptive cross-sectional study. Systematic sampling was applied for children and adolescent group while a census was done for health workers group. Mini Neuropsychiatric Interview for children and adolescents (MINI Kid) was used for measuring psychiatric morbidity among children and adolescents with HIV infection. Researcher designed questionnaires were used to obtain sociodemographic data, clinical information and assess the models of mental health care. The study was carried out at MTRH - Academic Model Providing Access to Healthcare (AMPATH) Paediatric/Adolescent HIV clinics. Approval to conduct the study was given by Institutional Research and Ethics Committee. A total of *391* children/adolescents with HIV infection and 18 health workers at the AMPATH Paediatric/Adolescent HIV clinics were interviewed. Descriptive statistics were used to explore the data while Chi-square test, Fishers exact test and logistic regression were used to assess associations. Associations with p value less than 0.05 were considered statistically significant.

Results The median age of the children/adolescents was 13 years (Interquartile range 11 - 15 years) with a female to male ratio of 1:1. The prevalence of psychiatric morbidity among children/adolescents with HIV infection was 57.5%. The most prevalent disorders were Anxiety 53.8%, Suicidality 10.4% and Attention Deficit Hyperactivity Disorder 10%. Only 1.7 % of those who screened positive for psychiatric disorders had ever been diagnosed or received treatment. Compared to those less than 12 years, children older than 12 years had 36.3% reduced odds of having anxiety (O.R=0.637 C.I [0.425 - 0.953]; p value=0.028). Majority of the health workers were nurses and clinical officers and half of them were below 35 years of age. Only 38.9% of them had any mental health training. Mental health services available at the clinics were psychological counselling, group therapy and review by a psychiatrist once a week. There was ongoing screening for mental disorders and referral to appropriate mental health services.

Conclusion There was a high prevalence of psychiatric disorders among children/adolescents with HIV infection. Most of the disorders were undiagnosed and therefore not treated despite there being mental health services at the AMPATH Pediatrics/Adolescent HIV clinics.

Recommendations Due to the high prevalence, screening for psychiatric disorders should be enhanced at the AMPATH Paediatric/Adolescent HIV clinics. Secondly, health care providers should have regular training on basic mental health care. Finally, further research needs to be done to determine the barriers to access and uptake of mental health services at the AMPATH Paediatric/Adolescent HIV clinics.

CHAPTER ONE

INTRODUCTION

1.1 Background of the Study

Studies have shown that 1/5 of children and adolescents suffer incapacitating mental illness with suicide being among the top 3causes of death among the youth. Furthermore, the commencement of about 50% of mental disorders experienced in adulthood can be traced back to adolescence or childhood (Belfer, 2008). Human Immunodeficiency Virus (HIV) infection is among the common factors contributing towards mental disorders among children (Nassen et al., 2014). This is especially evident in the developing world which carries the highest HIV burden. HIV and psychiatric disorders were projected to be among the 10 leading causes of morbidity especially in low income countries (Murray & Lopez, 1997). A more recent survey of 2010 established that mental health disorders were responsible for up to 183·9 million Disability-Adjusted Life Years (DALYs) (Whiteford, Degenhardt, Rehm, Baxter, Ferrari, Erskine, Charlson, Norman, Flaxman, Johns, & others, 2013). This means that a surmountable number of years of potential life and years of productive life were lost secondary to disability and premature death as a result of mental disorders.

Human Immunodeficiency Virus has undeniably been one of the most catastrophic global pandemics with an estimated 3.4 million children 15 years and below living with HIV in 2010 (WHO, 2011). In 2018 UNAIDS established that 1.7 million were children below 15 years of age (https://www.unaids.org/en/resources/fact-sheet). In 2010 Sub-Saharan Africa was estimated to have more than 3 million children of 15 years and below living with HIV. This indicated that Sub-Saharan Africa was carrying more than 90% of the global HIV burden among children. Furthermore, data indicates that Eastern and Southern Africa bear a larger burden in Africa with 2.2

million children living with HIV, compared to the 990,000 children living with HIV in West and Central Africa (Sohn & Hazra, 2013).

The high prevalence of HIV among children and adolescents is an indicator that HIV is of great public health concern given that the youth are hardest hit by the epidemic. Furthermore, evidence has indicated that without treatment, deaths among children vertically infected with HIV would increase by up to 3 times (Ferrand, Corbett, Wood, Hargrove, & Chiratidzo, 2012). However, advances in treatment of HIV infected children with Highly Active Antiretroviral Treatment (HAART) have drastically transformed the HIV pandemic from an acute illness with high mortality to a chronic and manageable condition (Dorrell, Earle, Katz, & Reveley, 2008; Organization, Unicef, & others, 2011). HAART has been defined as antiretroviral therapy (ART) which is potent enough to suppress the HIV virus to undetectable levels, as measured by the most sensitive assay available. Levels of the HIV virus in the human body are measured using a serum viral load, a measure that is used to monitor the efficacy of ART. Ideally HAART includes three or more antiretroviral drugs. (Sik-to, Chin-peng, Chung-ki, & Tak-yin, 2011).

Strong evidence has demonstrated that a substantial and prolonged epidemic of HIV in older children is emerging, after the introduction of treatment for all HIV infected children with HARRT, with a considerable number of survivors living well into adulthood (Ferrand, Corbett,et al., 2012). This may be attributed to significant reduction in HIV/AIDS mortality in both the paediatric and adult population, with Autoimmune Deficiency Syndrome (AIDS) - related deaths being estimated to have reduced by more than 55% since the peak of the pandemic in 2004 (https://www.unaids.org/en/resources/fact-sheet). Reduction in mortality rates has

increased life expectancy, with children and adolescents living with HIV living longer, well into adulthood. These children and adolescents are thereby at high risk for mental health problems common among children with other chronic disorders, and this risk is compounded by genetic, biomedical, familial and environmental factors (Mellins & Malee et al., 2013).

The patho-physiology of the HIV virus infection involves damage to the central nervous system (CNS) resulting in neuropsychiatric complications including depression, mania, HIV encephalopathy and cognitive disorders among others. Among children with HIV infection, deficits in motor and cognitive development have been found to be prominent (Board E., 2008). A number of aetiologies have been proposed as causes for mental disorders among HIV-infected children; brain damage secondary to HIV infection being one of the principal etiological factors (Nozyce et al., 2006). Neuroimaging techniques have been utilized to demonstrate evidence of HIV involvement in the neurologic functioning of the frontal cortex, basal ganglia, and connecting structures in the central nervous system. Noteworthy is that these structures (cortex, basal ganglia and connecting structures) have been associated with regulation of attention and concentration and other regulatory behaviours that are problematic in children diagnosed with ADHD and other childhood psychiatric disorders (Brouwers et al., 1995). Furthermore recent studies have shown that children living with HIV experience significant mental and motor developmental delays when compared to a similar group of uninfected children (Blanchette, Smith, Fernandes-penney, King, & Read, 2001). It has also been observed that children remain susceptible to the effects of HIV on the brain even when on treatment with HAART. This is because the CNS acts as a reservoir for persistent viral replication.

Initiation of ART, then, may not fully reverse CNS insults of the HIV virus, mostly if treatment was not commenced during infancy (Nassen et al., 2014).

Children/adolescents living with HIV are at high risk for mental health issues that are common among children with other chronic disorders (Wolman, Resnick, Harris, & Blum, 1994). In addition, burdening social determinants of health like poverty and orphan-hood, as well as psychosocial stressors related to living with HIV, such as stigma and emotional strain, play an important role in the development of mental disorders among HIV infected children (Cluver, Gardner, & Operario, n.d.). Many children and adolescents with HIV infection are infected through mother to child transmission while others through sexual abuse and others through early sexual activity (Musisi & Kinyanda, 2009); https://www.avert.org/professionals/hiv-programming/prevention/prevention-mother-child) Children who acquire HIV perinataly have been observed to be affected by HIV issues their entire lifespan. They face peculiar life stressors including: accepting their HIV status and disclosure issues, maintaining adherence to treatment and coping with feelings of isolation. Moreover, challenges of emerging sexuality, avoiding high risk behaviours and disclosure of HIV status to sexual partners add on to the myriad of issues these youth are facing (UNICEF Report, 2013). Consequently, poverty, orphan-hood and parental illness (physical and mental), place them at further risk of poor educational and mental health outcomes. Furthermore, the mental health issues, lack of adolescent-friendly clinical environment and life changes pose challenges with adherence to treatment plans, worsening the double disease tragedy (Nassen et al., 2014).

In view of the evidently significant public health burden resulting from HIV and mental disorders, there is need for a holistic approach in the care of

children/adolescents with these conditions. This builds the rationale for the comprehensive integration of mental health services into HIV programs. Mental disorders often impact heavily on HIV treatment course and untreated mental illness can result in children having poor educational and medical outcomes, being vulnerable to depression, school failure or dropout, sexual risk behaviours and substance use disorders (Nassen et al., 2014). In addition studies have shown that addressing the psychosocial and health care needs of People Living With HIV (PLWH) with psychological interventions such as counselling, cognitive-behavioural therapies, anxiety management and other modes of psychotherapy results in reduction of mental health problems (Ammassari et al., 2004). Similarly, perinataly exposed HIV positive youth who had been engaged in comprehensive HIV programs inclusive of psychopharmacological and psychotherapeutic interventions, seem to have better identification and treatment of mental health needs (Dolezal, et al., 2013)

Research in mental health is central and mandatory in order to investigate and address emerging issues. However very little research on mental health and HIV has been done in Africa with compounding challenges of availability of simple and validated screening tools. One of the screening tools previously used in Kenya for research in Child and Adolescent Psychiatry is the Mini Neuropsychiatric Interview for children and adolescents (MINI Kid) (Kamau, Kuria, Mathai, Atwoli, & Kangethe, 2012; Syengo-Mutisya, Kathuku, & Ndetei, 2008). Other tools developed for child psychiatry research and mental health screening include: Diagnostic Interview for Children and Adolescents (DICA); Diagnostic Interview Schedule for Children (DSC); Child Assessment Schedule (CAS); and Child and Adolescent Psychiatric Assessment (CAPA). These tools generally target children from ages 6 to 18 yrs and take an average time of 60 to 120 minutes to administer (Ebert & Leckman, 2015).

The MINI kid tool on the other hand takes between 21 to 50 minutes to administer which may contribute to its increasing popularity above the other tools (D V Sheehan et al., 2010).

This study was carried out within the Paediatric and Adolescent HIV clinics at AMPATH-MTRH, Eldoret Kenya. Academic Model Providing Access to Healthcare (AMPATH) is an academic and medical partnership between North American academic health centres led by the Indiana University School of Medicine in Indianapolis-Indiana(USA) and the Moi University School of Medicine together with Moi teaching and Referral Hospital (MTRH) - Eldoret, Kenya (Detailed description of the study site is provided in the methodology). Some of the observations reported from clinicians at the AMPATH Paediatric HIV clinics included psychosocial challenges that some of the children and adolescents were experiencing. At about 10 years of age, most children and adolescents are taken through a disclosure process. Some clinicians have observed that during the disclosure process some children express emotional or psychological distress and even depressive symptoms. The clinicians have also observed that as a result of difficult situations at home or at school the adolescents experience mental health challenges. This has led to an increasing need for screening, early detection and management of psychological and mental health issues among these children and adolescents with HIV infection.

1.2 Statement of the Problem

The effects of HIV/AIDS and mental disorders are diverse and have far reaching implications that impact on communities not only psychologically but also economically and socially**.** The global burden of disease survey projected that by the year 2020, mental disorders and HIV/AIDS would be among the top 10 causes of morbidity in developing countries with mental disorders projected to contribute to 15% of the world's burden of disease by 2020 (Harpham et al., 2003; Whiteford, Degenhardt, Rehm, Baxter, Ferrari, Erskine, Charlson, Norman, Flaxman, Johns, Burstein, et al., 2013). The high cost of the two diseases wreaks havoc within communities where the already fragile structures are not capable of absorbing further strain (Harpham et al., 2003; Rosen et al., 2004). Furthermore, almost half of mental disorders seen among adults commence early in life and can be traced back to childhood or adolescence, and as such have a heavy impact on the child, family, and community leading to a lower quality of life (Belfer, 2008). In addition, children with psychological difficulties have been seen to be more likely to undergo more debilitating adverse life events with progression of the psychiatric disorders. Moreover, the experience of these adverse events often negatively influence the children's prognosis forming a vicious cycle between psychiatric disorders and adverse life events (Ford, Collishaw, Meltzer, & Goodman, 2007).

Children and adolescents make up a significant proportion of the population in low and middle income countries and many of them are living with HIV (Woollett, Cluver, et al., 2017). In Kenya, youth 15-24 years of age accounted for 12% (184,719) of the total number of people living with HIV and while 105,213 (6%) were children 0-14 years of age. Uasin Gishu County where this study was carried out, accounted for approximately 2.1% (4000) of the youth 15-24 years of age living with HIV and

2.4% (2,620) of children 0-14 years living with HIV (Kenya, n.d.). This paints a picture of a huge burden of HIV among the youth and children in Kenya and Uasin Gishu County where this study was carried out.

The prevalence of mental health problems among children and adolescents infected with HIV has been estimated to range between 25 - 50% (Nassen et al., 2014). This was higher than the prevalence rate of mental disorders among children in the general population at 17% in south Africa and 20% in other parts of the world (Belfer, 2008; Kleintjes, Fick, Railoun, Lund, & Molteno, 2006).

Many children and adolescents with HIV infection face peculiar life stressors including: accepting their HIV status and disclosure issues, maintaining adherence to treatment and coping with feelings of isolation. Moreover, challenges of emerging sexuality, avoiding high risk behaviours and disclosure of HIV status to sexual partners add on to the myriad of psychosocial issues these youth have to constantly battle with (UNICEF & others, 2013). In addition, poverty, orphan-hood and parental illness (physical or mental), place them at further risk of poor educational and mental health outcomes (Musisi & Kinyanda, 2009; Nozyce et al., 2006). Furthermore, the mental health issues, lack of adolescent-friendly clinical environment and life changes pose challenges with adherence to HIV medication treatment plans, worsening the double HIV/Mental illness disease tragedy (UNICEF & others, 2013). It has also been observed that, children receiving HAART may remain susceptible to the effects of HIV on the brain. This is because the CNS acts as a reservoir for persistent viral replication. Initiation of ART, then, may not fully reverse CNS insults of the HIV virus, mostly if treatment was not commenced during infancy (Nassen et al., 2014).

However, the burden of mental disorders especially among children and adolescents with HIV infection is often underestimated because the link between mental illness and other health conditions is most often underappreciated (Myer et al., 2008). Furthermore, very little knowledge is available about the occurrence of mental health disorders among children and adolescents with HIV-infection. This is because research on mental health among children and adolescents lags behind especially in developing countries (Vreeman, McCoy, & Lee, 2017). It has also been observed that health care workers in HIV care programs especially in low income countries, have little knowledge and capacity to give the much needed mental health services. This has resulted in inadequate integration of mental health services in HIV programs especially in the developing world (Freeman, Patel,et al., 2005). Furthermore, mental health training for health workers has been found to be limited and often out-of-date (Vreeman et al., 2017). One study in Kenya having observed such huge gaps, emphasised that it is critical to integrate mental health services into the routine care of HIV-infected children (Kamau et al., 2012). Health services are not provided equitably to people - much less to children with psychiatric disorders, and the quality of mental health care especially for children and adolescents needs to be improved. The gaps in resources for mental health care for children have been identified as follows: Economic, Manpower, Training, Services and Policy (Belfer, 2008).

This study therefore set out to address above gaps by investigating and establishing the burden and patterns of psychiatric disorders among children and adolescents with HIV infection between 6 and 17 years of age at AMPATH-MTRH. The study also aims to highlight the existing capacities and possible challenges with integration of mental health services in the AMPATH Paediatric and Adolescent HIV clinics by assessing the models of mental health care in use at the clinic.

1.3 Justification

A rising prevalence of mental disorders among children and adolescents has been documented (Belfer, 2008). However there is paucity of data on this subject especially concerning vulnerable children and adolescents living with HIV. This justifies the need for more research to be carried out documenting the trends of mental disorders among children and adolescents especially in low and middle income countries.

Research in mental health is central and mandatory in order to investigate and address emerging issues. However not much mental health research is being carried out seeing that only 3.5% of internationally accessible health literature was related to mental health (Saxena & Par, 2002). Furthermore, mental health research in Africa and many low income countries is severely limited by challenges like limited access to information, lack of advice on research design and statistics and lack of simple and validated screening tools (Mabugu, Revill, & van den Berg, 2013; Saxena & Par, 2002).

To further demonstrate the paucity of research, only one similar study to this current study has been carried out Kenya, investigating the psychiatric morbidity among children and adolescents with HIV disease. This study, that engaged participants from a predominantly poor socioeconomic background in Nairobi-Kenya, reported a 48% prevalence of psychiatric disorders among the children and adolescents living with HIV (CALHIV) (Kamau et al., 2012). This current study purposed to challenge those findings by engaging participants coming from different socio-economic backgrounds in that the clients coming to the AMPATH clinics in MTRH are drawn from both rural, urban and semi-urban regions within Uasin Gishu county and other counties in the western part of Kenya (https://www.mtrh.go.ke/?page_id=598). Furthermore, the

MINI Kid that Kamau et al used to measure psychiatric morbidity was later revised to a more updated version with considerations of revision of the diagnostic statistical manual from DSM IV to DSM 5 (D V Sheehan et al., 2010). In addition HIV protocols on treatment of HIV infected children and adolescents have been updated since the Nairobi study was carried out. Therefore this study set out to investigate any differences in patterns of psychiatric disorders in view of the sociodemographic and clinical differences between the two population samples.

The study carried out in Nairobi also observed the importance of integrating mental health services into the routine care of HIV-infected children especially routine screening for commonly occurring disorders (Kamau et al., 2012). The state of child welfare in HIV care can only be comprehensive with a holistic approach to care, bearing in mind that children deserve the opportunity to have psychosocial and mental disorders identified early so as to ensure they obtain optimum quality of life (Woollett et al., 2017). This study therefore takes into account that all childhood mental health pathways and prevention services are informed better by growing knowledge of the substantial role that childhood trauma - in this case HIV infection, plays in causing and exacerbating mental illnesses.

The need for integration of mental health services in HIV care cannot be overemphasized. The rationale for integration of mental health services into HIV care is necessitated by observations that untreated mental illness may result in children having poor educational and medical outcomes including vulnerability to depression, school failure/dropout, risky sexual behaviours and substance use disorders (Musisi & Kinyanda, 2009; Nozyce et al., 2006). In addition, it has been noted that comprehensive management of mental illness in HIV infected individuals resulted in

improved adherence, social well being, cognition and even motivational aspects (Freeman et al., 2005).

MTRH already has a working liaison system which integrates mental health services with the inpatient services in various departments like Internal Medicine, Paediatrics and Child Health, General Surgery, Orthopaedic Surgery, Ante-natal and Postnatal wards and others. In the recent past, an outpatient mental health clinic was integrated into the Accident and Emergency unit of the Hospital. This strategy is presumed to work very well, with patients often linked to appropriate mental health services. A mental health clinic has also been running at the AMPATH HIV outpatient clinic for adults, hosted at Module 1. This study therefore set out to investigate the models of mental health care that were in place at the AMPATH Paediatric and Adolescent Clinics. Findings of this study therefore will be of significance to clinicians at the AMPATH paediatric and adolescent HIV clinics in view of initiating or strengthening existing HIV-Mental health care models that will lead to early diagnoses of mental health disorders resulting in early treatment and aversion of long term disability caused by the disorders.

Apart from raising awareness of the prevalence and patterns of psychiatric disorders among children/adolescents with HIV at MTRH, and assessing the models of mental health care at the AMPATH Paediatric and Adolescent HIV clinics, this study aims to stimulate the formulation of policies and guidelines that will enhance the integration of mental health services in HIV care.

1.4 Research Questions

1. What is the prevalence and patterns of psychiatric morbidity among children and adolescents with HIV infection at the AMPATH-MTRH Paediatric/Adolescent HIV clinics?
2. What are the factors associated with psychiatric morbidity among children and adolescents with HIV infection at the AMPATH-MTRH Paediatric/Adolescent HIV clinics?
3. What are the existing models of mental health care for children and adolescents on HIV care at the AMPATH-MTRH Paediatric/Adolescent HIV clinics?

1.5 Objectives

1.5.1 Broad Objective

To determine the prevalence, patterns and factors associated with psychiatric morbidity among children and adolescents with HIV infection aged 6 to 17 years and to assess models of mental health care at the Paediatric and Adolescent HIV clinics at AMPATH-MTRH.

1.5.2 Specific Objectives

1. To describe the prevalence and patterns and of psychiatric morbidity among children and adolescents with HIV infection at the AMPATH-MTRH Paediatric/Adolescent HIV clinics.
2. To determine the factors associated with the occurrence of psychiatric morbidity among children and adolescents with HIV infection at the AMPATH-MTRH Paediatric/Adolescent HIV clinics.
3. To assess the models of mental health care for children and adolescents on HIV care at the AMPATH-MTRH Paediatric/Adolescent HIV clinics.

CHAPTER TWO

LITERATURE REVIEW

2.1 Prevalence and Patterns

The mental health of children and adolescents is a significant public health concern given the high and increasing prevalence of mental disorders in this population. Globally, it has been estimated that up to 20% of children and adolescents suffer debilitating mental illness with suicide ranking third among the leading causes of death among adolescents. Furthermore it has been established that up to 50% mental disorders among the adult population had their onset in adolescence (Belfer, 2008). In keeping with the global trend, a study done in South Africa estimated the prevalence of psychiatric disorders among children and adolescents at 17% (Kleintjes, et al., 2006). In Kenya, a study among primary school children found an even higher occurrence of any mental disorder at 37.7% (Ndetei et al., 2016).

Mental disorders and HIV/AIDS have been closely interlinked, with a causal relationship having been demonstrated. Studies in both low and high-income countries have reported higher rates of depression in HIV-positive people compared to HIV-negative control groups. The level of distress often seemed to be related to the severity of symptoms of HIV infection (Board E., 2008).

In the USA, one study found that 52% of the HIV infected children manifested with more than one behavioural problem. Using the CPRS - Conner's Parent Rating Scale the study found that the most occurring behavioural problems were psychosomatic problems (28%), learning problems (25%), conduct problems (16%), hyperactivity (20%) and anxiety problems (8%) (Nozyce et al., 2006). Case control or cohort studies have been instrumental in comparing different groups of children with and

without HIV infection. One such cohort study that drew participants from four New York City (NYC) medical centres, found that the prevalence of any psychiatric disorder was high for all youth with no significant HIV status group differences. The perinatally exposed and infected (PHIV+) youth with a 68.7% prevalence, and a 69.3% prevalence rate among those perinatally exposed but uninfected (PHIV-) (Dolezal et al., 2013). This prevalence rate was notably higher than that in the previous USA study. Among those with any psychiatric disorder, 22% met criteria for two or more disorders at baseline and 14% at follow-up, with no significant HIV-status group differences in co-morbidity. Between baseline and follow-up, the odds of having any psychiatric disorder decreased significantly among PHIV+ youth (OR=0.52; $p < 0.001$), but remained relatively unchanged among PHIV− youth. Due to similarities in prevalence of psychiatric disorder among PHIV+ and PHIV− youth, researchers in this study opined that factors other than perinatal HIV infection may have played an important role in determining mental health outcomes (Dolezal et al., 2013). Using the Diagnostic Interview Schedule for Children (DISC-IV) the study above found that Anxiety and behavioural disorders were the most frequently occurring conditions for both groups. The PHIV+ youth were three times more likely to have a mood disorder (OR=3.16; 95% CI=1.17, 8.52, p=0.02). The PHIV+ were also two times more likely to have ADHD (OR=2.13; 95% CI=0.98, 4.61, p=0.06) compared to PHIV− youth, but this was not statistically significant (Dolezal et al., 2013).

Another comparative cross-sectional study done among perinatally HIV exposed youths receiving care at medical centres located in urban settings across the United States found that the prevalence of mental health problems was higher among the perinatally exposed but uninfected youths (PHEU) at 38% than the perinatally

exposed HIV positive youths (PHIV+) at 25%. This study suggested that the benefits of comprehensive medical and psychological care may have not been easily accessible to PHEU youth compared to the PHIV+ youth who received this care throughout childhood and adolescence. This could have reduced the occurrence of mental health problems among PHIV+ youth. Using the Behaviour Assessment System for Children-second edition (BASI-2) behavioural problems were reported by 29% of PHEU youth and 19% of PHIV+ youth ($p = 0.03$). Emotional problems were reported by 17% of PHEU youth and 12% of PHIV+ youth ($p = 0.29$). These findings indicate that the PHEU youths were more likely to report both behavioural and emotional problems, but only the behavioural problems outcome was statistically significant (Kapetanovic, et al., 2012). One census study carried out in France among children on HIV care in one hospital enumerated the psychiatric disorders for 17 participants who had consulted mental health services at least once in the course of their treatment. This study did not give a prevalence rate for psychiatric disorders since all the participants were already suspected to have a mental disorders before assessment. The DSM IV psychiatric disorders reported were, major depressive disorder 8(47%), ADHD 5(29.4%), brief psychotic syndrome 2(11.7%) and anxiety 4(23.5%) (Misdrahi, Vila, Tardieu, & Blanche, 2004).

Sub-Saharan Africa has been one of the worse hit regions by the HIV pandemic with an estimated 2.09 million children living with HIV; this is approximately 65% out of a global 3.2 million children living with HIV in 2013 (Sohn & Hazra, 2013). Subsequently, much has been studied about HIV and other co-morbidities, but mental health problems have not been adequately addressed, much less in the paediatric age group. In South Africa, a meta-analytical review for guideline development found that the overall prevalence of mental disorders among children and adolescents with HIV

infection was estimated at 25 - 50% (Nassen et al., 2014). This was higher than the prevalence rate of mental disorders among children in the general population in South Africa at 17% and higher than an adjusted prevalence of 14.5% from a review of overall psychopathology among children in sub-Saharan Africa (Cortina, Sodha, Fazel, & Ramchandani, 2012; Kleintjes et al., 2006). The South African review, found that the most common psychiatric manifestations included Attention Deficit Hyperactivity disorder (ADHD), mood disorders, anxiety disorders and substance use disorders (Nassen et al., 2014). Similarly, one quantitative study done in South Africa, found that adolescents living with and receiving HIV care at 5 different paediatric HIV clinics in Johannesburg had high prevalence of mental health problems. Using at least 4 standardized scales including MINI Kid, the study found that 27% of them screened positive for depression, anxiety or post traumatic stress disorder (PTSD) while 24% reported suicidality (Woollett et al., 2017).

In Nigeria a cross sectional comparative study that utilized the MINI Kid to assess for depression and suicidality estimated a 20% prevalence of depression and a 16.0% rate for suicidality (Bankole et al., 2017). In Rwanda, a qualitative study that investigated local perceptions of mental health problems affecting HIV infected youth revealed that "*agahinda kenshi"*(sadness or sorrow) was mentioned as a problem by 14% of adolescents living with HIV. Key features of agahinda kenshi included loneliness, unhappiness, crying and low morale. Another term *"kwiheba"* was associated with severe hopelessness and suicidal ideation that was expressed as “wishing to die” and “feeling that life is meaningless”. Respondents also identified *"ihahamuka"* as a state of shock commonly attributed to acute traumatising events such as genocide-related violence or the disclosure of HIV-positive status. Ihahamuka was frequently associated with “losing one's mind” or “behaving like a mad person”

(BetancourtaTheresa Stichick , et al., 2012). This study brought out the importance of using culturally sensitive measures in assessing mental disorders. Such approaches focused on local cultures may be able to pick symptoms that tools formulated based on western cultures often miss. However, the use of culturally derived tools may present problems when trying to establish rates of similar disorders in different settings (Cortina et al., 2012).

Using the WHO/Self Report Questionnaire-25 tools, a cross-sectional study in Uganda found that 51.2% of the CALHIV had significant psychological distress. Using ICD-10 symptom checklists for those with above threshold psychological distress, Musisi et al found that the most frequently occurring conditions were Anxiety at 45.6% and Depression at 40.8% while the least occurring was manic episodes at 1.2%. The study found that there were more females living with HIV, with a male to female ratio of 1: 1.3. It was suggested that the trend may be due to the higher vulnerability of the girl child to be infected with HIV/AIDS in Uganda, with a sad revelation that 5 % of the HIV infected adolescents girls had experienced coercive sexual abuse in form of rape (Musisi & Kinyanda et al., 2009)

Here in Kenya, a study similar to this current study, carried out at paediatric HIV clinics in Kariobangi - Nairobi, found that 48% of the CALHIV had a psychiatric disorder (Kamau et al., 2012). This prevalence was similar to the South African systematic review and Ugandan prevalence rates among CALHIV at approximately 50% but higher than the rate among Kenyan primary school children at 37.7% (Musisi & Kinyanda, 2009; Nassen et al., 2014; Ndetei et al., 2016). In the Nairobi study, 34% of the CALHIV were orphans due to parental HIV/AIDS and only 27.8% had both parents alive. Almost half of the children were found to be in two or more

classes lower than the age expected grade and poor health was cited as the most common reason for this. Only 30.2% of the children and adolescents knew their HIV status and the median age of disclosure was approximately 10 years. Kamau et al found that anxiety disorders were the most common occurring psychiatric disorder at 32.2% followed by depression at 17.3%, while Post-traumatic stress disorder and Pervasive development disorder were the least occurring at 1.3% and 0.6% respectively (Kamau et al., 2012).

In summary, the literature review above suggests a range prevalence of psychiatric problems among children and adolescents living with HIV infection ranging from 25% to 62%. The findings from comparative studies suggest that perinatal HIV infection may not necessarily increase the risk for having a psychiatric disorder over those who are not infected. However, there may have been confounding medical and psychological factors that were protective for CALHIV. Mood and Anxiety disorders were identified as the most common psychiatric disorders among CALHIV.

2.2 Factors Associated with Occurrence of Psychiatric Disorders

2.2.1 Sociodemographic factors

Studies have found varying associations between age and psychiatric disorders among children and adolescents with HIV infection. Nozyce et al in a multicenter randomized clinical trial in the USA found that children more than 9 years of age were more likely to have anxiety problems than younger children (16% vs 5%; P= 0.006) (Nozyce et al., 2006). Similarly in the USA Dolezal et al., found that adolescents older than 13 years were more likely to report mood disorders (OR=2.31, 95% CI=1.02, 5.20, p =0.044) and behavioural disorders (OR=1.92, 95% CI{1.17; 3.16} p=0.010). However in contrast to Nozyce et al, this study reported that older

adolescents were less likely to report anxiety disorders (OR = 0.58, 95% CI{0.37: 0.92} p=0.020) (Dolezal et al., 2013). Here in Kenya a similar study to this current study found that older age (>11 years) was considerably associated to suicidality (Kamau et al., 2012). In contrast however, a study in Uganda established that that the younger children living with HIV (10- 12 years) were more likely to have psychological disturbances compared to 13 to 18 year olds (O.R=2.68 95% C.I{1.06; 6.77}P= 0.037) (Musisi & Kinyanda, 2009).

Other studies have also found considerable associations between gender and mental disorders among children and adolescents with HIV. One comparative cohort study in the USA found that that the likelihood of having any psychiatric disorder (OR=0.62, 95% CI=0.38, 0.99, p=.050) and anxiety disorders (OR=0.56, 95% CI=0.35, 0.89, p =0.015) was significantly higher in girls than boys. On the other hand, though not statistically significant, the same study found that the likelihood of having any behavioural disorder (O.R 1.60 at 95% C.I (0.94, 2.72) and more specifically ADHD (O.R 1.73 at 95% CI (0.93, 3.12) was higher in boys than girls (Dolezal et al., 2013). In Johannesburg-South Africa, a quantitative study found that being female was significantly associated with depression ($p < 0.001$), anxiety ($p < 0.01$), and PTSD ($p < 0.001$) (Woollett et al., 2017). Findings from a cross-sectional study carried out in Nairobi-Kenya contrasted the Johannesburg findings by showing a statistically significant association between male gender and major depressive disorder (p=0.035) but corresponded with other studies in finding an association between female gender and specific phobia (p=0.028) (Kamau et al., 2012). Some studies however did not find any statistically significant association between gender and psychiatric problems (Musisi & Kinyanda, 2009; Nozyce et al., 2006) .

Another sociodemographic variable that was measured for associations among children and adolescents living with HIV was family or caregiver characteristics. Nozyce et al in a clinical trial in the USA established that, conduct problems, learning problems, and hyperactivity were less likely to occur among children living with their biological parent (with p=0.02, p=0.02, and p=0.04, respectively) (Nozyce et al., 2006). Similarly, in Nigeria one study reported less depression among children living with biological parents. Furthermore, this study reported that orphans, were more likely to experience depression (Bankole et al., 2017). In addition, a cross-sectional study done in the USA revealed that caregiver limit-setting problems and caregiver psychiatric problems were associated with mental health problems among CALHIV. This study further found that the association between caregiver psychiatric status and youth mental health problems appeared to be stronger for youth living with biological mothers as compared to youth living with other caregivers, however this was not statistically significant (OR = 4.51; p = 0.15) (Kapetanovic et al., 2012). In Uganda one study reported that the caretaker being HIV positive was associated with psychological distress (Musisi & Kinyanda, 2009). In Nairobi however, a similar study did not find any association between psychiatric morbidity and the type of primary guardian or parental status for CALHIV (whether orphaned or both parents alive) (Kamau et al., 2012).

School attendance was also analyzed for associations by a few studies. Musisi & Kinyanda in Uganda found that being out of school (O.R=3.00; C.I (1.14-7.89); p= 0.026) and not being able to play sports at school (O.R=5.94; C.I(2.29-15.40); p=0.00) were associated with having psychological distress (Musisi & Kinyanda, 2009). A cross sectional comparative study in Nigeria also reported that children who had repeated classes were more likely to report depression (Bankole et al., 2017).

Findings from the Nairobi study however indicated no associations between school attendance and psychiatric disorders among CALHIV (Kamau et al., 2012).

2.2.2 HIV characteristics and Clinical factors

Two surrogate markers are routinely used to monitor patients living with HIV: CD4 T lymphocyte (CD4) cell count is used to assess immune function, and plasma HIV Ribonucleic acid (RNA) - Viral Load (VL) to assess level of HIV viral suppression by the antiretroviral drugs. These two markers have been analyzed by many studies to show association with psychiatric disorders among CALHIV. A clinical trial in the USA reported that children with a lower CD4 count were more likely to experience a conduct problem (Nozyce et al., 2006). In contrast however, a comparative cohort study carried out in the USA found that at baseline and at follow-up, CD4 count=200 cells/mm3, was not associated with presence or absence of any psychiatric disorders. In addition though, it was documented that at baseline a VL=100,000 or undetectable VL was also not associated with any psychiatric disorder. At follow-up, however, those with undetectable VL were less likely to have behavioural disorders (OR=0.41, 95% CI=0.19, 0.92, p=0.031) (Dolezal et al., 2013). Similar to the USA study, Kamau et al in Kenya, found that major depression was significantly associated with a CD4 count <350 cells/mm3 (p=0.04) (Kamau et al., 2012; Nozyce et al., 2006).

Some antiretroviral drugs have also been observed to be associated to neuropsychiatric manifestations among People Living with HIV (PLWH). Currently in Kenya, any person who tests HIV positive is required to use HAART (Highly Active Antiretroviral Therapy) in order to suppress the HIV virus (Guidelines for the Use of Antiretroviral Agents). According to laid down standards, most HAART regimens include three or more antiretroviral drugs (ARVs) (Sik-to et al., 2011).

There are many combinations of ARVs based on whether it is the 1st, 2nd or 3rd line of treatment and also depending on the age of the patient. For children 3 to 14 years, the 1st line of treatment would constitute Abacavir + Lamivudine + Efavirenz. For children above 15 years the 1st line would constitute Tenofovir +Lamivudine +Dolutegravir or Tenofovir +Lamivdine +Efavirenz (Guidelines for the Use of Antiretroviral Agents); (Drugs, Infection, Aids, & Program, n.d.) There are many other combinations of ARVs and also alternative substitutions, but for purposes of this study we focused on Efavirenz since it has been demonstrated to have neuropsychiatric adverse reactions and therefore may contribute to the occurrence of psychiatric disorders. Studies have identified high rates of these adverse reactions including, insomnia, mood changes, abnormal dreams, sadness, irritability, nervousness and lightheadedness. Depressive episodes have also been observed as late complications (Arendt & Nolting, 2014). Although neuropsychiatric side effects have occurred with use of other antiretroviral drugs like Zidovudine, significantly higher rates of the side effects are reported with Efavirenz (Fumaz, Mun, & Jose, 2005; Hawkins et al., 2005). Efavirenz has been reported to cause depression although the symptoms are often mild and temporary (Drugs et al., n.d.). None of the studies we reviewed however had measured the association between use of Efavirenz and occurrence of psychiatric disorders among children and adolescents with HIV infection.

The association between having a psychiatric disorder and the disclosure process has been investigated by some studies among CALHIV. One study involving participants from the USA and Puerto Rico reported that HIV aware children were rated by their caregiver as having more severe oppositional defiant ($p=0.015$), generalized anxiety ($p=0.001$) and separation anxiety ($p=0.011$) symptoms than those who were unaware

of their HIV status (Gadow et al., 2010). In contrast, a quantitative study in South Africa documented that knowing one's HIV status was found to be protective with lower scores for depression ($p < 0.001$), anxiety ($p < 0.001$), and PTSD ($p < 0.05$) (Woollett et al., 2017). A systematic review that included studies from Africa, Asia and South America agreed with both the USA and South African studies suggesting that disclosure had both positive and negative effects for CALHIV (Vreeman, Gramelspacher, Gisore, Scanlon, & Nyandiko, 2013).

The socio-demographic and clinical factors identified in the literature review above formed the basis for selection of factors to be measured in this current study (Walter & Tiemeier, 2009). The factors selected including age, gender, orphan status, primary care giver, school attendance, viral suppression among others are further elaborated in the methodology section.

2.3 Models Mental Health Care in HIV Settings

The term "Model of Care" has been used to generally define the way health services are delivered. It outlines best practice care and services for a person or population group or patient. A model of care aims to ensure that people get the quality health care, that is timely, delivered by the right team and in the right place (Framework, n.d.). For purposes of this study, this definition was used to define "Models of Mental Health care" as the way mental health services are delivered; focusing of the type of care and the team delivering the care.

Comprehensive management of mental illness among HIV infected individuals has been shown to result in improved health outcomes in terms of adherence to treatment, social well being, cognitive functions and even motivational aspects (Freeman et al., 2005). Similarly, a systematic review of the psychosocial and health care needs of

PLWHs observed that psychological interventions such as counselling, cognitive-behavioural therapies, stress/anxiety management and other modes of psychotherapy for people living with HIV would result in a reduction of depressive symptoms (Ammassari et al., 2004)

With a similar view, a taskforce looking into how mental health should be integrated into HIV care, recommended that there is need to develop appropriate materials and models for the delivery of mental healthcare in HIV programs putting into consideration principles of affordability, acceptability and availability. The panelists suggested that the front-line mental health service providers should be the existing primary healthcare workers and counsellors who would ideally receive additional mental health training and relevant materials in order to offer the services (Freeman et al., 2005). This model where mental health services were delivered by trained primary health care workers could be referred to as the Community mental health team system. Other models of mental health services in the primary care setting have been identified as Shifted outpatient clinics, Attached mental health professional and Consultation-liaison models (Gask, Sibbald, & Creed, 1997). In addition, a team of WHO policy makers in South East Asia, while reviewing policies on mental health care, recommended the primary health care system as an efficient model of care for the mentally ill. The review revealed that up to 50% of mental disorders can be diagnosed and treated by non specialist health care staff sufficiently with lasting recovery for patients and significant reduction in burden of suffering on the care giving family. This system of care was found relevant especially in resource poor settings where mental health specialists and specialized mental health care are limited (Collins, Holman, Freeman, & Patel, 2006).

To further highlight the impact of integrating mental health in HIV care, one meta-analytical study in the USA analysed the mental health interventions for PHIV+ youth. The authors observed that many hospitals and community-based organizations across the globe provide psychosocial services for youth living with HIV but few studies had examined the impact of this treatment on mental health outcomes. One of the studies reviewed indicated that Among PHIV+ and PHEU youth, 18% of them had received psychotropic medications, and 22% received behavioural treatment that included individual therapy, family and group counselling, behaviour modification, after-school tutoring and psychiatric hospitalization. Important to note was that PHIV+ youth were more likely to receive mental health interventions than the PHEU (Claude A Mellins & Malee 2013). Elsewhere, a comparative cohort study done in the USA demonstrated that both PHIV+ and PHIV− youth had similar rates of mental health services at baseline (31.3% vs. 26.8% respectively). However, PHIV+ youth had significantly higher rates of mental health services at follow-up (37.9% vs. 23.1% respectively). The study also established that over time the PHIV+ youth, had a significant decrease in the prevalence of any psychiatric disorder, especially anxiety disorders, while prevalence of any psychiatric disorder among PHIV− youth remained the same with an increase in mood disorders (Kapetanovic et al., 2012). One study carried out in Uganda reported that interpersonal psychotherapy was effective in reducing depressive symptoms (Collins et al., 2006). In view of such findings it is safe to conclude that there is a dire need for mental health treatment programs for children and adolescents living with HIV as well as mental health-related research, particularly in low and middle income counties (Claude A Mellins & Malee, 2013).

In South Africa, a policy document guiding the management of mental health disorders and central nervous system outcomes in HIV-positive children and

adolescents identified the following as key components of a comprehensive model of care for integrating mental health services into the HIV program:

→ Screening for mental disorders

→ Referral criteria for mental health services based on mental health screen

→ Assessment and diagnosis of mental disorders

→ Psycho-pharmacotherapy and Psychotherapy

→ And finally multidisciplinary consultation (Nassen et al., 2014).

Despite such glaring evidence of the need to integrate mental health services into HIV care, there is lack of data especially from developing countries on how people living with HIV/AIDS seek mental health services and receive care. However some findings suggests that only a dismal number of HIV treatment programmes in developing countries provide mental health services (Freeman et al., 2005). This further builds the case for the need for extensive research geared towards informing guidelines and policy on integration of mental health services into the HIV care programs.

In summary, integration of mental health care services in the primary HIV care services was observed to have positive mental health outcomes. Components of an ideal model of integration in the primary HIV care setting included; screening for mental disorders, referral criteria to mental health services, assessment and diagnosis of mental disorders, pharmacotherapy, psychotherapy, and multidisciplinary consultation.

2.4 Screening Tool - Mini Kid

The Mini international Neuropsychiatric Interview for children and adolescents (MINI Kid) has been used for studies done in Kenya and in other African countries (Kamau et al., 2012; Syengo-Mutisya et al., 2008; Woollett et al., 2017). It is a brief prearranged psychiatry diagnostic tool that captures up to 24 child and adolescent psychiatric disorders in keeping with Diagnostic Statistical Manual, 4th Edition (DSM IV) and International classification of diseases 10th edition (ICD10) classifications. Disorders investigated include Depressive disorders, Bipolar Mood disorders, Suicidality, Anxiety disorders, Alcohol or Substance use disorders, Attention Deficit Hyperactivity Disorders (ADHD), Psychotic disorders, Feeding disorders, among others. It was developed due to need for a short and structured psychiatric interview that would close the gap between the previously detailed, academic, research targeted interviews and the very short screening tools intended for primary care. Additionally, it was intended for growth of the field of child and adolescent psychiatry (David V Sheehan et al., 1998)

A more recent study on the reliability and validity of the MINI Kid revealed that the specificity was excellent at 0.81 to 1 for up to 18 disorders, and inter-rater and test Kappas were substantial to almost perfect at 0.6 to 1 for all disorders. The revised version 7.0.1 of MINI Kid was also found to be reliable and valid in eliciting symptoms in the DSM 5 and ICD10 classifications of diagnosis and also its ability to carry out an interview in less than half of the time used by other tools like K-SADS (D V Sheehan et al., 2010).

Paediatric mental health research tools have undergone a rigorous transition from complex and time consuming formats to more comprehensive and user friendly

designs. Validity and reliability of the tools in various setting poses unique challenges in utilization of the tools by researchers. The Mini Kid tool was deemed to be highly reliable and valid in various settings and therefore most relevant for this study.

CHAPTER THREE

METHODOLOGY

3.1 Study Design

This was a cross sectional descriptive study.

3.2 Study Site

The study was carried out at the Paediatric and Adolescent HIV clinics in AMPATH-MTRH, Eldoret Kenya. Moi Teaching and Referral Hospital (MTRH) is the second largest National Teaching and Referral Hospital in the country with a bed capacity of 991 patients, and caters for about 1500 out patients per day. The hospital is located in Eldoret town in Uasin Gishu county and serves residents of western Kenya region (representing at least 22 Counties), parts of eastern Uganda and southern Sudan with covering a population of approximately 24 Million people. MTRH is structured to provide a wide range of health services, both out-patient and in-patient that are supported by modern state of the art clinical and diagnostic equipment (https://www.mtrh.go.ke/?page_id=598). AMPATH (Academic Model Providing Access to Healthcare), is a Moi University - MTRH and a consortium of North American Universities partnership program with the Government of Kenya**.** The academic health centres that make up AMPATH are structured to practice a tri-partite mission of Care, Training, and Research, all of which are essential for successfully addressing the short and long-term challenges of global health (https://www.ampathkenya.org/).

AMPATH was created in response to the challenge of providing life-saving care in the face of the HIV pandemic but emerging needs necessitated expanding from an HIV focus to address the critical needs for Primary healthcare, chronic disease care and Specialty care. AMPATH operates HIV/AIDS care clinics and screening

programs in Eldoret town at MTRH, networking with18 other district hospitals and over 60 urban and rural health clinics in Uasin Gishu County. Utilizing the expertise of Moi University School of medicine faculty, and North American academic physicians, combined with the clinical facilities and personnel of MTRH, AMPATH has developed a successful model for HIV/AIDS management which currently delivers care to over 3.5 million people in western Kenya and including more than 14,000 HIV positive children. The program also caters for over 20,000 orphaned and vulnerable children due to HIV/AIDS (Inui et al., 2007). AMPATH is further structured into 4 modules offering care to the various groups of individuals living with HIV as follows: Module 1 - comprehensive HIV care for adults and special clinics for adults with HIV with co-morbid conditions like mental disorders and dermatology conditions; Module 2 - comprehensive HIV care for Adults; Module 3 - comprehensive HIV care for adults with special attention to those with blood resistance to anti-retroviral treatment; and Module 4 - comprehensive HIV care for children and adolescents.

The paediatric HIV clinic, hosted in module 4 at AMPATH - MTRH has been structured as a child friendly environment with a holistic approach to treatment, inclusive of play and other engaging activities. The clinic runs from Monday to Friday. Children from 3 years of age are attended at the module 4 clinic. The adolescent HIV clinic was established at the MTRH-Rafiki adolescent and youth centre and runs from Monday to Saturday. The MTRH-Rafiki Center for Excellence in Adolescent Health is a space dedicated to the unique needs of teenagers and youth with or without HIV infection. The center provides treatment, nutritional support, peer support groups, educational sessions, and more. This separation of teenagers and youth was informed by unique psychosocial issues that have been observed during

adolescence and also after disclosure process. Disclosure is a process of revealing to the child of their HIV positive status that is usually commenced at around 10 years of age for children living with HIV and continues until the child fully understands and accepts their HIV status.

Based on verbal report given by the clinicians at the clinics, approximately 2500 children and adolescents were actively on care and follow up in 2016. The children and adolescents attending the clinics would access comprehensive HIV care including antiretroviral therapy, prevention and treatment of opportunistic infections, nutritional care and psychosocial care. Part of the psychosocial care included enrolment into support groups, and various forms of psycho-education within those groups. The health services offered also included primary health care services which included screening for co-morbid illness like TB, assessing for drug adherence and adverse reactions, screening for reproductive health issues, screening for substance abuse, and screening for some mental health issues. The screening tool in use at the time was the initial encounter form which is structured in two versions; the paediatric encounter form and the youth encounter form. The paediatric encounter form has a section on clinical psychiatric exam with non standardized questions touching on mood, suicidal thoughts, anxiety and abnormal behaviour. The youth encounter form also has one section screening for mental health with structured questions based on a PHQ-9 tool used to screen for depression. One more section on the youth encounter form screens for substance use including tobacco, alcohol, glue, marijuana and miraa (khat). However, the clinicians confessed that they would sometimes forget to carry out the mental health screening. Furthermore, when using the electronic patient encounter files, a clinician would only be prompted to carry out the mental health screening if the patient was found to have high viral load counts indicating poor adherence to

antiretroviral treatment. This indicates some gaps and limitations in the processes for mental health screening at the AMPATH-MTRH paediatric and adolescent HIV clinics.

3.3 Study Population

The study engaged two sample groups at the AMPATH Module 4 and MTRH Rafiki Adolescent centres. The first group was children and adolescents with HIV infection attending the clinics accompanied by their Parent/guardian. The second group was the Health Care Workers attending to the children and adolescents on HIV care at the clinics.

This study recruited children and adolescents between 6 to17 years of age. Children and adolescents in this age group were selected owing to the fact that the MINI Kid was validated from a sample of children from 6 to 17 years of age (D V Sheehan et al., 2010). Children from 6 years to 12 years were recruited at the AMPATH Module 4 clinics. Those who were 12 years and above or those who had completed the disclosure process were recruited from the MTRH Rafiki Adolescent centre. Both centres are under the AMPATH-MTRH umbrella of management.

The total health care providers at both the module 4 and Rafiki centres were 30 at the beginning of this study. These comprised of 2 Paediatric consultants, 7 clinical officers, 6 nurses, 2 social workers, 3 outreach officers, 2 record officers, 3 nutritionists, 2 Psychologists, 2 Comprehensive Care Clinic (CCC) assistants and 1 pharmacist. Peer mentors had also been recruited in order to reach out to the adolescents with someone at their own level.

3.4 Sample Size

The sample size for the children/adolescents group was determined using the Cochran formula for descriptive studies (Israel, 1992)

$$n = \left(\frac{Z_{1-\alpha/2}}{\delta} \right)^2 P(1-P)$$

Where: n was the sample size being calculated

$Z_{1-\alpha/2}$ was the area of the normal curve that cuts off an area α at the tails

α was the level of significance at 0.05

δ was the margin of error = 5%

P was the known population prevalence of psychiatric morbidity among children and adolescents with HIV

Using this formula, a prevalence (P) of 48 % was applied, which was obtained from a similar study done in Nairobi (Kamau et al., 2012).

Therefore: $n = \left(\frac{1.96}{0.05} \right)^2 0.48(1-0.48)$

n = 384

Thus the exact sample size was therefore 384 participants. However, in order to cater for those who would opt out of the study midway, or for incomplete questionnaires, the number of participants was inflated by 20% of the sample population giving us 461 participants to be sampled. The study therefore set out to recruit a sample population of 461 children/adolescents.

I set out to carry out a census for the health care providers group who were 30 in number.

3.5 Sampling Procedure

The sample was hospital based, selected from the AMPATH Paediatric and Adolescent HIV clinics. The children and adolescent groups were stratified into AMPATH Module 4 group and MTRH Rafiki group based on where they were interviewed from. Participants were then selected through systematic random sampling. In this method, the first participant of the sample was selected through a simple random procedure using the patient attendance register at the clinic. Subsequently every 6th participant was selected in a systematic way using a predetermined sampling interval which is elaborated below. The adolescents above 10 years or those for whom disclosure had been completed were interviewed at the MTRH Rafiki Adolescent centre, and the children below 10 years or who had not undergone disclosure were interviewed to at the AMPATH Module 4 clinic. Therefore the calculation for sampling interval was done according to the number of clients seen at the respective clinics separately.

The participants were interviewed on a weekly basis using approximately 3 days per week, for approximately 40 weeks. Therefore by distributing the 461 participants over the 40 weeks, approximately 12 participants would be interviewed per week and 4 participants per day (this was considered the sample size per day = n).

At the Module 4 clinic, total attendance was taken from the 3 months preceding onset of data collection. An average of 489 children were estimated to be seen per month i.e.

(Feb) 553 + (March) 400 + (April) 513 = 1466

1466/3 = 488.67 which was rounded off to 489 children in a month

To estimate number of children seen in one week 489 was divided by 4 weeks, giving 122.25

This was rounded off to 122 children per week and therefore approximately 24 children per day (this was considered the sample population per day = N).

Taking **N** as the sample population per day and **n** as the sample size per day and **R** as the sampling interval then the formula:

R = N/n, was applied.

Calculation: N = 24

n = 4

R = 24/4

R= 6

This gave an interval of every 6th participant for the AMPATH Module 4 sample group.

At the MTRH Rafiki adolescent centre, total attendance taken from the 3 months preceding onset of data collection was 1489 giving an average of 496 adolescents estimated to be seen per month and 124 per week and eventually approximately 25 adolescents per day (this was considered the sample population per day = N). Using the same formula to calculate the sampling interval;

R = 25/4

R = 6.25

The final value was every 6th participant for the MTRH Rafiki group too.

It is important to note that the AMPATH Module 4 clinic and the MTRH Rafiki centre were located at different sections of the hospital approximately 5 minutes walk apart. Due to this geographical challenge the researcher would alternate data collection between the two clinics on a weekly basis until the required sample size was achieved.

The researcher would assign numbers 1 to 6 to the first 6 clients present on the queue when she arrived in the clinic and have the numbers written down on pieces of paper and then fold them up. The registration clerk would then assist in randomly picking one of the folded papers and the participant whose number came up would be first to be recruited. Every 6th client on the attendance register following the first participant would then be recruited until the sample size for the day was achieved.

If the client identified did not meet the inclusion criteria or had been interviewed before or declined to participate, the next participant on the register would be recruited to replace them. Participants were informed about the study by word of mouth by the registration clerks and peer counsellors at the clinics who would then direct them to enter into the room where the researcher was conducting the interviews. The researcher would then administer the consent and assent forms and the data collection tools to the participants. The registration clerk and peer counsellors assisted with informing the children/adolescent and their Parents/guardian about the study and escorting them to the researchers/consultation room.

Hospital records of interviewed participants were accessed from electronic client files on tablets or computers available at the AMPATH module 4 and MTRH Rafiki centres. These records were used to obtain information like weight and height, ARV

regimen and Viral load. (It is important to note that the consent forms had informed the participants that their medical records would be accessed by the researcher).

A census was carried out for the health care providers group who were available at the clinic, during the study period. All the front line health care providers were given consent forms and Models of Mental Health Care questioners to fill at their own time and give the forms back to the researcher during the 40 week period. Self administered questionnaires were handed out to the health care providers who were willing to participate and were available at the clinics during the 40 week period. 18 questionnaires were returned to the researcher.

3.6 Eligibility Criteria

Criteria for children and adolescents group

Inclusion criteria

i. A child or adolescent 6 to 17 years with HIV infection on follow up at the AMPATH paediatric and adolescent HIV clinics.
ii. A child or adolescent had to be accompanied by a Parent or Adult Guardian.
iii. Respondent or participant must be able to communicate in English or Kiswahili.

Exclusion criteria

i. Any child or adolescent with acute illness requiring urgent medical attention.
ii. Any child or adolescent who had already been interviewed

NB: Whether or not a child had an acute illness was determined by the triage nurse at the clinic, using examination of vital signs and assessment of presenting complaints.

Any child or adolescent who had clinical features requiring immediate medical attention was excluded from the study.

The children and adolescents who had already undergone the interview process were identified from memory. The participant would be asked if they had previously been interviewed, or the interviewer would remember participants who had been interviewed before.

Criteria for healthcare workers group

Inclusion criteria

i. Health care providers working at AMPATH Module 4 and MTRH Rafiki clinics.

3.7 Study Procedure

Data was collected between May 2017 and April 2018.

Using the systematic random sampling elaborated above, and upon the participant meeting the eligibility criteria and being successfully recruited, the researcher would then administer the printed copy of the consent form and ensure that they were signed by the parent/guardian for all children between 6 and 10 years. For children and adolescents between 11 and 17 years, the consent form was read out or read to and signed by the Parent/guardian and an assent form was administered to and signed by the child/adolescent.

The researcher would then administer printed copies of semi-structured sociodemographic questionnaires which would elicit responses from both the parents/guardians and children/adolescents. Printed copies of MINI Kid questionnaires were afterward administered to the children/adolescents and their parent/guardian. The sociodemographic questionnaire had a question on level of

disclosure of HIV, this question was asked last for children/adolescents who had not undergone disclosure and the child/adolescent was asked to step out of the consultation room before this question was asked. This was to avoid unintended disclosure to the child or adolescent who had not yet undergone full disclosure of their HIV status. All participants were interviewed by one researcher - the primary investigator Mary W. Njuguna, a Master of Medicine in Psychiatry student at Moi University in her third year of study.

The MINI Kid was organised into diagnostic sections or modules with 2 to 4 screening questions for each module with yes or no answers. If a participant screened positive on the screening questions then additional symptom questions were asked within each disorder module to assess if the participant met criteria for the disorder. If the participant did not answer yes to the screening questions, the interview ended there. Diagnostic criteria were summarised and documented at the end of each module and on a summary sheet at the end of the interview (D V Sheehan et al., 2010). Upon completion of the Mini Kid Questionnaire, any child or adolescent who met criteria for any psychiatric disorder was referred to the psychologists who were available at the module 4 or Rafiki centres clinics and to the outpatient child and adolescent mental health clinic in MTRH for appropriate management.

Between the months of May 2017 and April 2018 there was a total of 11,234 visits of children and adolescents were seen at both the module 4 clinic and Rafiki Adolescent centre. This would translate to an estimated 3,744 children and adolescents on care by dividing 11,234 by the 4 month revisit schedule. A total of 391 children and adolescents with HIV infection between ages 6 to 17 years were enrolled into the study. This figure exceeds the exact sample size of 384 because the sample size had

been inflated to 461 to cater for drop out cases and data collection errors. However, 391 children/adolescents were recruited because the data collection period had elapsed.

The models of mental health care questionnaire attached to a written consent form was distributed to the health care workers after a brief sensitisation meeting where the nature and purpose of the study was highlighted. The questionnaire was self-administered and 18 health care providers completed and returned the questionnaires.

3.8 Data Management

3.8.1 Data Collection tools

A child/adolescent sociodemographic and clinical characteristics tool was a semi-structured questionnaire designed by the researcher to collect sociodemographic and information on the clinical/HIV characteristics about the child or adolescent. The socio-demographic and clinical factors selected were those likely to be routinely assessed by clinicians and had also been documented in prior scientific literature (Walter & Tiemeier, 2009). In addition to age and gender the questionnaire was used to obtain the following measurement outcomes:

1. Level of education
2. Knowledge of HIV status (level of disclosure)
3. Age at which full disclosure was achieved,
4. Emotional reaction during disclosure
5. Current ARV regimen
6. Biological markers of Viral suppression - Viral load
7. Height, weight and Z score
8. Whether the parent was alive or not

9. Primary care giver to the child/adolescent,
10. Whether the child/ adolescent had ever been diagnosed with or treated for mental illness.

The sociodemographic questionnaires were printed out and administered to the participants. The answers were hand written by the researcher on the questionnaires.

Information from hospital records was obtained from electronic client files that were accessed on tablets or computers available at the Module 4 or Rafiki centres. The AMPATH staff at the clinics would log in to the AMPATH Medical Records System (AMRS) application containing the client files and the researcher would extract only the information needed like, weight, height and BMI, initial and current viral load and current ARV regimen. This information was then written down on the printed questionnaires. The researcher did not have access to some parts of the electronic files like the clinician's notes.

On level of education, this study set out to assess whether or not the children/adolescents were currently in school and which class the children were in. According to the early childhood development Service standard guidelines for Kenya of 2006, education for children had been grouped as follows according to the appropriate age ("Republic Of Kenya Early Childhood Development Service Standard Guidelines For Kenya," 2006):

Age in Years	**Group**
6 months to 2 years	Play group
3 years	Baby class
4 to 6 years	Pre-primary 1 and Pre-primary 2
7 to 14 years	Primary School

From Primary school, the student is expected to progress to Secondary school for 4 years and thereafter to various post- secondary institutions.

For purposes of this study, children in Pre-primary 1 and 2 were categorised as being in nursery school. The children who were not in formal education as expected according to their age, were categorised as not being in school.

Disclosure guidelines at AMPATH recommend initiating the disclosure process to children at the age of 10 years and aim at implementing full disclosure before the age of 14 years (Vreeman et al., 2015). For this study disclosure was categorized into Full disclosure for those who had completed the disclosure process; Some disclosure for those who were still undergoing disclosure and No disclosure for those who had not yet started the disclosure process.

Varied measurements of viral load (VL) for the children and adolescents were recorded. For purposes of analysis the viral load measure was categorized into those who had attained viral suppression and those who had not. Viral suppression was defined as an undetectable level of HIV RNA which was recorded as Lowest Detectable Level (LDL) of viral load. Those with detectable levels of viral load were considered not to have attained viral suppression and according to the National ARV guidelines were at risk of treatment failure (VL < 1000 copies/ml) or in treatment failure (VL > 1000 copies/ml) (Drugs et al., n.d.).

The weight and height measurements were further used to estimate Z score which is the BMI for age for children 5 to 17 years of Age. A research assistant who was a Nutrition and Dietetics student was employed to convert height and weight measurements for age into Z scores using the paediatric nutrition reference charts available at the AMPATH clinics. The Z score was arrived at by checking the weight

and height of child against their age on the paediatric nutrition reference chart available at the HIV clinics. The child would then be classified as having - 1 SD, -2 SD or -3 SD (negative 1SD, negative 2SD or negative 3SD) on the Z score chart. The national nutrition guidelines classify nutritional status of the HIV-Infected Child as follows (Nutrion guidelines for HIV exposed and infected children):

Signs	Classify As
Weight-height for age less than **-3 z-score**, or MUAC less than 115 mm in children 6-60 months	SEVERE MALNUTRITION
Weight for age less than **-2 z-score**	POOR WEIGHT GAIN
Weight for age more than **-2SD (-1SD)**	GROWING APPROPRIATELY

For purposes of analysis the nutritional scores were categorised into:

- Those with poor growth, where we combined those with severe malnutrition and poor weight gain
- Those with normal growth meaning those growing appropriately.

Information about previous mental health history was given by the children/adolescents or their parents, but not collaborated from the hospital records. However at the time of data collection, the AMPATH electronic medical records system had not been structured to capture mental health encounters. Outcomes of mental health screening or mental health reviews were documented as part of HIV clinical care notes. This made it difficult to extract the information since the researcher did not have rights to access that part of the electronic files.

The MINI kid questionnaire was printed out and administered to the children/adolescents and their Parents/guardians. This was used to obtain data on

presence and patterns of psychiatric morbidity. The responses were hand written on the MINI Kid tool. The MINI Kid had been found to be reliable and valid in eliciting symptoms in the DSM IV and ICD10 classifications of diagnosis (D V Sheehan et al., 2010). The most recent version of Mini Kid tool – Version 7.0.1 and permission to use it for this study were given by Dr. David Sheehan through email. I - the primary investigator was trained on how to administer the MINI Kid questionnaire at Bradley Hospital in Rhode Island-USA during my elective term studies. Bradley Hospital is a child and adolescent psychiatric hospital that serves as a teaching hospital for The Warren Alpert Medical School of Brown University, and a national centre for research in child and adolescent psychiatry (https://www.bradleyhospital.org/). The training was done by a qualified psychologist. The MINI Kid version 7.0.1 screened for 24 DSM 5 and ICD-10 psychiatric disorders including mood disorders, suicidality, panic disorder, separation anxiety disorder, alcohol or substance use disorders, attention deficit hyperactivity disorder, psychotic disorders, feeding disorders, autistic spectrum disorders among others. The time used to administer the MINI Kid questionnaire was between 20 to 50 minutes based on the MINI kid validation study done by the developer of the instrument (D V Sheehan et al., 2010). The ability to carry out an interview using the MINI Kid in less than half of the time used by other tools was found as an added advantage. Researchers who conducted a similar study in Nairobi, administered the tool in 15 to 30 minutes (Kamau et al., 2012). Despite the tool being detailed, it was possible to use the relatively short time range because only 2 to 4 screening questions were asked for each disorder module and additional questions in the module were asked only if the screening questions were positively endorsed (D V Sheehan et al., 2010). A summary is made at the end of each module indicating whether the participant has met the criteria for the disorder or not.

A semi-structured questionnaire was designed for health care providers in order to answer questions on mental health services available in the Module 4 and Rafiki HIV clinics. This questionnaire was used to obtain the following measurement outcomes:

1. Age, Profession/ Cadre, Level of education
2. Exposure to mental health training of the health care providers
3. Whether they encounter children/adolescents with mental disorders
4. Whether they screen for mental disorders at the clinic
5. How competent they felt with managing a child or adolescent with a mental disorder at the clinic
6. Existing mental health services i.e. presence of screening for mental disorders, referral to mental health services and psychosocial services.
7. What the health care providers think can be done to improve mental health care at the clinics.

The researcher designed questionnaires and the MINI kid tools were not validated before use, however, feasibility and acceptability was tested during a pilot exercise carried out at the paediatric comprehensive HIV clinic in Uasin Gishu District Hospital. This exercise was useful in assessing clarity of the questions, patient acceptability and approximate time for application.

Data was collected on printed questionnaires which were stored in locked cabinets only accessible to the researcher.

3.8.2 Data Entry and Analysis

Data was entered into data entry tools on Access and was analyzed using STATA version 14. Descriptive statistics such as mean, median and inter-quartile range were used for continuous variables while frequency listings were used for categorical variables. Chi square test, Fishers exact test and multiple logistic regression were used to assess factors associated with mental disorder. The Fisher's exact test was used in cases where the cell counts were 5 or less. Associations were considered statistically significant at $p < 0.05$. Where no associations or very few associations were found at bivariate analysis, the level of significance was expanded to 0.2 in order to get factors to enter into a multiple logistic regression model. This was done to control for confounding variables and to determine the direction of association between the factors measured and psychiatric morbidity. Adjusted odds ratios with 95% confidence intervals were reported. All analysis was carried out at the 95% level of significance. Data for models of mental health care was reported in prose.

3.8.3 Data dissemination

The findings from this study will be presented at seminars and conferences. This thesis will also be submitted to reputable journals for publishing. A copy will be availed to the management of AMPATH and MTRH to help inform the management on the prevalence of psychiatric and mental health care disorders at the Paediatric and Adolescent HIV clinics. The findings of this study are intended to trigger evidence based decision making by the AMPATH-MTRH management and clinical teams.

3.9 Ethical Considerations

Approval to conduct the study was sought and obtained from the Institutional Research and Ethics Committee (IREC). IREC is an institution formed by both Moi University and Moi Teaching and Referral Hospital. Permission to interview clients at the AMPATH clinics was also sought and obtained from the Chief Executive Officer - MTRH and from the Chief of Party - AMPATH. Written informed consent was sought and obtained from the parents or guardians of all the children and adolescents interviewed. The written consent was printed in English and the Parent or Guardian was required to sign at the bottom. Those who were not able to write were required to give a finger-print impression. All Children between 11 and 17 years of age were also required to give assent to accompany the written informed consent by the parent or guardian. The assent form was also printed in English, and the children were required to write their name or initial of their names. Written informed consent was also sought from the health workers group.

The study participants, their guardians and health workers were assured of anonymity and confidentiality by omitting names on the questionnaires, and data was stored in a confidential and safe location. Computers used for data entry and analysis were password protected.

All children and adolescents who were found to have psychiatric morbidity were referred to the child and adolescent mental health clinic at MTRH for further assessment and management by the consultant Psychiatrist.

CHAPTER FOUR

RESULTS

This chapter provides detailed analyzed results for 391 children and adolescents living with HIV (CALHIV) on HIV care and for 18 Health care providers working at AMPATH pediatric and adolescent HIV clinics who participated in the study. The initial section of the chapter describes the socio-demographic as well as the clinical characteristics of the children and adolescents, followed by a section on prevalence and patterns of psychiatric disorders among CALHIV and finally a section on the models of mental health care for children and adolescents on HIV care at AMPATH-MTRH paediatric and adolescent HIV clinics.

4.1. Socio demographic characteristics of children and adolescents on HIV care at AMPATH-MTRH.

Table 1 shows that the median age of the children and adolescents was 13 years (IQR: 11, 15) with a male to female ratio of 1:1.1. More than half (53.6%) of the CALHIV had poor growth or malnutrition based on the Z-score charts. Majority (95.4%) of the CALHIV were in school with 74.5% of them in Primary school. Only 4.6% of the participants were not in school. Seven of those not in school had dropped out at primary school level with the most common reason given for not being in school as financial challenges followed by poor health. The other 11 had completed secondary school and were in transition to the next level of education.

In terms of family characteristics, nearly half (49.6%) of the CALHIV were orphans with 26.2% of them having lost both parents. The 12 children who reported that they did not know whether their parents were alive or not were living in foster care. Majority (96.1%) of the participants were living in a family set up with only 3.9%

living in foster care. Almost half of children and adolescents came from households with 2 to 5 people 214 with only 7.3% coming from households with more than 10 people. The last group comprised mostly of the participants living in foster care. More than 2/3 of the children and adolescents resided in Uasin Gishu county with 33.5% of them coming from 15 other counties.

It is important to note that some variables including nutritional status, orphan status, primary care giver and number of people in the household had missing data which was explained by missing information from the questionnaires.

Table 1:Sociodemographic Characteristics For Children And Adolescents On HIV Care At AMPATH-MTRH

Variable	Freq/ Median	%/ IQR
Age in years	13	(11,15)
Gender	N= 391	
Female	205	52.4
Male	186	47.6
Nutritional status	N=334	
Poor growth + Malnutrition	179	53.6
Growing appropriately	155	46.4
Missing	57	
Attending School	N=391	
No	18	4.6
Yes	373	95.4
Current Class for those in School	N=373	
Nursery	7	1.9
Primary	278	74.5
Secondary	84	22.5
Post-secondary	4	1.1
Both Parents alive	N=391	
No	188	48.1
Yes	191	48.8
Unknown	12	3.1
Orphan status	N=183	
Father alive	51	27.9
Mother alive	84	45.9
Total orphan	48	26.2
Missing	5	
Primary Caregiver	N=386	
Foster care	15	3.9
Both parents	123	31.9
Mother only	130	33.7
Father only	37	9.6
Grandparents	29	7.5
Aunt/Uncle	41	10.6
Sibling	11	2.8
Missing	5	
Number of people in a household	N=382	
2 – 5	214	55.7
6 – 9	143	37.2
>=10	27	7.1
Missing	7	
County of residence	N=391	
Uasin Gishu county	260	66.5
Trans Nzoia county	40	10.2
Nandi county	25	6.4
Elgeyo Marakwet county	21	5.4
Kakamega county	11	2.8
Baringo county	7	1.8

Bungoma county	5	1.3
Busia county	5	1.3
Nakuru county	4	1.0
Kisii county	3	0.7
Nairobi county	3	0.7
Kisumu county	2	0.5
Homabay county	2	0.5
Kericho county	1	0.3
Busia county	1	0.3
Turkana county	1	0.3

4.2. Clinical characteristics for children and adolescents on HIV care at AMPATH-MTRH

Table 2 shows HIV characteristic of the children and adolescents with HIV infection. Nearly half (49.9%) of the CALHIV had undergone full disclosure of HIV status while 35.1% were not yet disclosed to and another 15% had received some disclosure meaning they were still undergoing the disclosure process. The median age at disclosure of HIV status was 12 years. Nearly half (43.5%) of the children or adolescents who had undergone full disclosure expressed that they experienced emotional challenges while undergoing disclosure with 23.1% of them reporting sadness as the most common emotion experienced, followed by anger (8%). Other emotions experienced were confusion, denial, feeling bad, suicidal thoughts and fear. All 391 children and adolescents were on highly active anti-retroviral therapy (HAART) with nearly a third using an Efavirenz containing regime. Out of the 391 children/adolescents on HAART, viral load records were available for 371. Only 43% of the 371 had attained viral suppression based on the most recent viral load recorded.

Of note is that some variables had missing data that resulted from missing information from the questionnaires.

Table 2:Clinical Characteristics of Children and Adolescents on HIV Care at AMPATH-MTRH

Variable	Freq /Median	%/ IQR
Disclosure of HIV status		
	N=373	
Full disclosure	186	49.9%
No disclosure	131	35.1%
Some disclosure	56	15%
Missing	18	
Median age at disclosure	12	11,14
Emotional reaction during Disclosure (for those fully Disclosed to)	N=186	
Anger	15	8.1%
Sad	43	23.1%
Confusion	9	4.8%
Denial	2	1.1%
Feeling bad	6	3.2%
Suicidal thoughts	1	0.5%
Fear	5	2.7%
No reaction	105	56.5%
On HAART		
	N=391	
Yes	391	100%
ART Regimen	N=391	
EFV based	126	32.23%
Other	265	67.77%
Viral Suppression		
	N=371	
No	212	57%
Yes	160	43%
Missing	20	

EFV = Efavirenz

4.3. Diagnosis or Treatment for mental health conditions

Only 4 of the participants had ever been diagnosed or treated for a mental disorder before participating in this study. Two of them had schizophrenia 1 had intellectual disability and 1 had suicidal behaviour. The 2 with schizophrenia were on olanzapine, the one with Intellectual disability was on carbamazepine for seizure disorder and the one who had suicidal behaviour had received psychotherapy.

Disclaimer! Information on whether the child of adolescent had ever been diagnosed or treated for a mental disorder before was obtained from the participant and their parent/guardian and not from their medical records. However at the time of data collection, the outcomes of mental health screening or mental health reviews were documented as part of HIV clinical care notes. This made it difficult to extract the information since the researcher did not have access to that part of the electronic files.

4.4. Psychiatric morbidity among children and adolescents on HIV care at AMPATH-MTRH - Prevalence and Patterns

The prevalence of having any psychiatric disorder was **57.5 %** (95% CI: 52.5, 62.5) while 29.9% of the children/adolescents met criteria for more than one psychiatric disorder.

Anxiety disorders (panic disorder, agoraphobia, specific phobia, social phobia, acute stress disorder and generalized anxiety disorder) were the most common diagnosis at 53.8%, followed by Suicidality 10.4% and Attention Deficit Hyperactivity Disorder (ADHD) 10%. Other conditions identified included Major Depression 7.9%, Bipolar mood disorders 7.3%, Autistic Spectrum Traits 4.8% and Post traumatic Stress disorder 1.3% . Other less frequently occurring conditions were Conduct disorders,

Obsessive compulsive disorders, Oppositional defiant disorders and Adjustment disorders.

Table 3:Prevalence and Patterns of Psychiatric Morbidity Among Children and Adolescents on HIV Care at AMPATH-MTRH

Variable	Frequency	Percent
Psychiatric disorders		
Any disorder	225	**57.5**
2 or more disorders	117	29.9
No disorder	166	42.5
Specific psychiatric disorders		
Anxiety	183	**53.8**
Suicidality	35	**10.4**
ADHD	34	**10**
Major depression	27	7.9
Bipolar disorders	25	7.3
Autistic spectrum traits	16	4.8
Post traumatic stress disorder	5	1.3
Conduct disorder	5	1.3
Obsessive compulsive disorder	5	1.3
Opposition defiant disorder	3	0.8
Adjustment disorder	2	0.5

ADHD - Attention Deficit Hyperactivity Disorder

4.5. Factors associated with psychiatric morbidity among children and adolescents living with HIV

Table 4 a) gives details of variables that were tested for associations with having any psychiatric disorder among CALHIV. On bivariate analysis, none of the sociodemographic variables nor HIV characteristics were associated with having any psychiatric disorder.

Table 4 a):Factors Associated With Having any Psychiatric Disorder Among Chidren and Adolescents Living with HIV

Variable	Any disorder		
	No N(%)	Yes N(%)	P-value
Age in years			
Below 12	65 (38.0)	106 (62)	0.117[1]
Above 12	101 (45.9)	119 (54.1)	
Gender			
Female	86 (42)	119 (58)	0.832[1]
Male	80 (43)	106 (57)	
Disclosure of HIV status			
Full disclosure	74 (39.8)	112 (60.2)	0.717[1]
No disclosure	58 (44.3)	73 (55.7)	
Some disclosure	24 (42.9)	32 (57.1)	
Both Parent alive			
No	79 (42)	109 (58)	0.858[1]
Yes	82 (42.9)	109 (57.1)	
School attendance			
No	9 (50)	9 (50)	0.507[1]
Yes	157 (42.1)	216 (57.9)	
Caregiver			
Family setup	158(42.6)	213(57.4)	0.842[1]
Foster care	6(40)	9(60)	
Nutritional status			
Poor growth+ Malnut..	81 (45.3)	98 (54.7)	0.307[1]
Appropriate growth	59 (38.3)	95 (61.7)	
Viral suppression			
Yes	75 (46.9)	85 (53.1)	0.191[1]
No	85 (40.1)	127 (59.9)	
ARV regimen			
Other	114 (43)	151 (57)	0.744[1]
Efavirenz based	52 (41.3)	74 (58.7)	

[1] Chi square test

Table 4b) shows the multivariate analysis testing for an association between independent variables and having any psychiatric disorder. The sociodemographic and clinical factors that showed an association at bivariate analysis at a level of significance of < 0.2 were further subjected to multivariate analysis while applying the logistic regression model to test for independent association. None of the factors had an effect even on multiple logistic regression.

Table 4b) Multiple Logistic Regression for Factors Associated with Having any Psychiatric Disorder

Variable	Odds Ratio	P-value	[95% Conf.	Interval]
Age				
Below 12 years	1.000			
Above 12 years	0.690	0.083	0.453	1.050
Viral suppression	1.000			
No Viral suppression				
Viral Suppression	1.361	0.148	0.896	2.068

Having not found any association with having any psychiatric disorder, associations were tested with having anxiety disorders which were the most commonly occurring psychiatric disorders . **Table 5 a** indicates that only age was significantly associated with having an anxiety disorder on bivariate analysis (p=0.025).

Table 5 a):Factors Associated with Anxiety Disorders among Children and Adolescents Living with HIV

Variable	Anxiety		
	No N(%)	Yes N(%)	P-value
Age in years			
Below 12	80 (46.8)	91 (53.2)	**0.025**[1]
Above 12	196 (58.2)	92 (41.8)	
Gender			
Female	102 (49.8)	103 (50.2)	0.152[1]
Male	106 (57.0)	80 (43.0)	
Disclosure of HIV status			
Full disclosure	98 (52.7)	88 (47.3)	0.869[1]
No disclosure	71 (54.2)	60 (45.8)	
Some disclosure	28 (50.0)	28 (50.0)	
Both Parent alive			
No	102 (54.3)	86 (45.7)	0.637[1]
Yes	99 (51.8)	92 (48.2)	
School attendance			
No	12 (66.7)	6 (33.3)	0.241[1]
Yes	196 (52.5)	177 (47.5)	
Caregiver			
Family setup	196 (52.8)	175 (47.2)	0.292[2]
Foster care	10 (66.7)	5 (33.3)	
Nutritional status			
Poor growth + malnutrition	97 (54.2)	82 (45.8)	0.317[1]
Appropriate growth	74 (48.1)	80 (51.9)	
Viral suppression			
Yes	89 (55.6)	71 (44.4)	0.474[1]
No	110 (51.9)	102 (48.1)	
ARV regimen			
Other regimens	141 (53.2)	124 (46.8)	0.995[1]
Efavirenz based regimen	67 (53.2)	59 (46.8)	

[1] Chi square test [2] Fishers exact test

Table 4b) shows the multivariate analysis testing for an association between independent variables and having anxiety disorders among CALHIV. The sociodemographic and clinical factors that showed an association at bivariate analysis at a level of significance of 0.2 were further subjected to multivariate analysis while applying the logistic regression model to test for independent association. This analysis revealed that children above 12 years of age had a 36.3% reduced odds of having an anxiety disorder compared to younger children (O.R =0.637 C.I 0.425 - 0.953; p=0.028).

Table 5b:Multiple Logistic Regression for Factors Associated with Anxiety Disorders Among Children And Adolescents Living with HIV

Variable	Odds Ratio	P value	[95% Conf. Interval]	
Age				
Below 12 years	1			
Above 12 years	0.637	**0.028**	0.425	0.953
Gender				
Female	1			
Male	0.756	0.173	0.506	1.130

4.6. Models of mental health care

a) Human resources

A total of 18 health care providers participated in this study. Half of them were below 35 years of age. More than half (55%) of the health care providers who participated were nurses (5) and clinical officers (5) combined. Other providers included Psychological counsellors (2), Social Workers (2), Nutritionist (1) CCC assistants (3)

b) Level of health workers training

Half of them had a diploma with the remaining having a degree or higher level of education. Only 38.9% participants reported to have had any mental health training.

c) Mental health services

In terms of mental health services, 66.7% of the health care providers reported to have occasionally encountered children and adolescents with mental health issues at clinics. Nine (50%) participants reported that they screen for mental health disorders with the main screening method being use of questionnaires while others reporting use of unstructured one on one interviews. Seven (38.9%) of the participants reported that they felt incompetent in managing a child or adolescent with a mental disorder at the clinic.

The reported mental health services available for children and adolescents on HIV care at the AMPATH paediatric and HIV clinics were: psychological counselling and group therapy (reported by 56.3% of health workers) and review by a Psychiatrist clinic once a week (reported by 12.5% of the health workers). Linkages were often to a Social worker, Psychological counsellor, and Psychiatrist or to the MTRH child and adolescent mental health clinic. The reported referral channel available for linkage to a mental health specialist was a referral form as reported by 61.1% of the health workers.

On what can be done to improve mental health services at the clinic, the health workers suggested; building mental health awareness among the health care providers, mental health education, availing a mental health specialist at the clinic and establishing a mental health clinic at the Paediatric/Adolescents HIV clinics.

CHAPTER FIVE

DISCUSSION

5.1 Prevalence and patterns of psychiatric morbidity among children and adolescents living with HIV

5.1.1 Prevalence of having any psychiatric disorder

The prevalence of psychiatric morbidity among children and adolescents living with HIV (CALHIV) in this study was **57.5%** (95% CI: 52.5, 62.5). This prevalence was similar to what was found in Nairobi at 48.8% (95% CI 40.8, 56.7) with n=162 (Kamau et al., 2012). The two confidence intervals overlap and therefore we concluded that there was no difference between the two prevalence rates but this was shy of statistical significance based on p=0.059 that was calculated using chi square test for proportions. Finding that the prevalence from this study was similar to the Nairobi study indicates that the high prevalence of psychiatric morbidity among CALHIV was similar across different sociodemographic environments. This is because the Nairobi study engaged children from a low socio-economic background, in Kariobangi, one of the informal settlements in Nairobi county (Kamau et al., 2012). This current study on the other hand engaged children coming to the largest HIV care program in western Kenya – AMPATH, from 16 different counties. Up to 60% of the participants from this current study came from Uasin Gishu county with the rest coming from neighboring counties like Trans Nzoia, Nandi and Elgeyo Marakwet while others came from as far as Nairobi and Turkana counties. Although this study did not investigate the economic status of the participants, the vastness of the counties of residence suggests a mixture of urban, semi-urban and rural environments indicating varied sociodemographic backgrounds . The prevalence from this current study was within the upper limit of a 25% to 50% prevalence range of psychiatric

disorders among CALHIV given by a systematic review done in South Africa, and was even higher than a prevalence of mental disorders among school children in Kenya at 37.7% (Nassen et al., 2014; Ndetei et al., 2016). This indicates there was a high prevalence of psychiatric disorders among CALHIV on HIV care at AMPATH-MTRH.

Findings from a meta-analytical review of studies from high income countries indicated that PHIV+ youth (youth prenatally exposed to HIV, who are HIV positive) had higher than expected rates of psychiatric disorders, often exceeding rates among youth in the general population and other high-risk groups (Claude A Mellins & Malee, 2013). Compared to this current study, other studies have also found similar and even higher prevalence of behavioral and psychiatric disorders among children with HIV infection. One study in the USA found that 52% of the children living with HIV manifested with behavioural problems while another study in USA found a 68.7% prevalence rate of psychiatric disorder among PHIV+ youth (Dolezal et al., 2013; Nozyce et al., 2006). Closer home though investigating psychological distress, a study in Uganda found a 51.2% prevalence rate of significant psychological distress among adolescents living with HIV (Musisi & Kinyanda, 2009). Another study in South Africa however found a lower prevalence of any psychiatric disorder at 27% among adolescents receiving HIV care at different Paediatric HIV clinics in Johannesburg. However the South African study only measured depression, anxiety, PTSD, suicidality and not all possible psychopathology (Woollett et al., 2017). The high rates of psychiatric disorders among CALHIV are possibly secondary to compounding stressors that make adolescence difficult and increase the likelihood of mental health problems. These include HIV-related neurologic and developmental disabilities, stigma, death of a parent, and negative environmental situations such as

poverty, violence and discrimination (Dolezal et al., 2013). Other factors that have been seen to contribute to mental disorders among children and adolescents with HIV include poor cognitive functions, age, health of the parent (both physical and mental health) and stressful life events. On the other hand however, other factors such as parent-child involvement and communication, and social support from peers, parents and teachers have been associated with better mental health outcomes among CALHIV (Claude A Mellins & Malee, 2013). It has also been observed that, children receiving HAART may remain susceptible to the effects of HIV on the brain. This is because the CNS acts as a reservoir for persistent viral replication. Initiation of ART, then, may not fully reverse CNS insults of the HIV virus, mostly if treatment was not commenced during infancy (Nassen et al., 2014). This means that these children continue to be susceptible to neuropsychiatric complications of HIV despite optimal treatment and therefore remain at risk for poor mental health outcomes.

5.1.2 Diagnostic and treatment gap

One of the most important findings in this study was that despite more than half of the participants having one or more psychiatric disorders (57.5%), **only 1.7%** (4 out of 225 who screened positive) had ever been diagnosed with a mental illness or received treatment. This finding points to a glaring diagnostic and treatment gap for the children and adolescents with HIV infection and co-morbid psychiatric disorders. This was however not surprising, as other studies have shown that very few children with psychiatric disorders ever access the services of a mental health specialist. One study carried out in 42 low and middle income countries across different regions found that the median one-year prevalence for children and adolescents who had been treated for mental disorders in out-patient settings was 159 per 100,000 population. This was almost 4 times less than the rate of adults being treated for mental disorders

in the out-patient settings (Morris et al., 2011). In the USA it was documented that despite the high prevalence of mental disorders among the youth, less than 50% of them receive mental health services (Merikangas, Nakamura, & Kessler, 2009). This huge diagnostic and treatment gap in mental health has also been enumerated in Kenya with observations that people with common mental disorders like depression and anxiety, are rarely diagnosed, and rarely managed appropriately (Jenkins et al., 2010). One community study carried out in Nandi County, in the western part of Kenya estimated that only 3.6% people who screened positive for psychiatric disorders had ever received mental health care (Kwobah et al., 2017). Furthermore, these gaps have also been observed even in high income countries evidenced by a survey involving several European countries reporting that between 30% to 60% of people with serious mental disorders do not receive mental health treatment (Bijl et al., 2003). It is therefore unfortunate to emphasize that a majority of people, including children and adolescents suffering from psychiatric disorders remain undiagnosed and untreated. This calls for heightened efforts in employing early interventions like screening and treatment for those suffering from mental disorders (Bijl et al., 2003). Investing in bridging these gaps and applying early mental health interventions has been suggested to have a great impact with evidence showing that effectively treating mental illness among people living with HIV has benefits for their HIV treatment retention, ART adherence, and virologic suppression (Pence, O'donnell, & Gaynes, 2012).

5.1.3. Patterns of Psychiatric morbidity

In this current study anxiety disorders were the most commonly occurring psychiatric disorder at 53.8%. These findings corresponded to findings by the Nairobi study that reported anxiety as the most occurring disorder though at a lower rate at 32.2% (Kamau et al., 2012). Other similar studies among children and adolescents living with HIV in Africa and other parts of the world also found anxiety disorders among the most common disorders; Uganda - 45.6%, South Africa - 25%, New York - 30.1% and multiple centres in the U.S.A- 24% (Dolezal et al., 2013; Claude Ann Mellins, Brackis-cott, Dolezal, & Abrams, 2006; Musisi & Kinyanda, 2009; Woollett et al., 2017).

Similar to the finding in this current study that anxiety disorders were most commonly occurring among CALHIV, evidence from a range of studies have indicated that anxiety disorders are the most commonly occurring mental disorders among children and adolescents in the general population (Beesdo, Knappe, & Pine, 2009b; Merikangas et al., 2009). Among children/adolescents in the general population, the lifetime prevalence of any anxiety disorder was estimated at about 15% to 20% in high income countries (Beesdo et al., 2009b). One epidemiological review article also reported that the median prevalence rate of all anxiety disorders among children and adolescents was 8% with an estimated range of 2% to 24% (Merikangas et al., 2009). In Uganda the point prevalence of anxiety was 26.6% (Abbo et al., 2013). The estimated prevalence of anxiety disorders among children in the general population however appears to be lower than the prevalence in this current study. This may indicate that anxiety disorders are more prevalent among CALHIV than among children in the general population. Paucity of comparative research between children living with HIV and children in the general population however makes it difficult to

make such a conclusion. However, one comparative study between PHIV+ adolescents and PHIV- ones have indicated that there was no difference in prevalence of anxiety disorders between the 2 groups (Kapetanovic et al., 2012). Traumatic events such as accidents and disasters including violence and conflicts, have been observed to play a significant role in the development of anxiety and depression among those affected (Kenya mental health policy 2015). Risk factors for anxiety among children and adolescents in the general population have been identified as: overprotective parenting, general distress or negative affectivity and childhood traumas like abuse at home or in school, violence, neglect, death of a parent and separation from parents (Beesdo, Knappe, & Pine, 2009a). Some of the children and adolescents who participated in this study may have experienced the Post Election Violence (PEV) that happened in Kenya in 2007, and this together with other HIV related traumas like parental death, stigma, victimization and even sexual exploitation may have placed the children and adolescents living with HIV at higher risk of developing anxiety disorders (Musisi & Kinyanda, 2009; Woollett et al., 2017).

In this current study 10.4% of the CALHIV had suicidality, which was similar to the Nairobi study with a suicidality rate of 10.3% (Kamau et al., 2012). On the other hand however, in the current study, suicidality was the second most commonly occurring psychiatric disorder while suicidality ranked 5th in occurrence in the Nairobi study (Kamau et al., 2012). Higher rates of suicidality among youth with HIV infection have been reported in Nigeria, Uganda and South Africa at 16%, 19.5 % and 24% respectively (Bankole et al., 2017; Musisi & Kinyanda, 2009; Woollett et al., 2017). One case control study carried out in Nigeria reported even higher rates of suicidal ideation at 34.7% among adults living with HIV (Chikezie, Otakpor, Kuteyi, & James, 2012). With suicide being reported as the second leading

cause of death among youth 15-29 years of age globally, it is not surprising to observe such high rates of suicidality among adolescents living with HIV (https://www.who.int/news-room/fact-sheets/detail/suicide). The suicidality rate in the current study was however lower than a 12-month prevalence of suicidality of 16.2% among youth in the general population from 32 low and middle income countries including Kenya (McKinnon, Gariépy, Sentenac, & Elgar, 2016). The 12 month prevalence of suicidality was however similar to the rates among adolescents living with HIV in Nigeria and Uganda at 16% and 17% respectively (Bankole et al., 2017; Musisi & Kinyanda, 2009). A South African longitudinal study among children and adolescents in the community further demonstrated that adverse childhood events such as parental death resulting from HIV/AIDS and challenges of HIV illness itself were strongly associated with suicidal ideation (Cluver et al., 2015). This goes to show that despite the suicide rates among youth in the general population appearing higher than for youth with HIV infection, HIV disease contributes to suicidality among the youth. Cultural norms have been said to explain lower rates of suicidal ideation with some cultures treating suicide as a taboo, thus restricting people from reporting suicidal thoughts (Carrico et al., 2007). It is possible that the youth in our study may have been restricted by cultural norms and fear of speaking about suicide. This may explain the apparent lower rate of suicidality in this current study.

Not much has been documented concerning suicidality among children and adolescents living with HIV, however in South Africa, one study observed that an elevated suicidal ideation risk was significantly associated with a diagnosis of a seropositive HIV status among adults (Schlebusch & Govender, 2015). This may imply that diagnosis or disclosure of HIV status is associated with suicidality. In this current study, one participant reported suicidal thoughts as one of the psychological

challenges experienced during disclosure process. Furthermore, a similar study carried out in Nairobi found that older age (>11 years) was considerably associated to suicidality (Kamau et al., 2012). We can therefore speculate that older children who had undergone or were going through disclosure would be more likely to report suicidality.

Attention deficit Hyperactivity Disorder (ADHD) was the third most commonly occurring disorder among the CALHIV in this study at a rate of 10%. The Nairobi study reported a similar rate of ADHD at 12%, however it was ranked 3rd in occurrence (Kamau et al., 2012). A South African review also reported that ADHD was among most common psychiatric manifestations among children and adolescents living with HIV (Nassen et al., 2014). Studies from high income countries have documented higher rates of ADHD among children with HIV with prevalence rates of up to 28.6%, 29% and 36% (Dolezal et al., 2013; Misdrahi et al., 2004; Scharko, 2010). In Kenya, a 1.3% rate of ADHD among primary school going children was reported (Ndetei et al., 2016) . This was much lower than the ADHD prevalence the current study and other studies among children living with HIV. A study carried out in the same setting as ours, although among university students in Eldoret, reported a higher prevalence rate of ADHD symptoms at 21.8% (Atwoli, Owiti, Manguro, & Ndambuki, 2010).

Prevalence rates of ADHD among children in the general population in high income countries however seem to correspond with that in the current study with one study in the USA recording a rate of 8.6% (Kathleen, Merikangas, & He, 2010). A worldwide meta-analytical review which included 4 studies from African countries, however computed a lower overall prevalence of ADHD among children in the general

population at 5.29% (Lima et al., 2007). One other review article stated that ADHD prevalence among children varied widely ranging from 1.7% to 17.8% (Merikangas et al., 2009). One of the reviews further reported that geographic location was significantly associated with variability between estimates of ADHD in different parts of the world with estimates from Africa being significantly lower than estimates from North America (Lima et al., 2007). The ADHD rate in this current study was similar to the global prevalence of ADHD among children in the general population but lower than ADHD rates among children and adolescents with HIV infection in the USA. The wide variation of prevalence rates cited above may be also accounted for by different methodologies used by different studies (Lima et al., 2007).

Mood disorders including Major depression (7.9%) and Bipolar mood disorders (7.3%) were less frequently occurring among CALHIV in this current study compared to the Nairobi study where Major depression was 17.3%, and Bipolar mood disorders 6.4% (Kamau et al., 2012). CALHIV in Uganda had a very high prevalence of depression at 40.8% but a low prevalence of manic episodes at 1.2% (Musisi & Kinyanda, 2009). In South Africa, depression among youth with HIV was estimated at 14%, while in Nigeria the prevalence of depression was 20% (Bankole et al., 2017; Woollett et al., 2017). These rates were higher than what was found in this current study. Studies done elsewhere have also reported higher prevalence of mood disorders among children and adolescents living with HIV with one study in USA recording that 21% of PHIV+ had a mood disorder (Dolezal et al., 2013). In France one study reported that major depression was the most frequently occurring psychiatric disorder among children with HIV infection at a rate 47% (Misdrahi et al., 2004).

In Kenya, Ndetei et al reported a 14% prevalence of affective disorders among school going children this was notably higher than the rates in this current study (Ndetei et al., 2016). On the international platform, it is reported that there is scarce of information about the prevalence and phenomenology of pediatric bipolar disorder. The available data suggested that pediatric bipolar disorder is fairly rare among children in the general population with a review article reporting bipolar rates in population based studies among children ranging from 0% to 0.9% (Merikangas et al., 2009; Soutullo et al., 2005). In the USA, a cross-sectional survey conducted from 2001 to 2004 reported a 3.7% prevalence for mood disorders among children in the general population (2.7% for major depressive disorder and 1.0% for depressive disorder) (Kathleen et al., 2010). Of note here is that the rate of depressive disorders was much lower than the rate of major depression in this current study (7.9%). One review article reported prevalence rates of mood disorders among children in the general population from different countries as follows: Holland 7.2% for mood disorders, Denmark 1.2% of bipolar disorder; Spain 4% of bipolar disorder; India 2.5% of bipolar disorder and Brazil 7.2% of bipolar disorder (Soutullo et al., 2005). Some of these prevalence rates were lower than the rate found among the children living with HIV while others were similar to those reported in this current study. Above findings give a picture of varied prevalence rates of mood disorders, both among children living with HIV and those in the general population.

The variations in prevalence rates of mood disorders might be accounted for by the use of different methodologies and use of different tools to measure the mood disorders. Cross-cultural and ethnic factors have also been observed to influence the diagnosis of children with bipolar mood disorders possibly contributing to the differences in prevalence rates. For instance Kamau et al in Nairobi used two

versions of the MINI kid that is, the parent version for children aged 6 -10 years and the youth self-report for those aged between 11 and 18 years (Kamau et al., 2012). This current study only used the MINI Kid Version 7.0.1 that the researcher read out to the child/adolescent together with their parent/guardian. Musisi et al in Uganda used WHO/Self Report Questionnaire-25 and ICD-10 symptom checklists to estimate the prevalence of probable mental disorders/distress (Musisi & Kinyanda, 2009) while Woollett et al in South Africa used the short form of the Child Depression Inventory (CDI) to measure depression (Woollett et al., 2017). Differences in prevalence of mania symptoms have been noted to be influenced by whether the child is assessed or not. When only the parents are evaluated they have been observed to under-report certain symptoms such as elation, grandiosity, flight of ideas, racing thoughts or decreased need for sleep which are pertinent symptoms in making a diagnosis of mania (Soutullo et al., 2005). Evaluating young children for mood disorders has been found to be particularly challenging, especially when getting information from different sources. Parental psychopathology, conflicting reports, and limitations of child self-report have also been identified as factors that affect the outcome of mood evaluation among children (Carlson & Meyer, 2006). Furthermore it is important to acknowledge that the current DSM criteria for mania and depression were developed for adults and are often difficult to apply to children. This is demonstrated by the fact that many children with bipolar disorder often present with daily mood swings that occur for months to years and mixed or dysphoric symptoms rather than classic euphoric mania (Kowatch et al., n.d.).

A review of depression more than a decade ago estimated a lifetime prevalence rate of major depressive disorder (MDD) among adolescents in the general population to range from 15% to 20%, which was comparable with the lifetime rate of MDD

findings in adult populations at that time. This was taken to suggest that depression among adults often begins in adolescence (Neal, Ba, David, Ronald, & Rn, 1996). A review for guideline development also reported that the average of onset of mania and hypomania among children was approximately 7 years ± 3.5 years, with an average episode lasting of 3 to 5 years (Kowatch et al., n.d.). These findings therefore support the idea that mood disorders can commence in childhood and adolescence and hence the need for screening and early diagnosis for timely management of mood disorders among children and adolescents.

This study estimated the occurrence of Autism Spectrum Traits at 4.3%. Autism Spectrum Traits meant that the screening questions on the MINI Kid module were not adequate for making a diagnosis of Autism Spectrum Disorder (ASD) but the diagnosis could not be ruled out. The author of the MINI Kid recommends that a board certified child psychiatrist would be required to carry out further investigations in order to make a diagnosis of ASD (International & Interview, 2016). The participants who were found to have Autism spectrum traits were referred to the MTRH child and adolescent mental health clinic for further evaluation. In contrast, Kamau et al. did not have this as one of the psychiatric disorders, instead the Nairobi study reported pervasive development disorder at 0.6% which was a diagnosis that was in the DSM IV on which her version of MINI Kid was formulated but not currently in DSM 5 (Kamau et al., 2012). The current manual, DSM-5 was published in 2013 and introduced a change in the approach to diagnosis, from the traditional categorical approach to a more dimensional approach. In line with these changes, Aspergers Disorder and Pervasive developmental disorders (PDD) were removed and merged into Autism Spectrum Disorder (Dussen, 2013). None of the other studies reviewed reported occurrence of ASD among children and adolescents living with

HIV. A survey done in the USA, among 8 year old children in the general population found a 1.4% prevalence of ASD (Baio, 2014). This was noted to be lower than the rate among children and adolescents living with HIV in this current study. One review article that set out to assess the state of ASD in Africa observed that the prevalence of ASD was unclear. The few studies that were reviewed did not address the epidemiology of ASD among children in the general population. However, among children with developmental disorders the prevalence of ASD was estimated at 33.6% in Egypt and 11.5% in Tunisia (Bakare & Munir, 2011). These rates were noted to be higher than the rate of Autism in this current study. The scarcity of information on ASD has also been observed by WHO, stating that the epidemiology of ASD in many low- and middle-income countries is so far unknown. The WHO factsheet further reported that 1 in 160 children worldwide have ASD. This estimate however was an average figure, and it was reported that the prevalence of ASD had a wide variance across studies (https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders). The prevalence of ASD has otherwise been observed to be increasing globally. Possible explanations for this apparent increase, include improved awareness, expansion of diagnostic criteria, better diagnostic tools and improved reporting (Elsabbagh et al., 2012) (Newschaffer et al., n.d.). However as noted earlier, little research has been done on ASD in Africa and much less among CALHIV. Therefore more epidemiological studies need to be done, in order to define the extent of the problem as well as the characteristics of children with ASD especially sub-Saharan Africa (Bakare & Munir, 2011).

Other conditions diagnosed in this current study included Post traumatic Stress disorder 1.3%, Conduct disorders 1.3%, Obsessive compulsive disorders 1.3%, Oppositional defiant disorders 0.8% and Adjustment disorders 0.5%.

5.2 Factors associated with psychiatric morbidity among children and adolescents living with HIV

5.2.1 Factors associated with having any psychiatric disorder

Contrary to what was expected, this current study found that none of the sociodemographic variables nor HIV characteristics measured were associated with having a psychiatric disorder on both bivariate and multivariate analysis. This was in keeping with findings from the Nairobi study which also found no statistically significant association between having a psychiatric disorder and any of the sociodemographic characteristics of children and adolescents with HIV infection with n=162 (Kamau et al., 2012). One study in the USA among CALHIV with n=325 also established that only gender was associated with having any psychiatric disorder with females having higher odds of having any psychiatric disorder than boys (OR= 0.62, 95% CI=0.38, 0.99, p=.050) (Dolezal et al., 2013). The high prevalence of psychiatric disorders among children and adolescents living with HIV may explain the lack of association with sociodemographic factors. This is because a large proportion of the population has suffered the outcome of interest and most of the individuals in the proportion with the outcome will share characteristics with the proportion who do not have the outcome of interest. This may result in not finding any unique characteristics in the affected group or associations between their characteristics with the outcome of interest, in this case psychiatric morbidity.

The finding that there were no associations between having any psychiatric disorder and sociodemographic factors among these children might suggest that these characteristics of children and adolescents living with HIV may not necessarily be associated with having a psychiatric disorder. This has been observed by some comparative studies in high income countries that did not find a statistically

significant difference in the prevalence of psychiatric disorders among HIV-infected children and controls living in similar situations (Gadow et al., 2010). Due to similarities in prevalence of psychiatric disorders among perinatally exposed HIV positive (PHIV+) (68.7%) and perinatally exposed but uninfected (PHEU) (69.3%) youth, some researchers have opined that factors other than perinatal HIV infection may have played an important role in determining mental health outcomes (Dolezal et al., 2013). Furthermore similar comparative studies even found higher prevalence of mental health problems among PHEU children (38%) than PHIV+ children (25%) (Kapetanovic et al., 2012). Some authors have suggested that children and adolescents living with HIV may even have protective factors like access to medical specialists, including referral to relevant mental health specialists compared to the HIV exposed but uninfected children and adolescents (Gadow et al., 2010). In addition, some studies have even established that PHIV+ youth were more likely to receive mental health interventions including individual, family and group counselling, behavioural modification, after-school tutoring and psychiatric hospitalization (Claude A Mellins & Malee, 2013). Such interventions could have evened out the risk posed by HIV infection for having a psychiatric disorder among the HIV infected children and adolescents in our sample. Findings in my study indicated that there were similar mental health interventions at the AMPATH Paediatric and Adolescent HIV clinics as mentioned above by Mellins et al (Claude A Mellins & Malee, 2013). However the impact of these mental health services in the diagnosis and management of mental disorders in our setting remains uncertain.

Another explanation for not finding an association with the sociodemographic or clinical factors measured is that the underlying causes of psychiatric disorders are heterogeneous spanning across biological, psychological and social (biopsychosocial)

factors. Following incorporation of the biopsychosocial model in the explanatory model of psychiatric disorders, research has shown that no single factor has a monopoly on the explanation on its own (Babalola, Noel, White, & others, 2017). Furthermore, the developmental psychopathology theory indicates that no single causative or associated factor is responsible for development of psychopathology (Costello, Foley, & Angold, n.d.). These concepts suggest that some of the factors measured in our study may have had some contribution on having a psychiatric disorder but not individually rather in collaboration with other factors in an intertwined way.

5.2.2. Factors associated with having Anxiety disorder

Having not found any associations between having any psychiatric disorder among CALHIV and the variables measured, associations were tested with having anxiety disorders which were the most commonly occurring psychiatric disorder. On bivariate analysis this study found that age was significantly associated with having an anxiety disorder (p=0.025). On further multivariate analysis it was established that children older than 12 years of age had 36.3% reduced odds of having an anxiety disorder compared to younger children (O.R =0.637 C.I 0.425 - 0.953; p=0.028). In the USA however some researchers found that older children living with HIV (>9 years) were more likely to have anxiety problems, while others contrasted this by reporting that older children were less likely to report anxiety disorders (Dolezal et al., 2013; Nozyce et al., 2006). In South Africa, one study also found that adolescent females living with HIV scored significantly higher for anxiety than their male counterparts, while another study in Nairobi found that females were more likely to have specific phobia (Kamau et al., 2012; Woollett et al., 2017). These findings indicate varying impact of sociodemographic factors like age and gender on the

occurrence of anxiety disorders among children and adolescents living with HIV. One study investigating the course of anxiety among children in the general population observed an early age of onset of separation anxiety (at 8 years) indicating that anxiety disorders may begin earlier than expected. The study further established that the mean duration of the anxiety episodes was 4.5 years indicating that as the children became adolescents the anxiety symptoms may go into remission (Keller et al., 1992). A more recent epidemiological review drawing data from prospective community-based studies also indicated that onset of anxiety disorders among children was as early as 5 years of age. (Merikangas et al., 2009). These studies may support the finding that older children were less likely to report anxiety with speculation that anxiety symptoms may have gone into remission among older children and this may have been influenced by mental health interventions or disclosure process.

Furthermore the cut off age of 12 years was based on median age at full disclosure for CALHIV in this current study. This led to the speculation that younger children who had not undergone disclosure of HIV status may have been experiencing more anxiety related to not understanding their illness or why they were different from others and why they were on continuous medication unlike other children. Some studies have indicated that children or adolescents who have undergone disclosure of HIV status were less likely to have emotional difficulties (Menon, Glazebrook, Campain, & Ngoma, 2007). This was further demonstrated by findings that children who knew their HIV status tended to have higher self-esteem and fewer symptoms of depression (Claude Ann Mellins et al., 2002; Vreeman et al., 2013).

Based on the studies reviewed, it was observed that sociodemographic factors and HIV characteristics were more often found to be associated with specific psychiatric

disorders among children and adolescents with HIV infection rather than with having any psychiatric disorder. The Nairobi study reported that older age (>11 years) was considerably associated to suicidality, females were more likely to have specific phobia and male gender was significantly associated with major depression (Kamau et al., 2012). In Nigeria, CALHIV living with biological parents were less likely to report depression compared to orphans (Bankole et al., 2017). In South Africa, being female was significantly associated with depression, anxiety and PTSD (Woollett et al., 2017). On HIV characteristics the Nairobi study reported that major depression was significantly associated with a lower CD4 (having low immunity), and similarly one study in the USA reported that those with undetectable Viral Load (viral suppression) were less likely to have behavioural disorders (Dolezal et al., 2013; Kamau et al., 2012). These findings may indicate that sociodemographic factors and HIV characteristics of children and adolescents with HIV infection may not necessarily be associated with having general psychopathology, but are associated with the occurrence of specific psychiatric disorders like depression, anxiety and suicidality.

5.3. Models of mental health care

The 3rd objective in this study was to investigate the existing models of mental health care at the AMPATH Paediatric and Adolescent HIV clinics. The term "Models of Mental Health care" was defined as the way mental health services are delivered; focusing of the type of care and the team delivering the care (Framework, n.d.).

In terms of mental health services, more than 50% of the health care providers reported to have occasionally encountered children and adolescents with psychiatric issues at the clinics. The participants also reported that the mental health services available for children and adolescents living with HIV at the clinics included:

screening for mental disorders, psychological counselling, group therapy and review by a Psychiatrist once a week. Screening for mental disorders was done through provided structured questionnaires and unstructured one on one interviews. Availability of mental health services was very commendable since such mental health services have been observed to be lacking in many HIV care programs especially in developing countries compared to resource rich countries (Collins et al., 2006). Studies done previously have indicated that individuals living with HIV require comprehensive management of mental health problems through integration of mental health care into HIV care in order to improve their health outcomes (Freeman et al., 2005; Kamau et al., 2012). Interventions such as individual therapy, family therapy, group therapy and cognitive behavioral group interventions, have been seen to result in positive mental health outcomes for various individuals living with HIV. These positive outcomes include but are not limited to improved adherence to treatment, reduction in severity and occurrence of mental health problems, improved social well being, improved cognitive functions and improved motivational aspects of life (Freeman et al., 2005; Claude A Mellins & Malee, 2013). Similarly, psychological interventions such as counselling, cognitive-behavioural therapies, stress and anxiety management and other modes of psychotherapy for people living with HIV have been reported to reduce depressive symptoms (Ammassari, A., et al 2004). It is therefore important to emphasise that effective mental health interventions for children with impairing psychopathology need to be integrated into HIV care.

In terms of referral channels, the children/adolescents would be linked to social workers, psychological counsellors, a psychiatrist and the child and adolescent mental health clinic at MTRH. Linkage to the various mental health services was done through a referral form. These arrangements are commendable and in keeping with a

Consultation - liaison model of delivering mental health services in the primary care setting (Gask et al., 1997). This model encourages development of close links within a practice between the primary care team which comprised of the nurses and clinical officers and mental health services comprising of social worker, psychologist and psychiatrist with a view to;

- ✓ Reduce rather than increase referrals of milder mental disorders
- ✓ Selectively encourage referral of serious mental illness to mental health specialists and
- ✓ Enhance general practitioners skills in the detection and management of mental illness (Gask et al., 1997).

Other models of delivering mental health services that have been identified in other settings include:

- → Attached Mental Health professional: In which a community psychiatry nurse, psychologist or social worker working in a secondary care system is attached to a primary care system. The attached mental health professional offers outreach services.
- → Shifted outpatient clinic: In which visiting psychiatrist(s) operate clinics within primary care centers.
- → Community mental health team: In which a community psychiatry nurse, a psychologist and a social worker work as a multidisciplinary team together with primary care team within the primary care setting (Gask et al., 1997).

However, despite availability of these mental health services at the HIV clinics, **only 1.7 %** of the CALHIV who had psychiatric disorders had ever been diagnosed or treated for a mental illness. This as discussed earlier points to a huge diagnostic and

treatment gap, and a further disconnect between availability of mental health services and utilization or benefit to those who need the services. Minimal access and utilization of mental health services has been observed before with evidence that 4 out of 5 people with serious mental disorders don't get the mental health services that they need especially in low and middle income countries (Kenya mental health policy2015). One of the documented barriers to access of mental health care is the extremely limited availability of mental health specialists with estimated ratios of 1 psychiatrist per 4 to 5 million children in resource-limited countries (Vreeman et al., 2017). In our setting, only 2 psychological counsellors and 2 social workers were available at the AMPATH paediatric and adolescent HIV clinics while only one psychiatrist would review clients with mental health disorders once a week. However this current study did not investigate the barriers to access and uptake of mental health services. Studying these barriers then should be considered as an objective for future research.

In terms of human resources, this study found that the bulk of health care providers at the clinics were nurses and clinical officers. The clinics were also privileged to have psychologists and social workers, who have been seen to be instrumental in the delivery of mental health services. This indicates that most of the health workers at the clinics were front-line or primary health care workers with a few mental health care personnel. Freeman et al. opined that the front-line mental health service providers should be the existing primary healthcare workers and counsellors who would ideally require additional mental health training and relevant materials in order to offer mental health services (Freeman et al., 2005).

In this study, up to 60% of the health care providers reported having not had any mental health training. This finding is in keeping with a report by a review article that mental health training for health workers was limited and often out-of-date (Vreeman et al., 2017). This mental health training gap among primary health care workers in Kenya had already been observed with a need for continuous professional development (CPD) on mental health for front-line health workers being emphasized (Jenkins et al., 2010). In response to this training gap, a team of Ministry of Health (MOH), the Kenya Psychiatric Association (KPA) and the World Health Organization Collaborating Centre (WHOCC) designed a curriculum to train primary healthcare staff across Kenya on core concepts and skills in psychiatry. The training was integrated into the Kenya Medical Training College (KMTC) training system which is responsible for basic, post-basic and continuing training of the bulk of primary care staff in Kenya (nurses and clinical officers). This training commenced in 2005 and has been adopted by Universities and other medical training institutions. The curriculum has also been used in the basic training programs for the different health cadres and for post-basic courses (Jenkins et al., 2010). With such heavy investment in training for mental health, it was surprising to find that barely half of the staff at the AMPATH pediatric and adolescent clinics reported having had any mental health training. We could only speculate that maybe the training was started after many had finished their basic courses and therefore did not benefit from the integration of the mental health training in their basic training. It is also possible that this training had not been incorporated as part of CPD trainings at MTRH or AMPATH by the time this study was carried out. This further highlights the need for enhancing mental health training among primary health care providers, and especially among HIV care providers.

5.4. Strengths and Limitations of the Study.

One limitation of this study was that it was a cross-sectional study which limited the ability to show causality of associations as compared to a cohort or a case control study. A comparative study would have also been better in bringing out the differences between children and adolescents living with HIV (CALHIV) and control groups. However, the cross-sectional design was useful in bringing out the prevalence trends of psychiatric morbidity among CALHIV in Kenya, indicating that the prevalence has remained high at approximately 50% even in sociodemographically diverse settings. Secondly, the quantitative/descriptive design did not allow for in-depth exploration of the models of mental health care at the AMPATH clinics. However the descriptive design brought out the important finding that mental health services were present at the AMPATH-MTRH pediatric and adolescent clinics and that there is a gap between the presence of the services and their benefit to the children and adolescents. This lays ground for future qualitative studies on the processes and impact of integration of mental health services in HIV care. Thirdly, the MINI Kid tool and researcher designed questionnaires had not been validated in our setting. However, the MINI kid tool is a diagnostic tool and has been found to be reliable and accurate in measuring psychiatric disorders among children and adolescents (D V Sheehan et al., 2010). Furthermore MINI Kid has been used by other authors in Kenya and other parts of Africa and this forms a basis for comparison of findings (Bankole et al., 2017; Kamau et al., 2012; Syengo-Mutisya et al., 2008; Woollett et al., 2017).

The main strength of this study is that the sample was sociodemographically diverse, having been drawn from a population at the largest HIV treatment program in Kenya and probably in east Africa. This means that the results can be representative for

children and adolescents attending other HIV care programs in the region. Secondly, this was the first study in the region and probably in the country that has investigated the integration of mental health services in the HIV care of children and adolescents, and this lays a foundation for further research on this subject.

CHAPTER SIX

CONCLUSION AND RECOMMENDATION

6.1 Conclusion

This study established that there was a high prevalence of psychiatric morbidity among children and adolescents with HIV infection at **57.5%.** Anxiety disorders, suicidality and ADHD were the most commonly occurring psychiatric disorders. Only age was significantly associated with having an anxiety disorder with children older than 12 years having a 36.3% reduced odds of having anxiety than younger ones.

Mental health services were available at the AMPATH Pediatrics and Adolescent HIV clinics with ongoing screening and a working referral system. Psychologists, Social workers and a Psychiatrist were available at the clinics. However, up to 60% of the health care providers had not had any mental health training.

There was a glaring diagnostic and treatment gap indicating a severe disconnect between the existing mental health services and their actual benefit to children and adolescents on HIV care. This suggests that there could be barriers to access or utilization of mental health services at the AMPATH Pediatrics and Adolescent HIV clinics.

6.2 Recommendations

1. In view of the high prevalence of psychiatric disorders among children and adolescents with HIV infection, screening for mental disorders should be enhanced at the HIV clinics. Therefore, existing screening tools should be evaluated in terms of availability, ease of administration and efficiency. If they meet the acceptable standards, health care providers should be regularly trained on their use. Thereafter, monitoring and evaluation on screening for mental disorders should be carried out regularly. Screening should focus on the most commonly occurring disorders including anxiety disorders, suicidality and ADHD.
2. The health care providers should have regular training on basic mental health care. This can be done through continuous medical education sessions (CMEs), on- job training or by encouraging the health care providers to take up various mental health courses.
3. Further and in-depth research needs to be done on barriers to access and uptake of mental health services at the AMPATH paediatric and adolescent HIV clinics. A comparative study would also be useful in establishing whether psychiatric disorders are more prevalent among those with HIV infection than in the general population in our setting.

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APPENDICES

Appendix I: Research Consent Form

Study Title: **PSYCHIATRIC MORBIDITY AND CARE OF HIV INFECTED CHILDREN AND ADOLESCENTS IN MOI TEACHING AND REFERRAL HOSPITAL - ELDORET KENYA**

Name of Principal Investigator(s): Mary W. Njuguna

Name of Organization: Moi University and Moi Teaching and Refferal Hospital

Name of Sponsor: Self

Informed Consent Form for: 1.Parents or Guardians of Children and adolescents below 18 years of age

2. Health Workers attending to HIV infected Children and adolescents in the AMPATH clinics.

This Informed Consent Form has two parts:

• Information Sheet (to share information about the study with you)

• Certificate of Consent (for signatures if you choose to participate)

You will be given a copy of the signed Informed Consent Form

Part I: Information Sheet

Introduction:

You are being asked to take part in a research study. This information is provided to tell you about the study. Please read this form carefully. You will be given a chance to ask questions. If you decide to be in the study, you will be given a copy of this consent form for your records.

Taking part in this research study is voluntary. You may choose not to take part in the study. You could still receive other treatments. Saying no will not affect your rights to health care or services. You are also free to withdraw from this study at any time. If after data collection you choose to quit, you can request that the information provided by you be destroyed under supervision- and thus not used in the research study. You

will be notified if new information becomes available about the risks or benefits of this research. Then you can decide if you want to stay in the study.

Purpose of the study:

The purpose of this study is to investigate the occurrence of psychiatric disorders and assess the mental health care among HIV infected children and adolescents in Moi Teaching and Referral Hospital -AMPATH

Type of Research Project/Intervention:

The study will involve a set of interviews in order to answer the study questions.

Commonly asked questions

- **Why have I been identified to Participate in this study?**

You have been selected through a systematic random procedure from other clients attending the clinic.

- **How long will I be involved in the study?**

You will be involved in the study only during the interview.

If any medical or psychiatric condition is detected for children and adolescents and referral is needed, they will be linked to the appropriate mental health services.

- **What will happen to me during the study?**

We are asking you to help us learn more about mental illnesses among children and adolescents attending the paediatric HIV clinic. If you accept, you will be asked to answer a number of questions concerning the subject

You will be required to answer personal questions about yourself or about your child concerning the current illness or possible mental illness.

- **What side effects or risks I can expect from being in the study?**

We shall not be applying any interventions, or giving any medication, therefore we don't anticipate any risks nor side effects from the study.

- **Are there benefits to taking part in the study?**

The possible benefits of this study to society may include, better understanding of childhood mental illnesses among HIV infected children and possible development of better mental health care services at the paediatric HIV clinic.

The Children who are found to have previously undetected mental illness will also benefit from appropriate linkage to mental health services.

- **Reimbursements:**

There shall be no reimbursements to those who volunteer to participate in the study

- **Who do I call if I have questions about the study?**

For questions about the study, call the primary investigator Tel No: 0722165350
For questions about your rights as a research subject: You may contact Institutional Review Ethics Committee (IREC) 053 33471 Ext.3008. (IREC is a group of people that reviews studies for safety and to protect the rights of study subjects).

- **Will the information I provide be kept private?**

All reasonable efforts will be made to keep your protected information (private and confidential. Protected Information is information that is, or has been, collected or maintained and can be linked back to you. Using or sharing ("disclosure") of such information will follow National privacy guidelines. By signing the consent document for this study, you are giving permission ("authorization") for the uses and disclosures of your personal information. A decision to take part in this research means that you agree to let the research team use and share your protected information as described below.

As part of the study, Mary W. Njuguna and her study team may share the results of your [age, residence, level of education health status e.t.c]. These may be study or non-study related. They may also share portions of your medical record, with the groups named below:

- The National Bioethics Committee,
- The Institutional Review and Ethics Committee,
- MTRH, AMPATH and Moi University

National privacy regulations may not apply to these groups; however, they have their own policies and guidelines to assure that all reasonable efforts will be made to keep your personal information private and confidential.

The study results will be retained in your research record for at least 7 years after the study is completed. At that time, the research information not already in your medical record will be will be stored in a secure location, only accessible to the researcher. Research information will be kept for a period of 7 years and will then be destroyed permanently.

Unless otherwise indicated, this permission to use or share your Personal Information does not have an expiration date. If you decide to withdraw your permission, we ask that you contact Mary W. Njuguna - the primary researcher in writing and let her know that you are withdrawing your permission. The mailing address is wanjuguna77@gmail.com. At that time, we will stop further collection of any information about you. However, the health information collected before this withdrawal may continue to be used for the purposes of reporting and research quality.

You have the right to see and copy your personal information related to the research study for as long as the study doctor or research institution holds this information. However, to ensure the scientific quality of the research study, you will not be able to review some of your research information until after the research study has been completed.

Your treatment, payment or enrolment in any health plans or eligibility for benefits will not be affected if you decide not to take part. You will receive a copy of this form after it is signed.

Part II: Consent of Subject:

I have read (or have had read to me) the description of the research study. The investigator or his/her representative has explained the study to me and has answered all of the questions I have at this time. I have been told of the potential risks, discomforts and side effects as well as the possible benefits (if any) of the study. I freely volunteer to take part in this study.

_____ _____ _____

Name of Participant Signature of subject/thumbprint
Date

(Witness to print if the subject is unable to write)

_____ _____

Name of Representative/Witness Relationship to Subject

_____ _____ _____

Name of person Obtaining Consent Signature of person
Date

Obtaining Consent

_____ _____ _____

Printed name of Investigator Signature of Investigator

Appendix 2: Research Assent Form

NB: For children and adolescents 11 to 17 years of age

Only done after parent or guardian had given consent to the study

What is a research study?

Research studies help us learn new things. We can test new ideas. First, we ask a question. Then we try to find the answer.

This paper talks about our research and the choice that you have to take part in it. We want you to ask us any questions that you have. You can ask questions any time.

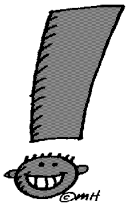
Important things to know…

You get to decide if you want to take part.

You can say 'No' or you can say 'Yes'.

No one will be upset if you say 'No'.

If you say 'Yes', you can always say 'No' later.



You can say 'No' at anytime.

We would still take good care of you no matter what you decide.

Why are we doing this research?

We are doing this research to find out more about illnesses that children like you may be having.

What would happen if I join this research?

If you decide to be in the research, we would ask you to do the following:

- Talking: A person on the research team would ask you questions. Then you would say your answers out loud.
- Medical records: We will look at your past doctor visits and use information about your care.

Could bad things happen if I join this research?

Some of the questions might be hard to answer. We will try to make sure that no bad things happen.

You can say 'no' to what we ask you to do for the research at any time and we will stop.

Could the research help me?

We think being in this research may help you because, if any illness is identified we will be able to advice you and your caregiver about the best treatment for the illness.

We also hope to learn something from this research, and someday we hope it will help other kids who have a similar illness.

What else should I know about this research?

If you don't want to be in the study, you don't have to be.

It is also OK to say yes and change your mind later. You can stop being in the research at any time. If you want to stop, please tell the research doctors.

You would not be paid to be in the study.

You can ask questions any time. You can talk to any research doctor available and ask us any questions you have. Take the time you need to make your choice.

Is there anything else?

If you want to be in the research after we talk, please write your name below. We will write our name too. This shows we talked about the research and that you want to take part.

Name of Participant _____

(To be written by child/adolescent)

Signature of subject/thumbprint _____

Printed Name of Researcher _____

Signature of Researcher _____

_____ _____

Date ***Time***

Appendix 3: The Child/Adolescent Sociodemographic and Clinical Questionnaire

NB!! Ask the disclosure questions to only the Parent/Guardian and ensure that the child or adolescent is not present in the room. This is to avoid unintended disclosure to the child or adolescent who has not yet undergone full disclosure of their HIV status.

1. Age

Year of birth.....

2. Gender

Male [ ] Female [ ]

3. Residence .....

4. Education

Is the child or adolescent attending school? Yes [ ] No [ ]

a) For those in school

- What class is the child in currently? .....

5. Knowledge of HIV status

a) How much does the child know about their HIV status?

No disclosure [ ]

Some disclosure [ ]

Full disclosure [ ]

b) At what age was full disclosure achieved? .....

c) Were there any emotional or psychological challenges faced during disclosure?

Yes [ ] No [ ] If yes list them

.....

6. Is the child or adolescent on HAART? Yes [ ] No [ ]

7. What ARV regimen is the child or adolescent on? .....

8. a) What are the initial and current viral load counts? .....

9. Height ..... Weight ..... Computed Z- score

.....

10. Parental status

a) Are both parents alive? Yes [ ] No [ ]

b) If No, indicate whether - Mother alive

- Father alive

- Total Orphan

11. Household information

a) Where does the child live? - In a family set up [ ]

- In foster care [ ]

b) How many people live in the same house with the child? .....

c) Who is the current primary care giver for the child? .....

12. Existing Mental illness

a)Has the child/adolescent ever been diagnosed or treated for a mental illness?

Yes [ ] No [ ]

b) If Yes, - what is the diagnosis.....

- are they currently on treatment for the mental illness?

Appendix 4: The Models of Mental Health Care Questionnaire
I. Sociodemographic data of the health workers

1. Age in years

18 - 25 [ ] 45 - 55 [ ]

25 -35 [ ] 55 - 65 [ ]

35 - 45 [ ] Over 65 [ ]

2. Cadre .....

3. Level of Education .....

4. Exposure to and level mental health training .....

II. Mental health services

1. How often do you encounter mentally ill children/adolescents in the module 4/Rafiki clinic? Never [ ] Rarely [ ] Occasionally [ ] Often [ ] Very often [ ]

2. a) Do you screen for mental health disorders in the Paediatric or Adolescent HIV clinic?

b) If so what method of screening is used? .....

3. How competent are you managing a child or adolescent with a mental disorder in the clinic?

Fully competent [ ] Some competence [ ] No competence [ ]

4. What are the mental health services available for HIV infected children and adolescents at the module 4 clinic?

.....

5. a) What referral channels are available for linkage to a mental health specialist?

.....

b) How efficient are these referral channels?

.....

6. What do you think can be done to improve mental health care for children or adolescents who attend this clinic?

.....

APPENDIX 5: MINI INTERNATIONAL NEUROPSYCHIATRIC INTERVIEW FOR CHILDREN AND ADOLESCENTS (MINI KID)
(attached)

Appendix 6:Budget

ITEM	**COST**
Stationary: including rims of paper, pens, pencils rulers	30,000
Laptop …….	45, 000
Printer ……	30,000
Toner ……	10,000
Allowances for research assistants ……	10,000
Data analysis ……	30, 000
Contingency ……	27,000

Total……

297,000**ksh.**

Appendix 7: Study Work Plan

1. Writing and submission of concept proposal to the Moi University Mental Health Department	Dec 2015 to Feb 2016
2. Submission of proposal to IREC	April 2016
3. Correcting comments from IREC	May to June 2016
4. Present proposal to IREC for approval	June 2016
5. IREC Approval	September 2016
6. Approval to conduct study at MTRH	September 2016
7. Permission to conduct research at AMPATH	September 2016
8. Pilot Study	December 2016
9. Data collection	May 2017 to April 2018
10. Data cleaning, coding and entry	Sept. 2018 to Dec. 2018
11. Data analysis and thesis writing	Jan. 2018 to June 2018
12. Mock defense	February 2019
13. Abstract submitted for marking and approval	March 2019 to Oct 2019
14. Thesis defense	November 2019
15. Correction, binding and submission of thesis	December 2019

Appendix 8:IREC Approval

INSTITUTIONAL RESEARCH AND ETHICS COMMITTEE (IREC)

MOI TEACHING AND REFERRAL HOSPITAL
P.O. BOX 3
ELDORET
Tel: 33471//2/3

MOI UNIVERSITY
SCHOOL OF MEDICINE
P.O. BOX 4606
ELDORET

Reference: IREC/2016/89
Approval Number: 0001707

1st September, 2016

Dr. Mary W. Njuguna,
Moi University,
School of Medicine,
P.O. Box 4606-30100,
ELDORET-KENYA.

INSTITUTIONAL RESEARCH & ETHICS COMMITTEE
01 SEP 2016
APPROVED
P. O. Box 4606-30100 ELDORET

Dear Dr. Njuguna,

RE: FORMAL APPROVAL

The Institutional Research and Ethics Committee has reviewed your research proposal titled:-

"Psychiatric Morbidity and Care of HIV Infected Children and Adolescents in Moi Teaching and Referral Hospital – Eldoret, Kenya".

Your proposal has been granted a Formal Approval Number: ***FAN: IREC 1707*** on 1st September, 2016. You are therefore permitted to begin your investigations.

Note that this approval is for 1 year; it will thus expire on 31st August, 2017. If it is necessary to continue with this research beyond the expiry date, a request for continuation should be made in writing to IREC Secretariat two months prior to the expiry date.

You are required to submit progress report(s) regularly as dictated by your proposal. Furthermore, you must notify the Committee of any proposal change (s) or amendment (s), serious or unexpected outcomes related to the conduct of the study, or study termination for any reason. The Committee expects to receive a final report at the end of the study.

Sincerely,

PROF. E. WERE
CHAIRMAN
INSTITUTIONAL RESEARCH AND ETHICS COMMITTEE

cc CEO - MTRH Dean - SOP Dean - SOM
Principal - CHS Dean - SON Dean - SOD

Appendix 9: Hospital Approval (MTRH)

MOI TEACHING AND REFERRAL HOSPITAL

Telephone: 2033471/2/3/4
Fax: 61749
Email: director@mtrh.or.ke
P. O. Box 3
ELDORET

Ref: ELD/MTRH/R.6/VOL.II/2008

8th September, 2016

Dr. Mary W. Njuguna,
Moi University,
School of Medicine,
P.O. Box 4606-30100,
ELDORET-KENYA.

RE: APPROVAL TO CONDUCT RESEARCH AT MTRH

Upon obtaining approval from the Institutional Research and Ethics Committee (IREC) to conduct your research proposal titled:-

"Psychiatric Morbidity and Care of HIV Infected Children and Adolescents in Moi Teaching and Referral Hospital – Eldoret, Kenya".

You are hereby permitted to commence your investigation at Moi Teaching and Referral Hospital.

08/09/2016

DR. WILSON ARUASA
CHIEF EXECUTIVE OFFICER
MOI TEACHING AND REFERRAL HOSPITAL

CC - Deputy Director (CS)
- Chief Nurse
- HOD, HRISM

Appendix 10: Ampath Approval

Academic Model Providing Access To Healthcare

Telephone: 254 53 2033471/2P.O. BOX 4606, ELDORET Fax: 254 53 2060727

RESEARCH

Ref: RES/STUD/1/2017 **January 31, 2017**

Mary W. Njuguna
Moi University
School of Medicine
P.O Box 4606-30100
Eldoret

Dr. Njuguna,

RE: PERMISSION TO CONDUCT RESEARCH AT AMPATH

This is to kindly inform you that your study "***Psychiatric Morbidity and Care of HIV Infected Children and Adolescents in Moi Teaching and Referral Hospital***" has been reviewed by the AMPATH Research Program Office. Permission is therefore granted to begin collecting your data at AMPATH.

Please note that your research activities should not in any way interfere with the care of patients. This approval does not support access to AMRS data at AMPATH.

You are required to submit a final report of your findings to the AMPATH Research Program Office.

Should you wish to publish your research findings, permission has to be sort from AMPATH Publications Committee. Please contact the AMPATH Research Office in case of any enquiry regarding this matter.

Thank you,

Jepchirchir Kiplagat
Ass. Program Manager, Research

CC: AMPATH Executive Director, Care
AMPATH Executive Director, Research

Appendix 11:Plegarism Report

Plagiarism Checker X Originality Report

Similarity Found: 19%

Date: Thursday, August 29, 2019
Statistics: 3716 words Plagiarized / 19558 Total words
Remarks: Medium Plagiarism Detected - Your Document needs Selective Improvement.

PSYCHIATRIC MORBIDITY AND CARE AMONG CHILDREN AND ADOLESCENTS WITH HIV INFECTION AT MOI TEACHING AND REFERRAL HOSPITAL ELDORET, KENYA BY MARY WANGUI NJUGUNA DEPARTMENT OF MENTAL HEALTH A THESIS SUBMITTED TO THE SCHOOL OF MEDICINE IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE AWARD OF THE DEGREE OF MASTER OF MEDICINE IN PSYCHIATRY MOI UNIVERSITY 2019