

**A QUALITATIVE STUDY OF MENTAL HEALTH EXPLANATORY MODELS, AND THE
PERCEIVED IMPACT OF LIFE EXPERIENCES ON MENTAL HEALTH, IN HIV INFECTED
ADOLESCENTS IN RURAL AND URBAN UGANDA**

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the degree MPhil in Public Mental Health.**

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ABSTRACT

Background: Survival of children and adolescents with HIV/AIDS has greatly improved with antiretroviral treatment. These young people now live with a chronic, rather than a fatal disease, which has brought into focus issues of quality of life, including the emotional and behavioral wellbeing of those living with the disease. HIV infection is associated with poor mental health and a high prevalence of behavioral and emotional problems in affected adolescents. Despite this burden of emotional and behavioral problems, the majority of HIV care services in sub-Saharan Africa do not have mental health care services specifically targeting adolescents with HIV. In order to address mental health in this population, it is important to explore their explanatory models to understand aspects such as how they view their symptoms, and what treatment or support they prefer. At the present time, research is scarce regarding explanatory models of mental disorders in HIV-positive adolescents and no study has been conducted in Uganda. This study aimed to address this gap by exploring the explanatory models of mental disorders and perceived daily life challenges in HIV-infected adolescents who had been diagnosed with a common mental disorder.

Methods: This qualitative study was nested in a longitudinal epidemiological study that investigated prevalence, incidence and risk factors for mental health problems in HIV-infected children and adolescents in rural and urban Uganda. In-depth interviews were conducted with adolescents aged 12 to 17 years who had been diagnosed with depression, anxiety or attention deficit hyperactivity disorder (ADHD). Case vignettes were used to enable adolescents to talk about their experiences and daily life challenges. Written consent and assent were sought from caregivers and adolescents respectively. Data were processed and analyzed thematically. NVivo-11 was used to manage data for analysis.

Results: Twenty-one adolescents participated in the study. Most adolescents (9/21) in the study were living with their grandparents. Twelve were in primary school and 4 had dropped out. The main findings were: (i) the adolescents had not been informed about their mental disorder diagnoses and none viewed their symptoms as illness, (ii) they attributed their symptoms to daily life problems, such as poverty and interpersonal relationship problems, and did not mention biomedical or spiritual causes, (iii) they thought that their symptoms would improve with time, and financial and emotional support were also important.

Conclusion: The findings of this study highlight the need for action at the mental health policy and practice levels. The main areas for such intervention include mental health literacy, screening and intervention in healthcare settings, and psychosocial interventions in community and school settings for affected adolescents and their caregivers.

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List of abbreviations

ADHD	Attention Deficit Hyperactivity Disorder
AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral therapy
CHAKA	Children and Adolescents in Kampala and Masaka (main study)
CFI	Cultural Formulation Interview
DSM IV	Diagnostic and Statistical Manual of Mental Disorders - Fourth edition
EMs	Explanatory Models
HIV	Human Immuno-Deficiency Virus
HSCl	Hopkins Symptom checklist
ICD-10	International Statistical Classification of Diseases and Related Health Problems Tenth Revision
MINI-Kid	Mini International Neuropsychiatric Interview for children and adolescents

CHAPTER ONE: INTRODUCTION

Survival of children and adolescents with HIV/AIDS has greatly improved with the increased access to effective ART (antiretroviral therapy). Children and adolescents now live with a chronic rather than a fatal disease, which has brought into focus issues of quality of life including the emotional and behavioral wellbeing of those living with the disease (Russell and Seeley, 2010, Hazra et al., 2010, Kamau et al., 2012). Growing up with HIV/AIDS, like any other chronic illness, puts additional challenges on adolescents' developing personalities and coping resources. There is also the direct effect of the virus on the developing brain of adolescents. Therefore, it is not surprising that HIV among children and adolescents is associated with poor mental health and impaired neurodevelopment (Donald et al., 2014, Malee et al., 2011). Epidemiological studies from high-income countries have established that HIV-infected children and adolescents experience high rates of emotional and behavioral problems, with estimates ranging between 27 and 61%. The emotional and behavioral problems detected include anxiety, depressive disorders and attention deficit hyperactivity disorder (ADHD) (Nachman et al., 2012, Gadow et al., 2012, Malee et al., 2011, Gadow et al., 2010).

In sub-Saharan Africa, a systematic review on mental health disorders among children from 0 to 16 years of age reported a prevalence rate of 9.5% in the general population (Cortina et al., 2012). Among HIV-infected children between 6 and 18 years of age in Kenya, a study on psychiatric morbidity reported that 48% of the children had a mental disorder. The disorders reported include: major depression (17.8%), social phobia (12.8%), oppositional defiant disorder (12.1%) and ADHD (12.1%), according to DSM IV (Diagnostic Statistical Manual-fourth edition) criteria (Kamau et al., 2012). A study of 82 HIV-infected adolescents from 10 to 18 years in one HIV clinic in Uganda documented the presence of mental disorders using the ICD-10 (International Classification of Diseases- tenth revision) criteria. This study found that anxiety (46.5%) and depression (40.8%) were the most common problems diagnosed (Musisi and Kinyanda, 2009).

Despite this burden of emotional and behavioral problems that afflicts these HIV-infected adolescents, the majority of HIV care services in sub-Saharan Africa do not have mental health care services specifically targeting adolescents with HIV (Freeman et al., 2005, Earls et al., 2008). Contributing to this problem is the poor recognition of mental disorders in HIV care. Furthermore, it is important that these services take cultural and social factors into account, when diagnosing and treating mental health disorders in this group.

Arthur Kleinman (1978) developed the concept of Explanatory Models (EMs) of mental illness that can be used to understand a patient's and the community's views on an illness and how they think it can be cured. The term explanatory model refers to an individual's or group's view on the cause of an illness, the nature of the illness, appropriate treatment and fears about the illness, and other aspects of the intersection between people and disease. In health, EMs may be sourced from the patient, caregiver and health professional in a bid to understand illness from different perspectives, thus allowing increased understanding and improved interaction between the individuals involved (Kleinman, 1978, Bhui and Bhugra, 2002, Patel, 1995a). While professionals use technical vocabulary to describe disease and illness, lay people (including patients, caregivers, relatives), use experience-based terms. The significance of EMs in mental health is increasingly being recognized across cultures and settings and EMs have been used in mental health clinical and research contexts (Kleinman, 1987, Patel, 1995a, Bhui and Bhugra, 2002).

A number of measures and interviewing approaches have been developed to include EMs and acknowledge cultural differences in an individual's experience of mental disorders (Flaskerud, 2000, Sweetland et al., 2014). These approaches are also important in clinical contexts where cultural aspects of mental illness may impact the accuracy of the diagnosis and treatment effectiveness (Haeri et al., 2011, Kleinman and Good, 2004). In research contexts, studies have either explored EMs in a certain population (Chipimo et al., 2011), or used EMs to adapt internationally recognized measures to specific localized situations or to develop mental disorder screening tools (Bolton, 2001, Betancourt et al., 2011). For example, a study in Zimbabwe documented EMs for mental health among HIV-infected and uninfected persons. While the medical workers used different terminologies to refer to the different mental health disorders, participants in the study generally referred to them as 'problems of the mind' (Chipimo et al., 2011). In Bolton's (2001) study of adults with depression in post genocide in Rwanda, the investigators validated the Hopkins Symptom Checklist (HSCL) depression sub-scales using EMs. Similar methods were used by Betancourt et al. (2009) in northern Uganda to develop a scale to understand depression symptoms among adolescents affected by war. EMs in mental health have also been investigated in Uganda in non-HIV adult populations, but to date no study has explored the mental health EMs of HIV-infected adolescents (Patel, 1995a, Okello and Neema, 2007, Teuton et al., 2007).

To address this gap, this study aimed to explore 12-17 year old HIV-infected adolescents' experiences and EMs of mental disorders, recognizing daily life and disease-related factors that influence their mental health. The study focused on depression, anxiety disorders and ADHD to explore how HIV-infected

adolescents' ideas and explanations of these behavioral and emotional problems or symptoms may aid researchers and health care workers in recognizing mental ill health in HIV infected adolescents.

1.1 Aim

To explore explanatory models of mental disorders among HIV-infected adolescents diagnosed with common mental disorders that include depression, anxiety disorders and ADHD in the districts of Masaka and Kampala, Uganda.

1.2 Objectives

- i. To elicit HIV-infected adolescents' views on the causes and nature of their mental health symptoms.
- ii. To explore HIV-infected adolescents' perceptions of the link between their daily life experiences and their mental health symptoms.
- iii. To elicit HIV-infected adolescents' suggestions for acceptable treatment options for their mental health symptoms.

CHAPTER TWO: LITERATURE REVIEW

In this review of the literature, an overview of the prevalence of HIV disease in adolescents globally and in Africa will be provided. This will be followed by a focus on the mental health of HIV-infected adolescents. The available literature investigating the positive and negative life experiences that may influence the mental health of HIV positive adolescents will be discussed. Lastly, an overview of mental health EMs will be given, followed by literature from low- and middle-income countries (LMICs).

2.1 Growing up with HIV

The United Nations Millennium Development Goal 6 aimed to combat HIV and other diseases. Since the declaration, HIV incidence among children has declined by 58% from 490,000 to 150,000 from 2000 to 2015 (UNAIDS, 2016). However, a large number of adolescents globally were reported to live in countries experiencing high HIV prevalence rates (Idele et al., 2014). In Eastern and Southern Africa, new HIV infections in children of up to the age of 14 years were estimated to be 56,000 by the end of the year 2015. New infections among children below the age of 15 years were estimated to be 9,472 by the end of 2014 in Uganda (UNAIDS, 2014). Of the estimated 1.2 to 1.5 million people living with HIV in Uganda, it was estimated that 176,948 were children below 15 years of age (UNAIDS, 2014, Ministry of Health Uganda, 2013, Donald et al., 2014). These numbers may be an indication of the growing HIV burden in Uganda resulting from the new infections that still occur and the longer lives of those living with the disease.

Despite the large numbers of people affected by HIV described above, with the increasing coverage of HIV treatment among those in need, many regions of the world are experiencing a reduction in the number of HIV-related deaths. There is a remarkable reduction in HIV-related child mortality, which has increased the number of those transitioning from childhood to adolescence and adulthood (Russell and Seeley, 2010, Hazra et al., 2010). Longer lives are largely attributed to ART that has changed the lives of HIV-infected people (Walensky et al., 2010). Despite the remarkable achievement, HIV-infected adolescents still face challenges that may also be problematic to their wellbeing with the disease.

While the lives of HIV-infected children and adolescents are significantly improved with HIV treatment, they still have a serious chronic disease and this can impact their emotional well-being (Pakenham and Rinaldis, 2001). Adolescents do not only have to cope with the HIV diagnosis and living with a chronic disease, they are also faced with the negative image of an HIV positive status and loss. Such losses include

losing a family member or close relative to HIV (Plattner and Meiring, 2006). These challenges may also be risk factors that increase the likelihood of mental disorders in HIV-infected adolescents.

2.2 The mental health treatment gap and mental health of HIV-infected adolescents

Globally, the gap between people suffering mental disorders and those receiving treatment and care is significant (WHO et al., 2008). Studies in low- and middle-income countries indicate that the treatment gap is also overwhelming. In Africa, the treatment gap for depression is 67% compared to 45% in Europe (Demyttenaere et al., 2004). In sub Saharan Africa, mental health services are not well developed. There is a scarcity of mental health services in HIV care and an extremely low ratio of mental health professionals to patients. It is estimated that there is less than one professional for 100,000 clients in Africa (WHO, 2005a). A recent systematic review looking at training of mental health workers in Africa over time has documented the challenges faced in addressing the lack of trained mental health professionals. There are no standard guidelines of training procedures and evaluation of the outcomes. Key focus has been placed on improvement of knowledge and attitudes of the mental health workers with no procedures for evaluating skills gained by the mental health workers (Liu et al., 2016), and this may partly account for ongoing issues with mental healthcare service delivery. Although many countries in sub Saharan Africa are transitioning towards the integration of mental health into primary care, primary care workers lack capacity to recognize mental disorders and the treatment given is sometimes inadequate (*WHO et al., 2008, Abas et al., 2003, Hirschfeld et al., 1997, Tylee and Walters, 2006*). Furthermore, child and adolescent mental health services are particularly scarce in LMICs and few mental healthcare professionals receive adequate training in providing such services (Morris et al., 2011).

Data from high-income and LMICs has shown that mental disorders are prevalent among children and adolescents living with HIV. A review of the literature quantifying the prevalence of mental health problems among children and adolescents with HIV in the United States found high rates of mental health problems. The problems included: anxiety, low self-esteem, attachment problems, inattention, tantrums, social withdrawal, and hyperactivity among others (Scharko, 2006). In a study investigating HIV and mental health in children between the ages of 10 and 17 years in Rwanda, Betancourt et al. (2011) reported even higher rates of depression, anxiety and conduct disorders among the HIV infected compared to the unaffected. In Kenya, Kamau et al. (2012) documented the prevalence and patterns of mental health problems among HIV-positive children and adolescents from 6 to 18 years of age. Of the

162 children and adolescents with HIV in the study, 79 (48.8%) had a mental health problem. The mental disorders included: major depression at 17.8%, social phobia at 12.8%, oppositional defiant disorder at 12.1% and attention deficit hyperactive disorder at 12.1%. The percentage of those with more than one mental health problem was 25%. Kinyanda and Musisi (2009) documented the presence of mental disorders among adolescents with HIV in Uganda. Among 82 HIV infected adolescents in the study, prevalence rates of anxiety were at 45.6%, depression at 40.8%, somatization at 18.0% and HIV-associated progressive encephalopathy at 4.8%. The majority of the adolescents in the study were orphaned and staying with non-biological parents and relatives.

It is important to identify and treat mental disorders in this vulnerable group for a number of reasons. First, paying attention to the mental health of young people with HIV can reduce the distress associated with the disease (Benton, 2011, Patel et al., 2007). Second, if untreated, mental disorders result in other serious problems for the adolescent, such as delinquency and poor performance in school (WHO et al., 2008). Third, adolescents challenged with mental disorders and HIV may also become sexually active at an early age, engage with multiple sexual partners and practice unprotected sex (Benton, 2011). It is also documented that many adolescents with HIV do not disclose HIV status to sexual partners (Koenig et al., 2011). Fourth, as mental health is a human right (WHO, 2001, Gable and Gostin, 2009), it is vital that mental health and psychosocial wellbeing are addressed in HIV-positive adolescents, although, proper management and recognition of mental disorders is still a challenge in this group (Kamau et al., 2012).

2.3 Life experiences and mental health problems in HIV-positive adolescents

This section presents the available literature on positive and negative life experiences that may impact on the mental health of adolescents living with HIV. Positive experiences include: 1) having a strong social support, and 2) the provision of effective treatment. Negative experiences are more social and HIV-related. These include issues such as: 1) poverty; 2) loss of family members; 3) the effects of HIV treatment; 4) the chronic nature of HIV disease; and 5) the dilemma of status disclosure (Pufall et al., 2014, Walker et al., 2007, Orkin et al., 2014, Cluver et al., 2012a). When treating and supporting HIV-infected adolescents, it is important to fully understand the experiences that they face. Both these positive and negative life experiences will be discussed in more detail below.

2.3.1 Support systems in HIV care

Through support systems, people living with the HIV are being provided with knowledge, coping skills and hope for the future (Visser et al., 2006, Bedelu et al., 2007). A study in Brazil compared the experiences of

adolescents with HIV and street children without HIV. Children living with HIV had much more hope for the future than street children. The investigators found that this was partly due to the lack of support systems in place for the street children, highlighting the protective role of the available support systems for the HIV-infected adolescents (Abadia-Barrero, 2002). HIV/AIDS care institutions provide much more than just treatment for their patients. They are also providing environments where young PLWHA feel connected, comfortable and supported to cope with HIV (Campbell et al., 2005). They make friends and feel less alone, take on responsibilities like mentoring other youths and engaging in activities that are useful to other people living with HIV/AIDS who feel isolated and may be having difficulty socializing and managing lifelong medication (Wright and Draimin, 2000, Greifinger and Dick, 2011).

Children and adolescents with HIV only know their HIV status once they are disclosed to, mostly by their caregivers when they think it's right for the child or adolescent to know their HIV status (see section 2.3.6 below for further literature on HIV status disclosure). Health workers and caregivers of the HIV infected children and adolescents prepare to break the news when they feel it is most appropriate, and this may be accompanied by intensive counseling (Wiener et al., 2007). HIV is a traumatic disease but once an individual comes to terms with their positive status, they cope with the HIV-related distress and live better lives (American Academy of Pediatrics Committee on Pediatrics AIDS, 1999, Elkington et al., 2011). Coming to terms with HIV disease can be facilitated through counseling, which has resulted in many people being able to cope with the chronic disease (Lee et al., 2007).

2.3.2 Availability of ART

It is estimated that HIV has killed over 36 million people since the outbreak of the epidemic (WHO, 2013). With the discovery of ART and PMTCT (Prevention of Mother to Child Transmission), transmission rates in adults and infants have reduced and there is increased hope of survival (Russell and Seeley, 2010). By the end of the year 2013, an estimated total of 793 893 HIV-infected people in Uganda were accessing ART with 570 373 on active treatment (Ministry of Health Uganda, 2013). With the improving ART availability, guidelines and policies in many parts of the world, it is now possible for people to get onto treatment as soon as they know that they are infected with HIV to curb the disease progression. This reduces HIV-related deaths and morbidity, as well as the fears and anxieties of those that get infected (Zolopa et al., 2009, Granich et al., 2009).

2.3.3 Poverty

The HIV epidemic has had far-reaching consequences, not least of these being poverty as an outcome, partly due to loss of income experienced by people living with HIV/AIDS (PLWHA) and their families (Weiser et al., 2010). Poverty is also risk factor for mental disorders (Lund et al., 2010, Patel et al., 2007). With poverty, there is insufficiency in provision of basic needs, such as food and access to education, perpetuating a person or family's low socioeconomic status. Poverty and mental health are closely related and one causes vulnerability to the other, and vice versa. Due to mental illness, individuals are less productive or not productive at all, leading to poverty, which increases the risk for mental illness (Patel et al., 2007). Additionally, people with poor socioeconomic status may be affected by food insecurity and reside in poor quality, overcrowded structures, both of which are linked to risk for mental illness, both in high-income and low- or middle-income settings (Lund et al., 2010, Shepherd et al., 2012).

Due to poverty, PLWHA are faced with stressors like food insecurity, lack of clothing, and lack of transport to reach support services and care (Tladi, 2006). Available literature on food insecurity links it to the HIV epidemic when productive family members are lost to the disease, or when caregivers are burdened with increasing care duties. These circumstances then lead to a reduction in agricultural production in affected households (Weiser et al., 2011). In East Africa, research indicates that HIV-infected people are severely affected by food insecurity and one of the studies in Uganda quantified the prevalence at 38% (Bukusuba et al., 2007, Willig, 2001, Tsai et al., 2012, Tsai et al., 2011). Not having safe and enough food leads to insufficient nutrients, thus enabling HIV progression and an increase in opportunistic infections. Failure to secure food leads to risky behaviors such as alcohol and drug use, risky sexual practices, poor adherence to ART, missing clinic visits and interruption of treatment (Kalichman et al., 2010, Shannon et al., 2011, Weiser et al., 2010, Tuller et al., 2010). Food insecurity also contributes to mental health consequences like depression and anxiety (Weiser et al., 2011). While food insecurity poses a problem in PLWHA, HIV-infected adolescents have other life pursuits like education that may also be challenging in their lives.

2.3.4 Being HIV-positive and school attendance, employment seeking and achieving independence

Adolescence is a stage during which many get school education. In school settings, HIV-infected adolescents face challenges such as stigma, bullying and discrimination. Other students may judge the morals of those infected with HIV, leading to a breakdown of support systems that would be useful to those infected (Cluver and Orkin, 2009). Benton (2011) reported that a support system that is poor or broken in the school environment results in poor academic performance, and dropping out of school, while a prospective cohort of 6643 school children and adolescents from 11-13 years in London boroughs

indicated that friendships in schools were associated with low levels of mental health problems (Bhui et al., 2012).

Furthermore, HIV-infected adolescents out of school may have problems securing jobs and achieving independence. A positive HIV status may be stigmatizing in a work place even when proper disclosure has happened (Siu et al., 2012), although employment improves the quality of life for an individual by reducing chances of social isolation and mental health difficulties such as depression and anxiety (Rodger et al., 2010). Apart from these challenges, there are other challenges that are more closely linked to having HIV, such as the need to take ART.

2.3.5 ART experiences in HIV-infected adolescents

Since ART became accessible to low-income countries like Uganda, governments and organizations have been struggling to make it accessible to those in need since 2004, leading to improvements in the health and survival of children and adolescents (Reynolds et al., 2011, Mannheimer et al., 2005, Russell and Seeley, 2010). Besides improved health and survival, HIV-infected adolescents are challenged with long term ART use like drug resistance and side effects that lead to poor treatment adherence (Donald et al., 2014, Koenig et al., 2011). Common effects being experienced by those using ART include skin rashes, nausea, vomiting and changes in body shape and are particularly distressing for adolescents as this stage is typically a time when individuals begin to worry about their appearance (Donald et al., 2014, Koenig et al., 2011, Evans et al., 2011, Mellins et al., 2006, DeLaMora et al., 2006). Adolescents are also required to make frequent hospital visits for treatment and care, take regular medication, manage ART almost independently and at the same time, fit in socially with other uninfected youths amidst struggles with stigma and discrimination, resulting in isolation (Walker et al., 2007, Orkin et al., 2014, Koenig et al., 2011). Given the environment where a person is and the level of support available, individuals may avoid taking ART for fear of the side effects and stigma. Kawuma et al. (2014) in a qualitative study multi-centered study, documented experiences of children and adolescents living with HIV/AIDS in Uganda and Zimbabwe. Results indicated that children and adolescents were aware of the stigma surrounding their condition and avoided being identified as HIV-infected. It is relevant to understand issues surrounding HIV infected adolescents' challenges that lead them to adopt secretive behavior, which could also result in less support for the adolescent.

2.3.6 HIV status disclosure and stigma

HIV status disclosure to children is related to good adherence to HIV treatment, enhances coping, increases self-esteem, improves involvement in health promotion activities, decreases disease related thoughts and improves CD4 cell counts (Bikaako-Kajura et al., 2006, Lam et al., 2007, Sherman et al., 2000, Wiener and Battles, 2006, Murphy et al., 2000). International guidelines on disclosure recommend for children to be disclosed to before adolescence and at the judgment of the parent or caregiver (WHO, 2011). The average age for HIV status disclosure was documented to be 13 years of age in a study on factors affecting sero-status disclosure to children in one of the hospitals in Uganda. Among caregivers of children aged 5 to 18 years, disclosure was at 56%, there was 19% non-disclosure and 25% deception (Namasopo-Oleja et al., 2015). Reasons for non-disclosure are: young age of the child, child being on ART with improved health and not attending psychosocial support groups for emotional help (Mutumba et al., 2015, Namasopo-Oleja et al., 2015, Vreeman et al., 2013). Furthermore, parents may disclose to their adolescent children about their own HIV-status and that of the adolescent with caution not to disclose further. Keeping the HIV status a secret affects the adolescent's emotional adjustment (Rao et al., 2007). Quantitative research done indicates that there is an association between being orphaned due to HIV and mental health disorders, which may be worsened by trying to keep their parent's cause of death a secret due to stigma (Cluver et al., 2008, Thupayagale-Tshweneagae and Benedict, 2011).

Disclosure of HIV status to others largely depends on perceived social support and the type of relationship. PLWHA disclose to close friends more than they do to family members (Kalichman et al., 2003, Qiao et al., 2013). Some investigators have found that HIV status disclosure to outsiders such as a friend or peer leads to an increase in emotional and behavioral problems for the person disclosing with fear that unconsented disclosure may happen further (Lee and Rotheram-Borus, 2002, Butler et al., 2009, Lester et al., 2002), while other studies have reported opposite findings (Elkington et al., 2011, Ferris et al., 2007, Blasini et al., 2004). Disclosing HIV status to outsiders leads to stigma when family members are branded HIV infected, affects the adolescents' self-esteem; they may be bullied, suffer anxiety and suicidal ideation (Rao et al., 2007, Stutterheim et al., 2009, Vreeman et al., 2010, Cluver and Orkin, 2009, Mutumba et al., 2015, Vreeman et al., 2013).

2.3.7 Loss, grief and displacement

Loss, displacement and bereavement also increase vulnerability for mental disorders. In the HIV/AIDS context, many children growing into adolescents and young adults are orphaned due to HIV/AIDS. Research on the mental health of young PLWHA documents high rates of mental disorders and many are orphaned, staying with other people who may not necessarily be blood relatives (Musisi and Kinyanda,

2009). During illness and after death of parents, children affected with HIV frequently change households leading to high levels of anxiety. This is especially when children are separated from their siblings, and also when the new household fostering them is poor. There is hopelessness and the future is uncertain (Kaggwa and Hindin, 2010). In Kenya, psychiatric morbidity in 162 children with HIV/AIDS indicated that 48.8% had mental disorders with 25% having more than one mental disorder (Kamau et al., 2012). Among 630 institutionalized children, there was 16.7% multiple mental health problems with 11.1% having more than three mental disorders (Mutiso et al., 2017).

2.4 Mental illness explanatory models

In this section, mental health EMs are defined according to Kleinman (1978), the importance of investigating EMs is discussed, and methods of eliciting EMs are outlined briefly. This is followed by a structured review focused on mental illness EMs in LMICs.

Kleinman (1978) stated that mental illness EMs refer to individuals' conceptualization of mental illness and include such aspects as the causes of illness, the onset, severity and prognosis of the illness, type of treatment, and treatment provider required. He also explained that EMs are derived from the knowledge and values of individuals in relation to health care systems, and as such, can come from 'family', 'professional' and 'folk' domains. EMs of mental illness also come from the patient and family through descriptions of how the illness began and what they think the problem could be about. From disease onset to the time it is recognized as a problem, the individual affected, the family or the community may be in position to narrate different aspects of the disease, such as the symptoms that are visible (externalized behavior and emotions). However, the patient's narrative may differ when they include explanations of symptoms that are invisible (internalized). These differences may be clinically challenging when the patient receives care that is not to their expectations or fitting in their view of the illness. Therefore, family and patient conceptualization of the illness through their beliefs and experiences of the illness may be different from clinical explanations and present significant barriers to effective treatment.

Thus, investigating EMs is important for a number of reasons. First, as Kleinman (1978) emphasizes, it is important that health care professionals attempt to create a relationship that respects non-clinician views and understanding of mental illness for effective interaction and treatment of the patient. Kleinman (1978) elaborated further that sometimes health care professionals want to treat physical illness and symptoms whereas patients seek not only relief of the symptoms, but also psychosocial support as part of the transaction. Second, since EMs include a patient's view of their symptoms, a clinician's knowledge

of local EMs could aid accurate diagnosis. For example, depression and anxiety are common disorders that often go untreated when patients present with somatic symptoms resulting in numerous hospital visits, unnecessary clinical investigations and misdiagnoses (Aidoo and Harpham. 2001). Third, EMs are vital in understanding help seeking and the way individuals are able to cope with their psychological circumstances (Ghane et al., 2012, Mathews, 2011). According to Kleinman (1978), disease care and cure is commonly handled by the 'family' domain that includes relatives and non-relatives in a community. There are important decisions made on disease management in the 'family' domain that include: when to consult, who to consult, and whether advice given should be taken and adhered to. Knowledge of EMs related to help-seeking could inform community mental health literacy campaigns and other psychosocial interventions to improve case-finding and early treatment. Fourth, an understanding of EMs in different contexts enables a broader understanding of mental health in various cultures, particularly in the context of the global mental health movement (Kleinman, 1978).

However, while clinicians and researchers may understand the importance of EMs and try to elicit a patient or community's EMs of mental illness, this can be challenging. Assessment of direct and indirect methods of soliciting EMS and assessment of culturally based EMs endorse that patients' constructs of mental illness are based on past experiences and how symptoms were perceived. But in some instances, patients are not able to verbally communicate some experiences even when they recall what it was (Ghane et al., 2012, Mathews, 2011). EMs may also be affected by social desirability and adjustment when certain aspects are deemed sensitive and unfit to mention leading to concealment of interpersonal explanations such as issues arising from family and violence (Ghane et al., 2012). There are tools available which attempt to accurately elicit EMs, and overcome some of these challenges.

Following the Kleinman (1978) model, diagnostic tools have taken such issues into consideration to meet the needs of people across cultures. The Diagnostic Statistical Manual (DSM) for mental health diagnostic guidelines (American Psychiatric Association, 2013), though developed in the western world, is adjustable to suit specific cultural settings globally. The tool has recognized the importance of EMs and cultural differences through presentation of guidelines on cross-cultural formulations of mental health. The cultural formulation interview (CFI) is intended to enable effective use globally and also to improve services for those in need of mental treatment and care (Aggarwal et al., 2015, Aggarwal et al., 2014, Lewis-Fernandez, 1996). The CFI also includes supplementary modules like social support, spirituality, religion, moral traditions and cultural identity to aid clinicians and researchers understand how an individual perceives their world and the mental disorder at hand. The CFI also considers people in different

situations and environments such as children and adolescents in school environments, older adults, immigrants and refugees. This has led to research across cultures investigating EMs in mental health and has enabled satisfactory transactions in mental health care when all stakeholders' ideas about the mental illness are taken into consideration.

2.4.1 EMs of mental disorders in low- and middle-income countries

This study aimed to elicit EMs of mental illness in a specific group of people, namely HIV-positive adolescents accessing care at clinics. During preliminary searches, few published studies reporting on mental illness EM in HIV positive people or adolescents were found. Thus, it was decided to search for mental illness EM studies from LMICs. A structured review was conducted with the following terms to incorporate all studies exploring explanatory models between 1990 and 2016 from LMICs. These studies will be discussed below.

PubMed, PsycINFO and CINAHL online electronic databases were searched for articles on EMs of mental health among adolescents from 2006 and 2016. The following search terms were used:

((((explanatory AND model)) AND (mental disorder OR mental illness OR psychiatric disorder OR psychiatric illness))) NOT (USA OR North America OR United States OR UK OR Britain OR England)

Criteria to select relevant research focused on:

1. All studies published between 1990 – 2016 investigating EMs of mental disorders in LMICs.
2. Studies published in peer-reviewed journals and in English language.
3. Qualitative and quantitative studies on EMs of mental disorders.

2.6.2 Search results

Using the search procedures described above, PubMed found 329, PsycINFO generated 245 and CINAHL found 98 articles. After going through the titles, non-English articles and duplicates were removed and a total of 79 articles remained for screening. All abstracts were downloaded and scrutinized further for relevance. Of the abstracts downloaded, 69 remained for further review and the full text of these articles were examined, after which 28 suited the inclusion criteria (see figure 2.1 below). The excluded papers were mainly reporting on studies from high-income countries. Two papers (Johnson et al., 2009, Chipimo et al., 2011) identified by communication with local experts and from reference lists were selected for inclusion in the section.

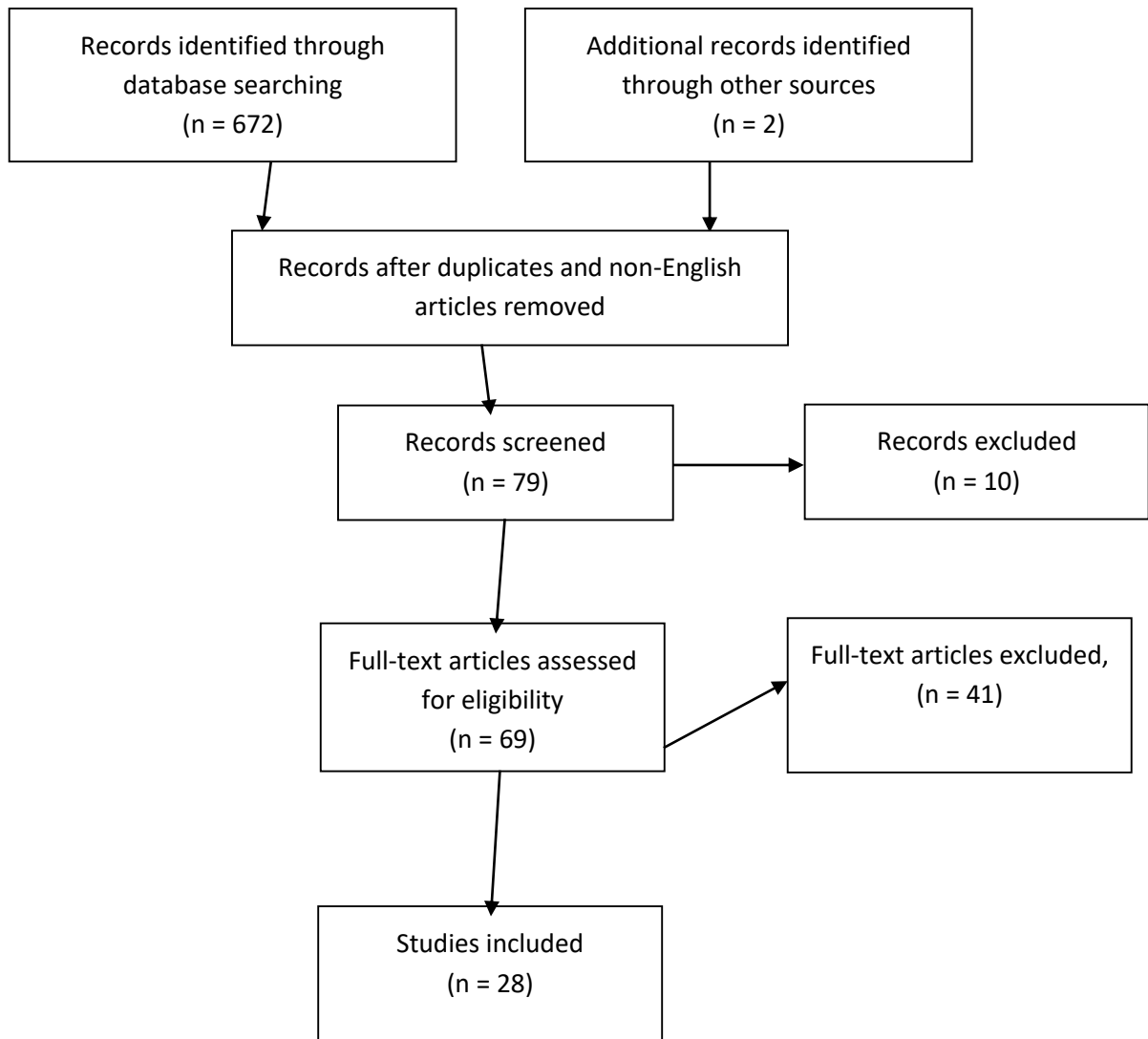


Figure 2.1 Selection procedures for studies included in the structured review

2.6.3 Description of studies retrieved

Of the 28 articles included in this section, 18 were qualitative studies, 8 were quantitative studies and two used mixed methods. Quantitative studies mostly used standardized instruments such as the Short Explanatory Model of Illness interview (SEMI), Explanatory Model Interview Catalogue (EMIC) and other locally adapted EM instruments to elicit patients' EMs. These were either self-administered or administered by healthcare personnel. Five of the studies were done on the African continent, others were from Asia and the Caribbean. The countries represented include India, Jamaica, Kenya, Sri Lanka, Zimbabwe, South Africa, Uganda, Iran, Ghana and Sierra Leone. In these studies, participants were recruited from healthcare facilities, community and school settings. Some themes relating to EMs were identified in the studies, namely common terms used to describe psychological distress or mental disorders, symptoms of mental disorders, causes of the disorders, help seeking for mental disorders and impact. The number of studies addressing each of these themes is shown in Table 2.1 below.

Table 2.1 A summary of themes in the structured review

Theme	Number of studies
Common terms used and general symptoms of mental disorders	11
Causes of mental disorders	19
Treatment and help seeking for mental disorders	15
Impact of mental disorders	04

2.6.4 Findings of retrieved studies

In this structured review, EMs of mental health from various research studies in LMICs will be discussed. This will include common terms used to describe mental disorders and mental disorder symptoms, causes of mental disorders, help seeking for mental disorders and preferences in seeking help for mental disorders.

2.6.4.1 Common terms used and general symptoms of mental disorders

In the studies retrieved, a range of different terms were used to explain mental illness and mental illness symptoms. The participants described physical and psychological manifestations of mental illness.

Physical problems presented by people with mental disorders include somatic complaints such as fever, body weakness, tiredness and sleep problems (Okello and Neema, 2007, Grover et al., 2012, Pereira et al., 2007, Henningsen et al., 2005, Grover et al., 2014). Researchers found that people with depression present with somatic complaints more often than with emotional complaints (Okello and Neema, 2007, Pereira et al., 2007, Shankar et al., 2006, Henningsen et al., 2005, Patel et al., 1995). Okello and Neema (2007) studied EMs of depression in patients admitted for depression in Mulago hospital, Uganda. They found that somatic complaints were common in the patients' explanations, which the patients reported as being mostly caused by daily challenges in their lives as elaborated in the next section (see section 2.6.4.3). In addition, some patients in care present with a range of non-specific symptoms especially when more than one mental disorder is involved (Menon et al., 2016, Grover et al., 2014). A study conducted with traditional healers together with their clients in the southern part of rural India, found that patients with comorbid depression and anxiety also presented with somatic complaints that included headache, heartache, and chest pains (Shankar et al., 2006).

The psychological complaints that patients present with include stress, thinking too much, 'voices in the head', poor concentration, forgetfulness, worrying, loneliness, feeling guilty, talking less and coping poorly when faced with problems (Grover et al., 2012, Dejman et al., 2011, Arthur and Whitley, 2015, Yoder et al., 2016). A study on child mental health in Sierra Leone that was qualitative in nature, documented other descriptions used in reference to the children's mental illness, including foolish behavior, playfulness and quietness. These were characteristic of the visible behavior of the children (Yoder et al., 2016). These psychological and physical complaints documented from different research which patients perceived to be due to various causes.

2.6.4.2 Causes of mental disorders in LMICs

Various studies retrieved explored the causes of mental disorders as perceived by different cultures in LMICs. These are attributed to supernatural, social and biological causes for psychotic and nonpsychotic mental illnesses as discussed below.

Studies on different mental disorders document causes to be ancestors' spirits or other bad spirits/demons, witchcraft, curses (which may be generational or directed at an individual), the evil eye or black magic (Grover et al., 2012, Grover et al., 2014, Thippeswamy et al., 2015, Hecker et al., 2016, James and Peltzer, 2012, Joel et al., 2003, Nambi et al., 2002, Patel et al., 1997, Amarasuriya et al., 2015, Shankar et al., 2006, Asamoah et al., 2014, Wilcox et al., 2007, Arthur and Whitley, 2015, Yoder et al.,

2016). A qualitative study conducted among 73 adults in the Eastern Democratic Republic of Congo set out to explore pathological spirit possession. Participants reported to have been sent spirits to attack them by another person in the family or someone else in the neighborhood. Sending spirits was done because of jealousy and other social conflicts (Hecker et al., 2016). A survey on child mental health that included a qualitative component in Sierra Leone, indicated that the dominant local explanations of mental illness in children were supernatural (Yoder et al., 2016). Other studies found that mental disorders were attributed to religious causes which occurred when a person did not follow the doctrines of their religion, were not 'spiritual' or were 'sinful'. It was further reported that God used mental illness as punishment while others perceived mental disorders to be the will of God for the person affected (Grover et al., 2012, Grover et al., 2014).

Additionally, adult research participants in the retrieved studies believed that mental disorders can result from various stressful events that occur at different points in a person's lifetime in their daily lives. Daily challenges led to worry and many thoughts, as well as social conflicts and associated problems which led to hospitalization in some cases (Okello and Neema, 2007). Social stressors said to cause mental disorders were experiences of violence, war, broken family and relationships (such as marital problems), grief, poverty and job loss (Mirabzadeh et al., 2014, Dejman et al., 2011, Mirza et al., 2006, Okello and Neema, 2007, Pereira et al., 2007). In Sierra Leone, Yoder et al. (2016) reported social factors resulting in childhood mental disorders to be family breakdown, poverty, poor parenting, child abuse and other problems in the community (Yoder et al., 2016).

Biomedical causes were also cited by some study participants. A study in Jamaica found that some participants thought that mental disorders are the result of multiple biological effects. They believed that mental disorders occur when there are alterations in the normal body functioning. When the brain fails to function properly, body chemicals failing to balance, presence of disease, brain and nervous disorders and medicines prescribed by psychiatrists. It further reported that some participants mentioned that mental disorders can be inherited and may also result from misuse of substances, such as marijuana and alcohol (Arthur and Whitley, 2015). In a study in India among children with ADHD and their parents, six parents out of the 24 related their child's condition to an illness, while others did not know whether ADHD was an illness or not (Wilcox et al., 2007). The believed cause of mental disorders also influences preference and choice of treatment options, and this will be addressed in the next section (Pereira et al., 2007).

2.6.4.3 Help-seeking behaviors and expectations from treatment

In this section, findings on help-seeking behaviors and expectations from treatment are reported. In the studies retrieved, help-seeking involved a number of different people in the decision to seek help, and help was sought from various sources.

Studies on mental health EMs also document help-seeking for mental disorders. Help-seeking was reported to be a long process that sometimes led to disagreement between patient and carers as to where help should be sought (Okello and Neema, 2007). The decision to seek help was either initiated by the patient alone or following advice from other people, including family members (Menon et al., 2016). Help was sought from multiple sources in relation to the perceived cause of the illness (Pereira et al., 2007, Okello and Neema, 2007, Wilcox et al., 2007).

Those attributing mental illness to witchcraft or spirit attacks, sought treatment from traditional healers and religious institutions with a view that since the illness happened as a result of witchcraft, traditional and religious approaches would be effective to bring about cure and relief (Mavundla et al., 2009, Okello and Neema, 2007, Muga and Jenkins, 2008, James and Peltzer, 2012, Johnson et al., 2009, Chipimo et al., 2011, Mirabzadeh et al., 2014, Dejman et al., 2011, Patel, 1995b, Savarimuthu et al., 2010, Wilcox et al., 2007, Yoder et al., 2016). In traditional treatment, EMs used to explain the various conditions that affect children and adolescents are often stigmatizing and discriminating. Caregivers of people with mental disorders report that their main reason for seeking traditional help is due to a belief that the illness is a result of witchcraft (Mavundla et al., 2009), and Shankar et al. (2006) reported that those seeking traditional help also believe that modern medicine cannot improve their condition. Large sums of money are spent seeking treatment from traditional healers and religious institutions where rituals, prayers and prophecy are used to deliver diagnosis to the affected (Yoder et al., 2016). There were also preferences to seek help from friends and family, professional psychosocial care providers and self-help strategies (Wilcox et al., 2007, Amarasuriya et al., 2015, Pereira et al., 2007). A study in Sri Lanka that investigated undergraduates' literacy for depression in 4671 university students, documented that student endorsed psychotherapy and self-care strategies such as meditation in overcoming depression (Amarasuriya et al., 2015).

Apart from seeking help from these various sources, help was also sought from health care providers (Okello and Neema, 2007, Johnson et al., 2009, Dejman et al., 2011, Mavundla et al., 2009, Yoder et al., 2016). Reasons for seeking biomedical care included the presence physical symptoms (somatic symptoms), stress, tension, and family conflicts (Okello and Neema, 2007, Pereira et al., 2007, Menon et al., 2016, Wilcox et al., 2007, Yoder et al., 2016). Dissatisfaction with biomedical services was due to various reasons. First, patients had expectations of reducing symptoms and getting cured of the condition from biomedical care, but were instead dissatisfied when their treatment needs were not met (Pereira et al., 2007, Okello and Neema, 2007, Mavundla et al., 2009). A qualitative study among women with depression in India reported dissatisfaction with biomedical care when they presented with somatic symptoms to health care and were treated with tonics, vitamins, pills and injections that never improved their conditions. They reported conflicts to have occurred as a result of the treatment strategy employed in health care. Patients reported illness arising from family problems to which treatment was continually given without involving the family to have their issues worked out. Second, healthcare providers were using vocabulary with which patients and caregivers were not familiar (Pereira et al., 2007). Third, patients reported being dissatisfied with treatment due to side effects experienced, which led them not adhering to medication (Mavundla et al., 2009).

While biomedical treatment was unsatisfactory to some, there were also reports of satisfaction when biomedical care was sought. These patients understood the problem affecting them and as such, their EMs also changed with the new information acquired. A qualitative study in India documented sources of help sought by parents of children with ADHD. Parents tried educational, religious, biomedical and non-biomedical approaches to improve the condition of their children. When help was sought from the organization offering mental health care, their EMs suddenly changed to biomedical explanations. Before seeking biomedical help, parents blamed themselves for poor parenting approaches, and also blamed other people in the community. Most parents found relief on discovering the problem affecting their child, while others got new worries about their child being having the said disorder and long term medication. (Wilcox et al., 2007).

2.6.4.4 Impact of mental disorders

Studies on EMs of mental health provide reports on the impact of mental illness. Functioning in various aspects of life (for example occupational and physical functioning or maintaining interpersonal relationships), are affected by mental health symptoms and associated behaviors, such as thinking too

much, worrying, sleep disturbances, broken relationships, isolation, aggressive behavior, hardships in doing daily work and destruction of property (Mavundla et al., 2009, Pereira et al., 2007, Wilcox et al., 2007). Mental health symptoms and associated behaviors in children affected their schooling and functioning both at home and their social environments (Wilcox et al., 2007, Yoder et al., 2016).

For example, a qualitative study in Goa, India, investigated EMs in 24 parents of children diagnosed with ADHD. The study was conducted at a non-governmental organization that provides child and adolescent mental health services. Children performed poorly at school; some parents got feedback from school about their child's behavioral problems while relating to their peers. Parents always worried what could happen to their children since neighbors, school authorities always had complaints about them. There were reports that children were easily distracted, had learning difficulties, violent, irritable, destructive, impulsive, with difficulty to socialize with peers (Wilcox et al., 2007).

Another consequence of mental disorders in children and adolescents is stigma towards the child, the family, and sometimes towards professionals working with children with a mental disorder (Wilcox et al., 2007, Yoder et al., 2016). In the Sierra Leone study, for example, children with mental disorders were stigmatized as they were thought to have been associating with witches (Yoder et al., 2016). In one case, a religious leader stated that a child's father had caused the mental disorder as he had been involved in demonic practices. Additionally, so-called 'slow' children were beaten at school as punishment for poor school performance, which often led to the child leaving the school. Children or adolescents with mental disorders were viewed as outcasts and families tended to move house often (Yoder et al., 2016).

In summary, few studies were found that specifically explored mental illness EMs in LMICs. Most of the studies identified targeted adult populations, while two qualitative research studies explored mental health EMs in adolescents in LMICs. Most studies explored causes of mental disorders and the help seeking aspects of EMs. Notably, vocabulary used to communicate mental disorders in adolescents is not widely documented. In the studies reviewed, no study explored EMs in HIV infected adolescents with mental disorders. Using a qualitative approach, this study sought to close this gap by exploring and documenting EMs of mental health, including the nature, causes, treatment seeking and the perceived impact of life experiences on mental health in HIV infected adolescents in rural and urban Uganda.

CHAPTER THREE: METHODOLOGY

3.1 Study design

The research was nested a longitudinal mental health 'CHAKA' study among children and adolescents in Masaka and Kampala, Uganda. 'CHAKA' study was undertaken in urban and rural HIV clinics in Uganda with the aims of determining the prevalence, incidence and risk factors for mental health problems (including neurocognitive impairment) among children and adolescents infected with HIV. Four HIV clinics offering services to people with HIV in both rural and urban Uganda are collaborating in the 'CHAKA' study. These clinics are operated by non-profit making, donor-funded non-governmental organizations that have been in existence since the 1980s and early 1990s. These were established through joint efforts to provide free HIV treatment and care services to affected people and also to participate in HIV research efforts populations in Uganda. The four HIV clinics are: the Joint Clinical Research Centre (JCRC) Department of Paediatrics clinic in Kampala; the Nsambya Home Care HIV clinic in Kampala; The AIDS Support Organization (TASO) HIV clinic and the Kitovu Mobile HIV Outreach clinics, and Uganda Cares in the Masaka district.

Qualitative methods of data collection that included semi- structured in-depth interviews were used. Qualitative research plays an important role in providing descriptions of events that are complicated and not known in a given context. It also looks for meaning people give to the situation being experienced and how it is understood, although a selection is made of what to include in the final report (Willig, 2001). Through qualitative research, the voice of those that are least heard can be documented using their own words rather than categorizing their thoughts and ideas. It is also flexible making it possible to explore sensitive topics and enable in-depth analysis (Denzin and Lincoln, 2005). Since this study was exploratory, it enabled analysis and documentation of experiences and meaning HIV infected adolescents attach to mental health problems in rural and urban settings in Uganda.

3.2 Sampling and procedure

A sample list of participants with depression, anxiety and ADHD from the four study clinics that comprised of both children (below 11 years of age) and adolescents (12 years of age and above) in CHAKA study was provided. The diagnoses were made during the CHAKA study by psychiatric nurses working on the study who used a validated behavior checklist, the adolescent (aged 12-18 years) versions of the children's Mini International Neuropsychiatric Interview (MINI-Kid) (Sheehan et al., 1998, Sheehan and Javans, 2008). The mental disorders in MINI-kid focused on in this study were: depression, anxiety disorders and ADHD.

Purposive sampling technique was then used to select potential participants for the study (Tongco, 2007). Criteria considered for purposive sampling were: HIV infected adolescents from 12 to 17 years of age with a mental disorder, ensuring a ‘balanced demographic sample’ of male and female HIV infected adolescents from rural and urban HIV clinics in Uganda. Gender was taken into account during sampling, as indicated in Table 1 below. Patton (1990)’s view of qualitative sampling states that qualitative research aims for an in-depth study of a small sample that is purposefully selected to attain ‘information-rich cases’. The study sites and participants for this study were therefore sampled using purposive sampling, by gender.

Table 3.1: Gender consideration in sampling

Gender	Rural clinic 1	Rural clinic 2	Urban clinic 1	Urban clinic 2
Male	3	3	3	3
Female	3	3	3	3

Table 3.1 above and purposive sampling plan was used as a guideline, and the researcher sampled to saturation; thus the final sample size was 21 adolescents.

Illustration of the process of sampling used in the study

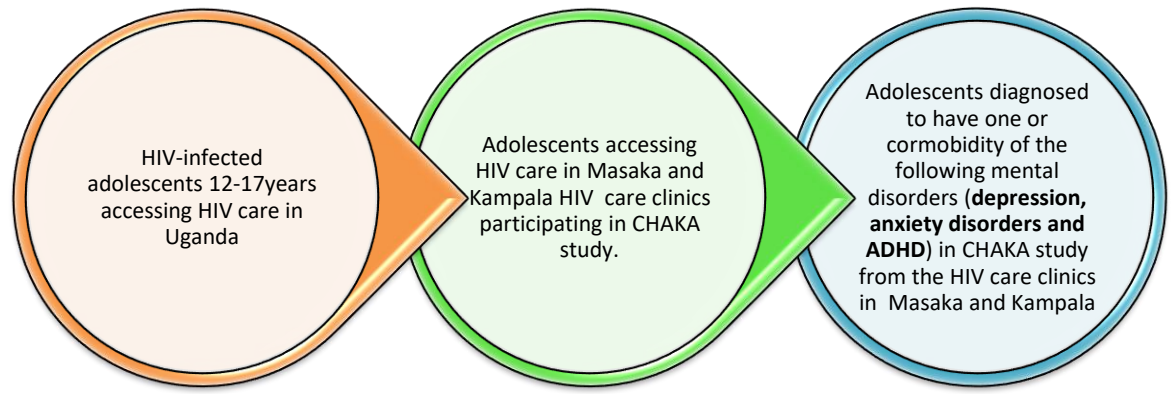


Figure 2: The flow chart above illustrates the steps followed by the researcher to recruit participants into the study.

Appointments were scheduled for assent and consent procedures with the caregiver and the adolescent. Before any study procedures were done such as interviews, all participants and their caregivers were given information about the study and time was allowed for them to ask any questions and make decision whether to participate in the study or not. The researcher read out information loud to the caregiver and potential adolescent participants. Interviews were conducted after consent and assent forms were fully signed. The adolescents were interviewed at the HIV clinic in a private room that was warm and welcoming for the adolescents. If the adolescent did not turn up for two consecutive appointments, they were replaced and the researcher made another random draw from the pool to give chance to another adolescent to participate in the study.

Apart from the challenges faced during recruitment, an additional problem was discovered during data collection. It became clear that the study participants were not aware that they had been diagnosed with a mental disorder by the study psychiatric nurses during previous study visits. The reason for this was not clear. This was reported to the main study leadership, and the matter was referred to a psychologist working on the main study so that they could contact the participants and caregivers involved.

3.2.1 Inclusion criteria

The following individuals were eligible for the study:

- HIV infected adolescents identified with a mental disorder participating in the CHAKA study.
- CHAKA participants aged between 12-17 years, and have had their HIV status disclosed to them.
- Fluency either in English or Luganda.

3.2.2 Exclusion criteria

The following potential participants were excluded:

- Those with serious mental or neurocognitive illness which affects their ability to give informed consent, as assessed by the CHAKA psychiatrist

3.3 Data collection

The researcher used in-depth interviews to enable adolescents to talk freely about events that were sensitive in their lives. The interviews were held at each clinic facility in a private room that is warm and welcoming to the adolescents. General interview guides were used to ensure that the same basic questions were asked of each participant about their experiences, with room to probe and explore responses deep for detail. For adolescents to be able to talk about the mental disorders affecting them, the researcher used vignettes specific to the diagnosis determined by the CHAKA study staff to open dialogue about their own experience of the disorders. Some of Kleinman's (1987) questions were then used to investigate EMs of the adolescents in the study. These questions covered the following aspects of EMs: patient experience of the mental disorders and treatment seeking. The vignettes used were created by the researcher to enable adolescent relate and talk about their own experiences of the mental disorders. The interviewer read the vignettes to the adolescents and then asked the participant to describe what was happening in the story and if they could identify with any aspect of the vignette. From there, the interviewer asked the participant about their daily lives and the challenges they experience. Interviews were audio recorded and notes taken with the consent and assent of the caregiver and the adolescent. Interviews were conducted either in English or Luganda (a local language widely used in Uganda), depending on the language a participant was comfortable with.

3.4 Data analysis

Recorded interviews were transcribed, translating non-English interview responses into English by the researcher. Special attention was given to the way local vocabulary was used to describe and explain

psychological phenomena. Since in-depth interview data were descriptive in nature, thematic analysis approach was used for analysis as this approach is flexible and allows researchers to describe the data without sacrificing complexity (Braun and Clarke, 2006). The following steps were followed:

1. The researchers read data to become familiar (familiarization process) with the discussions, while paying particular attention to the patterns that occurred. This involved taking some detailed notes.
2. Codes were generated, beginning with documenting the patterns through data reduction where the data was labelled to create categories. By the end of this phase comprehensive codes were developed. Data were then coded using the software NVivo 11.
3. Themes were searched for from the developed codes and combining codes into over-lapping themes to come up with the main themes. At this stage a second researcher independently coded the data. The researchers then discussed the themes and came to a consensus. If no consensus was reached, a third person was asked to provide an opinion. The second researcher was involved in each of the following steps.
4. Themes were reviewed to see how the emerging themes support the data.
5. Defining, naming and describing each theme with appropriate words to have a complete analysis of the themes in relation to the data.
6. Drafting a report. At this stage respondent validation was also be done whereby the researcher went back to some of the available participants to check whether the draft report accurately depicted their views, after which a final report was written.

3.5 Ethical considerations

Ethical approval to conduct the research was sought from the Human Research Ethics Committee of the Faculty of Health Sciences at the University of Cape Town, the Science and Ethics Committee of the Uganda Virus Research Institute and the Uganda National Council for Science and Technology.

Information about the research was given to caregivers and adolescents. Information sheets and consent forms were translated into Luganda for those who would prefer Luganda to English. Each got a copy of the information sheet to read through and decide whether they wanted to participate or not. They were given enough time to consider participation. If they wanted more time, an appointment was scheduled for another day. If they agreed to participate, a consent form was signed. Consent was sought from each caregiver in the first instance and assent was then sought from the adolescent to participate in the study.

A copy of the signed consent and assent form were given to the caregiver to keep. Refreshments and snacks were provided to both caregivers and adolescents in the study. Participants were reimbursed with 10,000/= (ZAR 33) to cover transport costs to the clinic for the interview. No other compensations were done in the study.

Confidentiality of information from all participants was ensured at all times; no names were used anywhere apart from a unique number that were given to each participant in the study. All signed consent and assent forms were kept in a locked drawer. Data were kept in a different a cabinet with locks in the office of the researcher. De-identified interview transcripts were stored on a password protected computer that was only accessed by the researcher and backed up on a password protected data server at the researcher's workplace.

Due to the nature of the study, participants who experienced discomfort or distress during the interviews, were carefully handled. The researcher, who was not a clinic staff member, had experience to sensitively conduct interviews and handle situations in which sensitive information was disclosed or emotional distress observed. Participants who experienced distress as a result of participating in this study were further referred to the CHAKA clinical team at the study site for management and referral. The CHAKA study team referred the adolescents to acute psychiatric facilities or other appropriate resources whenever need arose. Disclosure of physical or sexual abuse or information which suggested a high level of risk for self-harm were dealt with in accordance with standard guidelines. The attending clinician was informed after discussion with the adolescent, to enable take up the matter to higher authorities. The matter would be handled under the Ministry of Gender, Labour and Social Development. Working under the Ministry, are the District Community Development offices, and the Probation Office at every Police post in the community, where such cases are reported and handled.

4.0 CHAPTER FOUR: FINDINGS

This chapter presents findings from the 21 adolescents interviewed in the study. From the list of 41 potential participants generated for this qualitative study, four didn't have telephone or mobile phone numbers. Some of the mobile phone numbers provided were off the network throughout the study duration, while some never arrived for the appointments to come to the clinics to participate in the study. Two adolescents were bedridden and one had run away from home Findings from the 21 participants are presented in the order of: (1) sociodemographic characteristics of participants, (2) nature of psychological distress symptoms, (3) life experiences and psychological distress (4) consequences of psychological distress on HIV-infected adolescents (5) coping, support and help-seeking.

4.1 Sociodemographic characteristics of participants

Table 4.1, below, shows the sociodemographic characteristics of the sample of 21 adolescents recruited from four HIV clinics (2 rural and 2 urban) in Masaka and Kampala districts.

Table 4.1: Sociodemographic characteristics of participants

n=21		
Age	12-14	11(52%)
	15-17	10(48%)
Gender	Male	11 (52%)
	Female	10 (48%)
Primary caregiver	Both parents	3
	Mother	7
	Grandparent/s	9
	Other	3
Area	Urban	9 (43%)
	Rural	12 (57%)
Education	Primary	12
	Secondary	4
	Tertiary	1
	Dropped out	4
Mental disorders	Anxiety	5
	Depression	5
	ADHD	7
	Anxiety + ADHD	3
	Depression + ADHD	1

The total number of adolescents recruited into the study was 21. The age range of the adolescents recruited is presented in the range of 12-14 and 15-17 ranges. There were more adolescents of 12-14 range, totaling to 11 (52%) and 10 (48%) from the 15-17 age range. This was partly because the CHAKA main study started a year earlier and those recruited at 17 years of age in the study were 18 years by the

time this study commenced. The total number of males recruited in the study was 11 accounting for 52% and 10 females at 48%.

Adolescents in the study were living with different people who were their primary caregivers. Three adolescents were staying with both parents, while seven lived with their mothers. The fathers of these seven adolescents were either dead or separated from the mothers. In some cases, adolescents were not in contact with their fathers and had no idea whether they were still living or not. Nine of the adolescents whose parents had both passed away, were left under care of grandparents of either maternal or paternal family. The remaining three adolescents were living with caregivers that were neither parents nor grandparents to the adolescent. One adolescent was staying with another blood relative and one adolescent was living with a non-blood relative of the mother, who fostered him after noticing that the care given by the paternal grandparents seemed insufficient. One adolescent was in a foster home.

The total number of participants from the rural HIV clinics was 12, while nine were from the urban HIV clinics. There were seven male and five female participants from the rural clinics; and four male and five female participants from the urban clinics. Urban adolescents were mostly in boarding schools and were not able to participate in the study. Urban caregivers were also mobile and not always available to attend the clinic with the potential adolescent to participate in the study. This made participant recruitment from the urban clinics challenging during the school term and when they were not able to come to the clinic during course of the study.

The majority of adolescents were still at primary school level and three had dropped out for financial reasons, one dropped out due to child birth at 16 years of age. Those in secondary school were just joining this level (3), while one was waiting to advance to high school level. Tertiary level in Uganda is joined after the four years of secondary education for those not joining high school. In this case, the only adolescent at this level, after completing senior four and did not perform well, joined a catering institute to pursue a diploma in catering. Adolescents out of school were involved in casual labor such as tree planting and herding cattle.

The most common diagnosis in the sample was ADHD, with seven adolescents being diagnosed with the disorder. Those with depression were five and five had anxiety. Three adolescents with comorbidities of the selected disorders in the study were also included in the analysis. The comorbidities were: anxiety + ADHD (two adolescents) and depression + ADHD.

4.2 Mental disorder symptoms in HIV infected adolescents

This section presents findings on the nature of symptoms reported by the adolescents when responding to the vignettes (see appendix 4) read to them, and terminologies used to describe their symptoms.

Adolescents in the study talked about their symptoms in various ways that revealed the nature of their distress. The vignettes that got them talking about their own experiences of mental health symptoms. From the vignettes, they used various terminologies to describe the symptoms, which they then related to their own experiences.

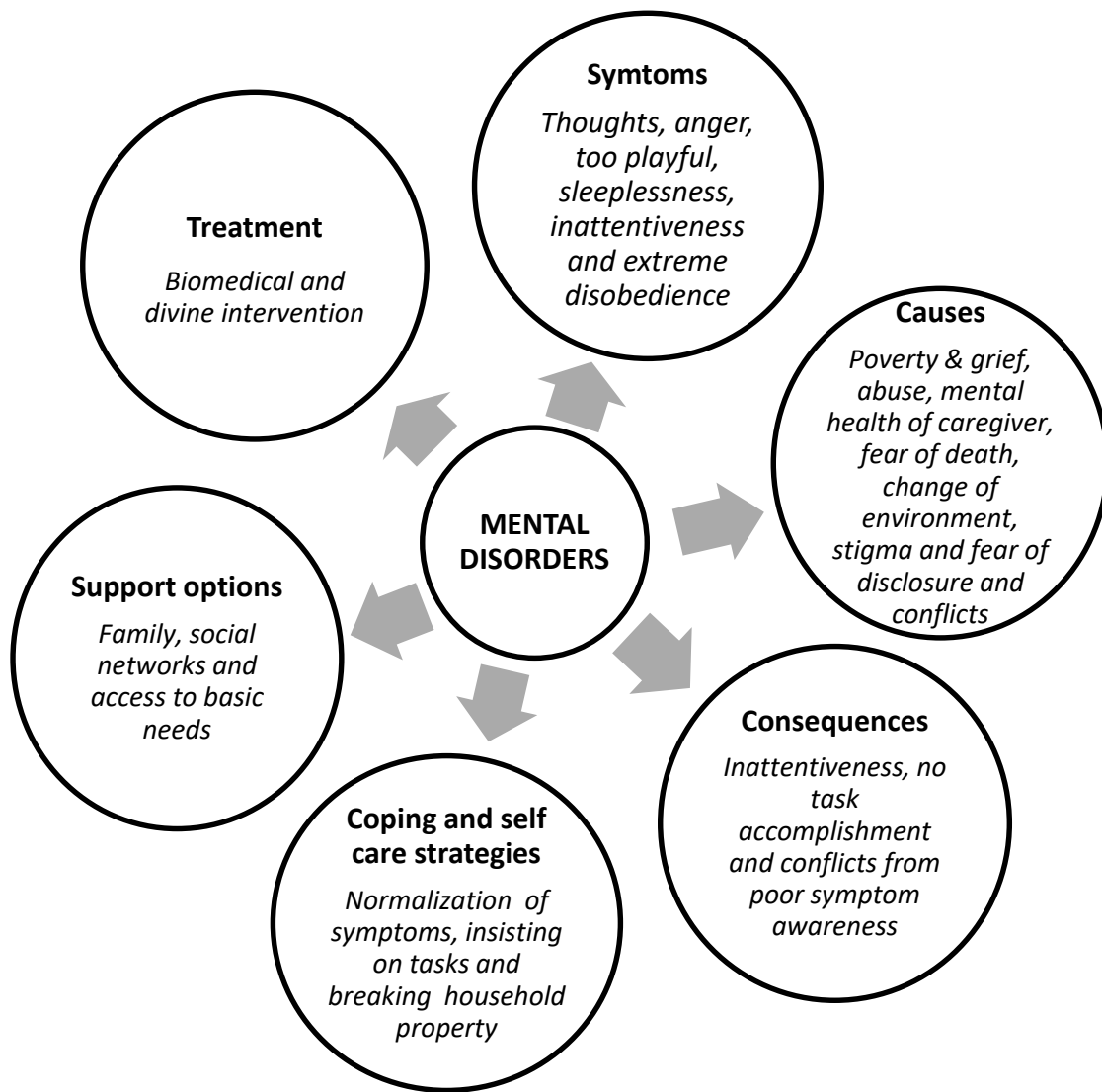


Figure 4.1: Adolescents' EMs for mental disorders

4.2.1 Adolescents' reaction to the vignettes

Adolescents in the study were unaware that they suffered from a mental disorder, despite having been diagnosed as part of the main study activities and supposedly receiving a referral to specialist services. The principal investigator of the main study was informed and action was taken (see section 3.2). They also did not see their symptoms as being caused by a mental disorder, but mostly by simple, temporary challenges that they face in everyday life. Only one adolescent thought that the symptoms might have been caused by a strange disease unknown to him, as he explained that:

In class, I would forget. At times when I was told to write, I would fall asleep and fail to write. I don't know what used to happen. I don't know, but I think it was some strange disease. I don't know what caused it (16 year old male with ADHD).

The adolescents offered various explanations for the symptoms or behaviors portrayed in the vignettes. Many of the adolescents linked the symptoms to life experiences (see section 4.3 for detailed results), while personality traits and disobedience also featured prominently in their explanations.

For the ADHD vignette, many respondents reported that the adolescent presented in the vignette was being "too playful" leading him to fail to do what he was told. A 12 year old male said this about the case in the vignette:

He is too playful. When he sees others playing, he doesn't complete what he is doing. He does it haphazardly and runs off to play with them (12 year old male with ADHD).

Other adolescents offered different explanations for the boy's behavior in the vignette. One 13 year old male adolescent felt that the problem was that the child "does not listen", while a 13 year old participant said that the child did not pay attention, making her teacher "unhappy". Another 16 year old male said it was the effect of using substances such as marijuana, while a 14 year old female said that the adolescent was impaired and could not hear all that she was told to do. The same adolescent went on to say that the adolescent presented in the case is too forgetful and does not adhere to ART very well.

One adolescent was amused by the ADHD vignette and narrated his own experience that was similar to the one presented.

There are things in the other story that were similar to mine. Grandmother shouts at me also ... he also does not understand things in class (13 year old male with ADHD and anxiety).

The adolescents generally had more difficulties relating to the anxiety and depression vignettes. One adolescent felt he could not comment at all on the vignettes. The majority of the participants felt that day-to-day challenges were behind the symptoms portrayed in the vignettes. For the anxiety and depression vignettes, some adolescents spoke about the character being HIV-positive. They said the child behaved in a certain way because she was infected with HIV, they were taking ART, feeling sick and living in a community where they feared others knowing about their status. This led to them feeling uncomfortable and hiding from others.

She is not comfortable with her life, taking medicine. The friends are okay and for her, she is sick (14 year old female with anxiety).

One participant felt that the child in the vignette was sick and that the adults around her had not spoken with her openly about being HIV-positive. She explained about what may be happening in the situation saying that:

I think she does not know that she is infected with HIV or she has not been disclosed to. Maybe she is not feeling well and does not take her medicine the right way. She is always sick and her parents never prepared for her future (14 year old female with depression).

For the anxiety and depression vignettes, most adolescents spoke about other problems related to attending school, poverty and lack of food. One adolescent said the problem was fear of the class environment, and another participant said it was due to change from primary school to secondary school:

He is not clever now yet he was before in the lower classes. It has changed in secondary. I think he was used to the other system and not this one (17 year old male with anxiety)

A 16 year old male responded as follows:

He was in a bad condition because he was not going to school and his parents never had money to pay for his school dues and he is on ART. So it leads him to be saddened (16 year old male with depression).

4.2.2 Vocabulary used to describe mental health symptoms

Adolescents used terminologies to describe their experiences that were characteristic of the disorder affecting them. These were also similar to the daily psychological distress they experienced. Terminologies used by adolescents diagnosed with depression to refer to their experiences of symptoms were: kunakuwala (feeling very sad) and okulowoozo ennyo (thinking a lot), ebirowoozo (many thoughts). A 16 year old male who had been diagnosed with depression narrated his experience and used the 'kunakuwala' idiom:

There is a time I was very sad (kunakuwala nnyo) before I got school sponsorship ... I would be sent home and I would spend a week at home doing chores. Money was scarce. I would then think that if father was still living, maybe I would go back to school quickly (16 year old male with depression).

Another adolescent using the 'ebirowoozo' idiom to express her own experiences:

While in class, I get thoughts (ebirowoozo). Too many thoughts (ebirowoozo bingi) come to me (16 year old female with depression).

For those who had been diagnosed with anxiety, the terms used to describe their experiences were: obusungu (anger), and okulowooza ennyo (thinking too much).

I used to feel bad...I was never comfortable. I would get very angry (nga nfuna obusungu bungi). So at times I would get out of class and go to the dormitory. I would skip that lesson (15 year old female with anxiety).

Another adolescent started to think a lot (okulowooza ennyo) and could not concentrate in class

You may be in class and things happen; you find yourself thinking a lot, you cannot be attentive and you are thinking a lot beyond them all (14 year old female with anxiety).

For the participants who had been diagnosed with ADHD, thought that they were just too playful and disrespectful to the adults and expressed it in the following terminologies: okuba n'omuzannyo omungi (being too playful), butawuliriza (not listening to others/inattentiveness), and mputtu (extreme disobedience). An adolescent who thought that the issue was being too playful expressed himself this way:

He is too playful (alina omuzannyo mungi). When he sees others playing, he doesn't complete what he is doing. He does it haphazardly and runs off to play ... He just loves playing and it is not an illness (12 year old male with ADHD).

Another adolescent who said that he was not listening to others/inattentive, also went further to define his behavior as being extreme disobedience:

I don't listen/pay attention (siwuliriza) to people who are not my parents ... I think this is extreme disobedience (mputtu) (14 year old male with ADHD).

4.3 Life experiences and mental health symptoms

From the vignettes (see appendix 4) presented to the adolescents during course of the interviews, they were able to further explore their own experience of mental health symptoms. Vignettes were reminders of what they were going through in their own lives. In this section, adolescents' views on their daily life challenges and how these are related to the psychological distress symptoms they were experiencing are presented.

Various factors made adolescents vulnerable to mental health symptoms. Adolescents were living in poverty where their basic needs are not always met. They grieved their dead parents whose care and support they still needed. While at school, constantly compared themselves to other peers who were not HIV-infected. From daily interactions with other people, adolescents experienced conflicts. They fearing death and described changes in their environments that led to psychological distress as elaborated below.

4.3.1 Poverty and grief

Participants described the cause of their mental health symptoms. to be a result of multiple interactive external factors that they think provoked onset of the distress. These were living in poverty in addition to parents' deaths. The surviving parent had to make ends meet for the family as before. This was not possible in some cases when they were also HIV-infected and on ART. These were reported as less energetic and unable to work enough to cover the family's needs as it was before. In such cases, adolescents coming from such families were affected by insufficient provision of basic needs. As a result, grief for deceased parents increasingly occurred and feelings that they would have provided better if they were still living. Two with depression adolescents from the rural setting, expressed how this situation of poverty also brought about feelings of grief for deceased parents. A 16 year old male in secondary school reported his experience:

Mother never worked, she never had a job. When father died, there was no one to help and pay our school fees. It was only my sister that was getting school fees. ... We were always sent home for school fees and as soon as I would go back to school, another sibling was also sent away ... I could not help to regret father's death thinking that maybe if he were around, I would not have been sent back home ... I play with other children and forget about these thoughts but when I go to sleep and think about those who attended school and I hadn't, the thoughts flood all over again ... I think that if father was still living,

I would be at school and life would be better than it is now because we were better off (16 year old male with depression).

The second adolescent having lost her mother at the age of three, grieved when her peers talked about their mothers and the mother-daughter relationships they were enjoying. The adolescent always got nostalgic about her mother, who could have been her confidante and she also reported missing the mother-daughter relationship. Such thoughts always ended in crying and sadness. She narrated her experience saying that:

While in class, I get thoughts. Many thoughts come to me when students talk about their mothers and what they left them doing. I also start getting thoughts and wishing that if my mother was living (begins to cry). I wish my mother was not dead; I miss her. There are times when I want to say something, but when there is no one to say it to ... There are certain things I need like sanitary pads. Sometimes I ask grandmother and she says that she does not have money. Sometimes I fear asking father ... (16 year old female with depression).

Some of the adolescents were living in poverty and this made it impossible to always get basic needs such as food, sanitary pads, school fees, among others. Sometimes they had to go hungry to school and return hungry to a home where food was scarce, often having only a single meal per day; yet people on ART require regular meals for their medication to be effective and to reduce side effects as they pointed out. A 16 year old male with ADHD narrated that:

Most of the times, I would leave home when I have not eaten enough. I had not eaten enough yet I had taken ART. So I would start thinking about lunch hour at 1pm. I did not hope to find any food at home (16 year old with ADHD).

4.3.2 Physical, verbal and psychological abuse

Some adolescents experienced different kinds of abuse in different environments, including physical punishments, verbal and sometimes psychological abuse. These brought feelings of rejection and untold pain in the daily life experiences adolescents narrated. There was intimidation from both family and people at school and those adolescents experiencing this, reported feelings of low self-esteem. Such continuous abuse experienced made the adolescents to be anxious in school and home environments. A 14 year old female with anxiety, narrated her experience of the different kinds of abuse she faced both at home and school saying that:

People at home can disturb me; they abuse me. I am not performing well in class; I am not comfortable at home. They beat me for no reason, abuse me for what I have not done ... Others

do wrong and then say that I am the one who did it. When they refuse to do something, they say that I am the one making them not to do it. I worry about my studies and my future, when I look at my performance and what is said at home (14 year old female with anxiety).

Food was sometimes withheld from adolescents when they did not perform well on chores to the family and caregivers' expectations. These adolescents had to perform equally at the chores like the fit and able-bodied members of their family. When it was farm work, the yardstick was equal for all and failure to accomplish the task resulted in denial of food. In the school environment, teachers equally harassed such adolescents when they failed to attempt classroom tasks given to them. Adolescents reported that ART affected them and they became sleepy, fatigued and weak. Caregivers and teachers never gave them much attention and support while going through such experiences. A 17 year old male with ADHD reported psychological abuse and being denied food at home. He reported about his experience saying that:

I feel weak. I can't go down in the garden. When I go, I dig a small portion from here to there and feel my arms not having any energy. When food is served, they tell me that the portion I dug is very small. I find that very disturbing. I feel bad and in most cases I get a solution like a man. The garden usually has jack fruit, sugar cane; I eat that and survive (17 year old male with ADHD).

4.3.3 Mental health of the caregiver

Some adolescents reported that their caregivers were distressed and as a result, sought emotional help from friends and neighbors. This was not always pleasing to adolescents and brought about conflicts between adolescent and caregiver. Adolescents felt these were familial issues not to be shared with other people in the community. A 17 year old adolescent disclosed her emotions when her mother shared about family disputes with her friends and neighbors in the community.

One day I was really angry when she was blaming me for my results. I yelled at her. So she went around to her friends and started saying that, "These kids don't care about me. They want me to die. I have sacrificed a lot for them." I felt bad, but she always does that. ... I can't even get used because she always does that. I always ignore or just give her a deaf ear ... She always doesn't care (17-year-old female with ADHD and anxiety).

4.3.4 Fear of death

Some adolescents experienced severe illness and the death of close relatives to HIV. While the adolescent experienced severe illness, family members and those surrounding them lost hope for their survival. Others' loss of hope in turn drained the hope of the adolescent to survive the illness. This brought about

fears of death as other people were perceiving it. An adolescent with anxiety experienced severe illness and reported his reaction to what others around him were saying:

When I was sick, they said that I would not recover, that I would die. I also started thinking that I would die. I was bedridden when father said that. I felt that I was going to die (14 year old male with anxiety).

While another adolescent who experienced a relative dying of HIV, feared she would also die:

The one I knew died. It was my maternal aunt. She used to tell us about HIV and she would come for ART. I felt very bad when she died. I knew that I was also going to die. But mummy supported me saying that if I take the medicine very well, I would not die. That is when I got strong (15 year old female with anxiety).

4.3.5 Change of environment

Adolescents spoke about their experiences of changing schools from primary into secondary schools. Some changed from one secondary school to another and this affected their performance and mental health. While they were performing better in their first school, it was not the same in the new schools where they reported facing academic stress. In the new environment, sometimes they were put in the same stream with all the other newcomers to the school. Some teachers compared these new adolescents to those in other streams telling them how the others were doing much better than them. Some participants felt that this lowered their self-esteem and limited their academic and social exploration. Poor performance also led to pressures from parents who expected better from the adolescents and this led to distress when they did not perform to the expectations of the caregiver. A 17 year old adolescent narrated her experience when her performance deteriorated in a new school she joined:

I stopped caring ... because most of the time when I read, I did not understand what I read ... I don't know what happened ... I would find myself talking or sleeping ... My mum was always tough. She would always scold me but my cousins would always tell me that it's okay, not everyone passes. I felt bad. I would go cry over it (17 year old female with ADHD and anxiety).

4.3.6 Stigma and fear of disclosure in the school environment

The majority of adolescents in the study were attending school and had to take ART while there. This made other students curious to know the reason behind their daily drug taking at school and this created fear and stigma in the HIV-infected students. To curb such inconveniences, some said they had diseases such as heart disease, while others went ahead to take their medicine and reported to teachers when they felt their privacy and medicine was being encroached on by others. Moreover, no matter how they

physically appeared with HIV, these adolescents actively attended school. Some reported to have been very thin at one time, while others reported skin rashes. They recalled that other pupils in the school, having experienced people with similar HIV symptoms before, stigmatized them as they had these symptoms. They then began to feel uncomfortable and avoided fellow pupils that always branded them HIV infected. A 15 year old female adolescent with anxiety described how she started being uncomfortable in primary school, always got angry and avoided the classroom when other pupils continued to refer to her as HIV infected and encouraged others to also reject her:

I used to feel bad and never wanted to go near the boys knowing that they would call me 'silimu' (HIV-infected) and embarrass me in front of other pupils ... I was never comfortable. I would get so angry ... I would skip lessons ... The time I was referred to as 'silimu', I was very thin. Some girls would ask the boys as to why they were referring to me like that. The boys would say that, "Don't you see how she is very thin? She looks like she has HIV." That is when they started to call me 'silimu'. I felt bad ... it was one pupil who first called me names and I ignored him. While we were going to the spring well to collect water for the school, the boys stood in a group as I collected water ... They started to call me names ... A girl came to me saying that I was being called 'silimu'. Another boy came up to us and told the girl that, "Why don't you reject her snacks because she has HIV?" I felt very angry (15 year old female with anxiety disorder).

Adolescents feared joining boarding school sections in fear that other students would get to know about their HIV positive status. These also felt that they would not manage taking ART in the school environment in the presence of other students. There were other fears that even moving with the medicine at school was a problem as the pills would shake in their containers and that would attract attention of other students to ask what it is that keeps shaking in their bags. An adolescent speaks about his fear of joining boarding school:

Hearing someone say that they are going to boarding, I feel I would also want to but I fear that it would lead to difficulties to me unlike the other students. Even the person who has been your friend can start to dislike you. In primary seven we had been told that we should go and stay at school during the last weeks before final exams so that we were able to keep busier than when we come from home daily. I felt uneasy thinking about those who did not know about my HIV status getting to know. That is where the problem was (16 year old male with depression).

More still, adolescents were afraid of other people getting to know their HIV-infected status, especially in the school environments. These adolescents guarded their secret in fear of peers to whom they disclosed, disclosing to others without the infected adolescent's approval. When there was temptation to tell, they always remembered the consequences of other people getting to know about it. There was also

discomfort when HIV was taught in class. As lessons progressed, the infected adolescents compared themselves to others in the class and negatively tagged themselves as not normal. A 14 year old adolescent narrated how she was uncomfortable about status disclosure and being taught about HIV in class saying:

It's like you think; and from thinking you see yourself as the only one infected around. You can't tell them. You are not free with it. You get tempted to tell them but you are like, she is my friend, I may tell her and she tells another one. You are not comfortable and they can teach about it [HIV] and you are like; so they are teaching things about it? So it means I am not normal and you get to think a lot. I am stressed every time and never pay attention; I never feel normal (14-year-old female with anxiety).

Students whose HIV disease had progressed to AIDS, experienced stigma in school. Some students called them names that were belittling and reflecting their sickly physical appearance. Name calling stirred feelings of anxiety in the affected students. An adolescent that was continually called stigmatizing names narrated her ordeal saying:

There was a group of boys who used to get together and started to abuse me that I have HIV and they laughed about it. One day a girl came and told me that they were referring to me as 'silimu' (HIV-infected). I went to the teacher and told him and he never took it seriously at first. We were in class and while he got in, he heard them say it. He again never minded them. I continued to report to the teacher every time I was called 'silimu' (15 year old female with anxiety disorder).

4.3.7 Self-isolation

Some adolescents in the study isolated themselves from other people whenever they were distressed. This mostly occurred when they were experiencing strong feelings of anger and sadness. Some hid themselves while in the home environment so that people in their homes did not notice such moments of sadness and anger. There were also those who wanted to stay on their own altogether and lead a life alone, away from their families. Two adolescents with anxiety and depression, reported how they isolated themselves whenever they were experiencing anger and sadness.

I get so angry and even think about killing myself, yet I can't. I also get very sad and isolate myself to sit alone. I never think about killing myself so much (15-year-old female with anxiety).

4.3.8 Social conflicts

Furthermore, adolescents experienced various conflicts in their daily lives both at home and in the schools they attended. These commonly occurred in the social circles of the adolescents: between adolescents and their peers, adolescents and the teachers, and adolescents and caregivers. In the home environments, caregivers and other people in the home had expectations from the adolescents and when these were not accomplished, the result was a conflict with the caregivers. This was sometimes in form of verbal and physical abuse. Teachers attempted to address conflict with the adolescents by punishing them. Teachers were sometimes portrayed as being fond of punishing adolescents even when there was no cause for punishment:

While at school, there were many things teachers used to do that made me angry. A teacher would come to class and beat you for no reason. Or he would find you and try to provoke you and if you do anything, he would use that as a reason for punishment. Such things made me so angry. I would leave the classroom and go to the dormitory and sleep (15 year old female with anxiety).

4.4 Consequences of mental health symptoms on HIV-infected adolescents

While living with mental health symptoms, adolescents faced challenges as a result of the distress experienced. Associates of the adolescents never understood their behavior and emotional changes and this sometimes led to conflicts. This section presents the consequences adolescents faced due to having symptoms of mental health symptoms.

As a result of having of mental health symptoms, some adolescents were less attentive to their surroundings. The effects of the distress were constantly occurring where they were doing home chores, moving on the road or playing with mates. Those inattentive on the road were aware of the dangers, such as accidents, which could occur when they were involved in thoughts and unable to pay attention to road traffic. An adolescent expressed her fear of these consequences:

... going to cross the road and you are still thinking. You talk alone and people think you are stupid, but when you are thinking about your problems and not knowing that you have already reached the road (14 year old female with anxiety).

Adolescents also said that they were socially inattentive while engaging in play with mates. These wondered why mates complained about them being aggressive during play. They were not aware of their aggression and felt uncomfortable when peers constantly rejected them during play. A 13 year old male had this to say about peers' complaints of his aggressive behavior:

... my friends disturb me all the time. While we are playing football, they want to kick me hard ...They say that I play badly for them ... They don't want the way I play, that is why they mistreat

me while playing. They say that I kick them hard even when I do not do so (13-year-old male with ADHD).

Some adolescents got frustrated when they failed to accomplish daily tasks; yet they were not aware that the psychological distress they experienced was affecting them. They wanted to work as hard as their peers in the classroom and those of their age group, but it seemed to not be possible. A 17 year old adolescent that dropped out of school complained about his academic struggles to study and stay focused on tasks given to him saying that:

I used to forget. I would forget work given to me in class. I would forget the times when I was told to write and I would fall asleep and fail to write. I don't know what used to happen, but I think it was some strange disease ... I don't know what caused it because I would be at home and they would tell me to sweep the yard. I was having thoughts and if they added a chore to also be done, I would forget the first one and do something else instead (17 year old male with ADHD).

As adolescents were not aware and wondering how it happens for them to face various challenges in their daily lives, so were the caregivers that they lived with daily. Adolescents reported that when teachers realized an adolescent was continuously being inattentive to classroom affairs, they did not intervene to find out exactly what it was that led the adolescent into such behavior but always punished them. The adolescents were punished to become attentive in class or were picked on in class to see if they were alert and following through. An adolescent with an anxiety disorder who frequently experienced thoughts during class times, explained how the teacher noticed her behavior and tried to bring her attention back to classroom by asking her questions. She reported that:

Sometimes I would wonder how the teachers get to know. You can be like this [opens her mouth and puts on blank gaze]. You can be in thoughts and the teacher picks on you to give the answer. And you wonder why he is picking on you yet other students' hands are raised and yours is not (14 year old female with anxiety).

4.5 Adolescents' coping and self-care

A number of adolescents in the study never sought treatment and did not view their mental health symptoms' disturbances as illness requiring treatment. Symptoms were normalized and many thought these would go away on their own. Others felt they could cope with the symptoms or do something on their own to get better. A bereaved participant spoke about needing to do something herself to overcome her grief and negative thoughts. She did not believe that there was a treatment available for her distress:

I have to treat myself because now thoughts are going away slowly. There are times when I think about her and I say to myself that she died. She can no longer return and continue doing my own things (16 year old with depression).

An adolescent narrated how she toiled during classroom time to be attentive and stay focused on what was being taught in class:

I had to do my level best not to think in class. I would tell myself that I will not stress myself. Whenever I switched to thinking, I would pull myself back saying, “No, why am I thinking yet I am in class?” Then I would pay attention again (14 year old female with anxiety).

Another adolescent with anxiety overcame anger by breaking household items such as plates and cups to feel better. Although this gave her relief, there was regret always when she realized what damage she had done. She reported her strategy for controlling her destructive behavior:

I have taken some time without breaking things. I control it. Sometimes when I feel like that, I go to sleep (17 year old female with ADHD and anxiety).

Some adolescents isolated themselves wherever they were distressed, yet they came to realize that isolation was not the solution and it would keep them distressed longer. They decided to stay in the company of their peers to avoid distress. The distress would then seem trivial when in company of others and would feel better. They were not aware of treatment, but saw no need for further help since chatting with friends provided relief for their distress:

I don't know because when I get angry, I keep to myself until my friends come and try to chat with me and the anger goes away ... One may tell a joke and we all get to laugh about it and the anger leaves me (15 year old female with anxiety).

4.6 Treatment and support options

In this section, findings about treatment and support options are presented. This includes reports of the services or support they accessed, and their opinions on the services or support that they needed.

The majority of adolescents in the study were not aware if there was any treatment for their mental health symptoms. When asked about the sort of treatment they thought would be helpful to overcome their symptoms, they reported that they had never heard or thought about it. However, one adolescent in the study had sought treatment when he got uncomfortable with the distress. The adolescent experienced sleep disturbances and when it continued, he was advised by the caregiver to seek help from the government Health Centre in his home area. Having received some relief from this treatment, the adolescent also wanted a full checkup by a specialist as his symptoms continued. He narrated his experience:

I went to a Health Centre and I was given some medicine. I told them that I get sleepy during day when I have things to be done, yet at night I don't get any sleep. I was given medicine and told to take it at bed time and I was also able to complete the work given to me (17 year old male with ADHD).

Although the above adolescent never sought treatment for the other mental health symptoms he experienced, he wanted to be completely better although he did not know where to go. He desired a medical examination to find out the exact cause and solution to his lack of sleep. When asked about the kind of help he needed, he narrated:

I don't know but it requires a doctor to examine me and find out what keeps me awake at night. Any doctor that is able to treat as long as he is explained to. I would want to be able to sleep at night like others instead of staying awake. It affects me when everyone is asleep and I am awake (17 year old male with ADHD).

More adolescents in the study were also bothered with the unpleasant symptoms and wanted to get better but did not know where to seek help. Some turned their hope for cure to divine intervention or other types of human help. A 14 year old adolescent with ADHD narrated her hope in both divine and human interventions to overcome the unpleasant symptoms:

I know it is God who can help me ... But maybe a human being may be able to help me. It is God who can help me. When they call me repeatedly and louder, I am able to hear. Sometimes I do not hear when I am doing something else. When I am washing dishes I cannot hear other things that they say to me. I concentrate on washing dishes and I can't hear what they are saying to me. But when I am just there not doing anything, I am able to hear (14 year old female with ADHD).

Other adolescents felt that they would be fine if given daily basic needs, and that their distress would improve. They felt that with support from other people, such as family members, who could understand their predicament and be supportive of them, life would improve. A 17 year old male elaborated on his ideas for a solution:

I wanted to have a good life. I wanted to go back home at 1pm and find food ready. To leave in the morning while satisfied, have all the school necessities like the books, without many thoughts (17 year old male with ADHD).

Another adolescent reported about the conflicts that arose due to his distress and how he would have wanted to be supported:

I was scolded and verbally abused at home until I did what they required me to do ... Teachers used to beat me saying that instead of writing, you are asleep ... After being beaten, I would then do what I had been told to do and complete it ... It used to just happen ... I feared being scolded

and beaten. I only wanted to be counselled so that I could do what I had been instructed to do (17 year old male with ADHD).

Some adolescents felt that family support would be helpful for them to overcome their behavioral challenges. These desired more understanding of their situation than consistently being punished for it. A 14 year old male expressed himself about how he desired support:

If they stop beating me all the time, I can also strive to change ... My own parents should be able to help me, [by]not harassing me like they have been doing ... I would want this behavior to change so that I have normal behavior (14 year old male).

Additionally, adolescents reported receiving support from various networks in their daily lives that enabled them to cope with the mental health symptoms. For some of the adolescents in school, the caregivers had disclosed to their teachers about the adolescent being HIV-infected in order to gain support and permission to always attend HIV clinics during the school term. All the adolescents involved had no problem with this disclosure. Disclosure enabled these adolescents attend their treatment and drug refill appointments easily and access support from the teachers. Teachers were supportive and trusted confidants who said they would not tell other students about the adolescent being infected with HIV. A 17 year old adolescent with depression reported about her teachers supporting her, which enabled her adhere to ART without other students noticing:

I got worried while when I was going to boarding school. I wondered how I would manage but one time I got counselling from the teacher. He gave me advice that, "When you wake up, get your pill and go to brush. Put the pill in your uniform pocket and while there, swallow the pill and go back to the dormitory" (17 year old female participant with depression).

4.7 Results summary

All in all, adolescents in the study had various experiences in their daily lives that made them vulnerable to mental health symptoms. More data was expected on the causes of the mental disorders, but since the participants did not know about their diagnoses it could not be explored adequately. However, the adolescents themselves did have opinions on the reasons for their mental health symptoms and these were linked to their life experiences (see section 4.3). The adolescents had developed ways of coping with their mental health symptoms and related problems. Some said they need to be listened to and understood by close associates and carers, while most thought they should get better on their own or get help from friends and saw no need for professional help. The study findings are discussed in the next chapter, according to the study objectives.

5.0 CHAPTER FIVE: DISCUSSION

This study aimed to explore explanatory models of mental disorders in HIV-infected adolescents diagnosed with common mental disorders, including depression, anxiety disorders and ADHD in the districts of Masaka and Kampala, Uganda. The objectives of the study were:

- i. To elicit HIV-infected adolescents' views on the causes and nature of their mental health symptoms.
- ii. To explore HIV-infected adolescents' perception of the link between their daily life experiences and their mental health symptoms.
- iii. To elicit HIV-infected adolescents' suggestions for acceptable treatment options for their mental health symptoms.

Major findings for each study objective will be highlighted and discussed in relation to available literature. Implications for research and policy will be discussed, the limitations of the study will be described and conclusions will be drawn.

5.1 Nature and cause of mental health symptoms

The main findings for this objective were: (i) adolescents had no awareness of the mental disorders they had been diagnosed with (see note under 'Sampling and procedure', section 3.2), although they were able to talk about their own experiences of the mental health symptoms, and (ii) in their EMs for the mental health symptoms experienced, adolescents attributed causes mainly to social hardships, HIV-related factors and interpersonal conflict in relationships. In this section, I will discuss findings related to the adolescents' awareness of mental disorder and their experiences, after which I will briefly discuss the adolescents' perceptions of the causes of their symptoms. Since most of the findings around this point relate to the second objective (the link between daily life experiences and mental health symptoms), I will discuss these in detail in the next section.

5.1.1 Adolescents' lack of awareness of their mental disorders

First, findings indicate that only one adolescent thought he could be suffering from a disease, but unexpectedly no one else offered other explanations, except those related to their daily life experiences. Second, adolescents did not recognize the vignettes in the study as indicating a form of mental illness. I will discuss these findings below in relation to the international literature.

Adolescents identified problems in their lives as the causes of the mental health symptoms they experienced. Other studies in LMICs have found that people spoke about their mental disorders as mostly being a result of the supernatural, i.e. due to spirits or witchcraft (Okello and Neema, 2007, Patel, 1995a, James and Peltzer, 2012, Johnson et al., 2009, Ganasen et al., 2008, Kigozi et al., 2008). In this study, not one participant mentioned these factors. This may be because adolescents had not experienced severe mental illness and had not been disclosed to about their mental disorders. If they had been informed of their diagnosis, they may have had different views on the possible causes. Additionally, in the literature, supernatural EMs are commonly used with psychosis, while studies recruiting people with depression or anxiety disorders also report that participants spoke of various challenges, such as economic and relationship problems (Pereira et al., 2007, Okello and Neema, 2007)

The findings from this study indicate low levels of mental health literacy in the adolescents, and possibly in their communities as well. Based on adolescents' reports of adults' responses to their symptoms and behaviors, it is possible that teachers and caregivers have low levels of mental health literacy too. Mental health symptoms experienced by the adolescents did not seem to indicate to teachers and older household members that the adolescents were suffering from a mental disorder. Adolescents reported repeated punishments for their behavior with no support, since no one at home or school seemed to suspect that they had a mental disorder.

A review of research on mental health literacy in LMICs, which included studies from sub-Saharan Africa, indicated that mental health literacy is low compared to developed countries. Authors further indicated that mental health literate individuals should be able to identify mental disorders and have knowledge of where to seek help (Ganasen et al., 2008). Increased mental health literacy could improve case-finding and support for people living with a mental disorder as it improves beliefs and attitudes towards those with mental illnesses when people are in position to recognize the mental disorder (Hugo et al., 2003). At the present time in Uganda, the education system does not offer any mental health literacy programs (Kigozi et al., 2008), although some mental health research has happened in school settings (Ssewamala et al., 2009, Devries et al., 2013b, Atwine et al., 2005). Mental health is being integrated into primary health care in Uganda with efforts to create awareness and improve help seeking (Petersen et al., 2011, Eaton et al., 2011). There is also ongoing effort by the Programme for Improving Mental Health Care (PRIME) project (an internationally funded research consortium working in Uganda and four other

countries) to improve mental health literacy through research, capacity building, and the media (Lund et al., 2012).

5.1.2 Adolescents' description of mental health symptoms experienced

Despite the lack of awareness for their mental disorders, adolescents were able to talk about their own experiences of mental health symptoms. The idioms used were similar to those used in earlier research with adults where 'feeling very sad', 'thinking too much' and 'anger', were used to describe emotional and behavioral phenomena in mental health (Cadigan and Skinner, 2015, Hertog et al., 2015, Johnson et al., 2009, Grover et al., 2012, Shankar et al., 2006, Arthur and Whitley, 2015, Menon et al., 2016, Yoder et al., 2016). The difference in this research is that most adolescents did not present with somatic symptoms, although one did report sleep disturbances, and neither did they attribute the cause of their mental health symptoms to spirits or demonic attacks and witchcraft like other studies in adult populations done in the same cultural setting and background. Some studies on depression in Uganda described adults presenting with headaches, fatigue, body pains and attributing it to spirit attacks, witchcraft, biomedical, social, financial and psychological causes (Okello and Neema, 2007, Johnson et al., 2009). In HIV infected populations, similar symptoms such as sleep problems, body aches and fatigue are often present and sometimes seen as an effect of ART (DeLaMora et al., 2006, Donald et al., 2014, Evans et al., 2011, Koenig et al., 2011, Mellins et al., 2006). Some adolescents thought that their symptoms were HIV and ART related. It may be that HIV infected adolescents take their mental health symptoms to be related to the effect of HIV disease and ART and since they are on treatment, they may assume that symptoms will go away with the treatment being administered, leading them to not seek help for mental health challenges they face daily.

5.2 Daily life experiences and mental health symptoms

The major finding for the second objective was the attribution of mental health symptoms to social hardships. These were daily problems in their lives as they interacted with their social environment such as the households and schools. The main challenges faced were: poverty, HIV related stigma, grief, interpersonal conflicts and violence as discussed below.

5.2.1 Poverty

There were two main findings that were related to poverty in the study. First, there was food insecurity in the households where adolescents lived. Adolescents went hungry yet they had to continue taking ART that required food along with it to be effective with minimal side effects. While at school, they worried about not finding enough to eat at home yet they had to take ART, which affected their concentration in school. These findings indicate the underlying challenges adolescents with HIV and mental disorders are experiencing that may be making their condition worse. Literature on food insecurity indicates that food insecurity affects many people living with HIV/AIDS globally (Weiser et al., 2009, Weiser et al., 2011, Normén et al., 2005). When it comes to lacking food and ART adherence, literature indicates that poor adherence to ART leads to drug resistance (Donald et al., 2014, Koenig et al., 2011). Weiser et al. (2011) and Patel et al. (2007) reported that lack of food has consequences for the mental health of an individual, a similar finding in this study whereby adolescents did not concentrate in school and became preoccupied with thoughts of whether they would find food at home.

Second, adolescents in the study lacked scholastic requirements after the demise of their parents. These young people were frequently sent away from school for lack of school fees and this resulted in psychological distress when they thought about their peers at school and what they were missing, which affected their mental health. It is documented that lacking the assurance that life goals will be accomplished, such as completing school education and acquiring good jobs hinder enhancement of adolescent mental health (Ssewamala et al., 2009). Adolescents had little hope for the future and some dropped out of school early with no support to enable them stay in school longer. By not staying in school they were affecting their future as they would be less likely to find jobs to enable them to overcome poverty and hence, their vulnerability for mental disorders would increase (Patel et al., 2007, Lund et al., 2010).

5.2.2 HIV related stigma

Adolescents in the study reported stigma that was HIV-related due to their appearance, taking daily medication and their frequent visits to the HIV clinic. Adolescents did not want other people to know that they are infected with HIV. They thought out ways to hide the fact that they were taking pills or attending the clinic. An adolescent in the study worried about going to boarding school in fear that his peers would find out that he is infected with HIV. Whenever the possibility of him leaving home to be in boarding school came up, he became worried about how he would manage taking ART without his peers finding

out. This kind of stigma has also been reported in other adolescent studies where they feared other people getting to know about their HIV positive status or anything that would relate them to being HIV infected such as being seen to be taking ART. Adolescents kept themselves in isolation and adopted secretive behavior, which is similar to our findings (Kawuma et al., 2014, Koenig et al., 2011, Orkin et al., 2014, Walker et al., 2007). Other research from Uganda, found similar findings on stigma in HIV affected adolescents. Kawuma et al. (2014) reported that children and adolescent with HIV hide their medication and also take it only in presence of carers due to stigma. At times, they failed to get a secret place to take their medication, resulting in poor adherence. Adolescents on ART need social support to take their medication without fear of being seen. This may require to disclose to a few trusted friends or school teachers who can help them ensure privacy while taking medication or other people they can talk to about their fears of being found taking medication.

5.2.3 Grief, orphanhood and fear of death

Findings also indicate adolescents in the study grieved for their deceased parents and feared losing their own lives. They overheard people discussing the likelihood of them dying and this made them scared. The majority of the study participants were not staying with their biological parents, and in addition to dealing with the loss of their parents they had to cope with being an orphan in a different household. While in the new homes where they had been fostered, some adolescents experienced rejection, some experienced violence and some were not given enough to eat. Some caregivers, despite knowing the adolescents' HIV status, expected them to complete as many chores as other members of the family. Literature in Africa documents orphanhood as one of the major impacts of HIV on the continent (Foster and Williamson, 2000, Foster, 2000, Atwine et al., 2005). Adolescents are reported to be affected by various mental problems such as anxiety, depression, anger, feelings of hopelessness and suicidal ideations (Musisi and Kinyanda, 2009, Cluver et al., 2012c). Often, those orphaned are fostered and join new households of other family members. With the increase in orphans, many grandparents and other distant relatives are carers to children and adolescents orphaned to HIV (Karimli et al., 2012, Foster, 2000, Atwine et al., 2005, Musisi and Kinyanda, 2009). Although the importance of extended family in caring for children and adolescents affected by HIV/AIDS is vital in Uganda (Karimli et al., 2012), caregivers need financial support to meet the basic needs of adolescents in their care. It is also important to provide psychosocial support and mental health education to caregivers to meet the emotional needs of adolescents affected with HIV and mental disorders and reduce acts of violence towards them. A qualitative study on mental health in children and adolescents orphaned by HIV in Tanzania documented the impact of orphan hood as being

mistreatment, lack of school requirements, lack of clothes, having no hope, being discriminated against in society, stress and thinking too much (Dorsey et al., 2015).

5.2.4 Interpersonal conflicts and violence

This study found that, with the presence of mental health symptoms, adolescents functioned poorly and experienced conflicts that sometimes included physical violence against them. The changes in behavioral and emotional ways of the adolescents turned out to be challenging to those they associated with and even to themselves. Adolescents could not effectively perform tasks given to them and experienced problems in relationships. When they played with others, there were complaints from peers. When they were given tasks, there were complaints. When they failed to accomplish a task, they were punished by authority figures who thought that they purposefully did not to do what was required of them. There was physical violence against them from family, peers and school teachers, and sometimes other abusive acts such as withholding food, which can be harmful to HIV-infected adolescents' health and nutrition as mentioned in section 5.2.1 above.

Violence in the school settings may have been due to ignorance about mental disorders existing in the community, as discussed in section 5.1.1 above, and if not addressed, those affected may continue to suffer violence. Additionally, physical punishment is still common in schools and households. Although corporal punishment is widely prohibited in schools on the African continent, use of violence still exists with some scholars arguing that its persistence in schools is because it is widely used in home environments as a means to discipline and manage behavior of children (Tafa, 2002, Morrell, 2001, Devries et al., 2013b, Muhanguzi, 2011, Leach et al., 2003, Parkes and Heslop, 2013). It is reported that in Uganda's schools there is use of violence, although prohibition of violent acts in schools was effected in 1997 (Naker, 2005, Muhanguzi, 2011). Such punishment is known to have negative effects on children. Negative outcomes of corporal punishment start from as early as 36 months of age in children (Mulvaney and Mebert, 2007). Use of corporal punishment results in low self-esteem, depression, anti-social behavior and poor educational outcomes (Morrell, 2001, Devries et al., 2013b, Murray et al., 2006).

5.3 Adolescents' coping strategies and suggestions for acceptable treatment options for mental health symptoms

Key findings for the third objective were that: i) adolescents were not aware of healthcare treatment options for mental health symptoms, and ii) the adolescents had developed various strategies to cope with their mental health symptoms.

5.3.1 Lack of awareness of available treatment for mental health symptoms

Generally, adolescents were not aware of any available treatment for their mental health symptoms and took their symptoms as normal and temporary. The only adolescent that sought treatment for sleep problems, did not know where else to go when his symptoms did not completely go away. The key reason for not seeking treatment was that the participants thought that the symptoms would go away without treatment, while others believed in self-help strategies. These findings closely relate with other research findings where people with mental disorders preferred to wait longer with no treatment, with the belief that symptoms would go away on their own (O'Loughlin et al., 2011). In this study, however, the adolescents had no awareness of their mental disorders and this could be the reason they thought of their symptoms as temporary and not serious enough to require treatment. Some research in Uganda reports that help seeking for mental health symptoms often begins with approaching community members, then consulting traditional healers and then biomedical expertise is sought after the traditional means have failed (Nsereko et al., 2011). Literature on mental literacy indicates that people in many countries around the globe lack knowledge about detecting mental disorders early, where to go for help, what to do to avoid mental disorders and self-help strategies for mild problems related to mental health (Jorm, 2012, Jorm, 2000, Kelly et al., 2006, Burns and Rapee, 2006, Ganasen et al., 2008).

5.3.2 Strategies to cope with mental health symptoms

The adolescents in the study reported using various strategies and support systems to cope with their symptoms. First, many of the adolescents took responsibility for their emotional wellbeing by seeking emotional support from peers. These friends got them out of isolation and comforted them, and the adolescents reported feeling better once peers intervened. Some adolescents felt that if they constantly got such support, their symptoms would go away. Martorell-Poveda et al. (2015) documented similar attitudes in adolescents with mental disorders who reported preferring to have control of their distress by using their own social networks and using other self-care strategies. Russell and Seeley (2009) in Uganda, reported the existence of post-test clubs, social groups, non-governmental organizations and churches that PLWHA get support from. Adolescents need encouragement to be involved in social groups to reduce isolation and participation in activities that are emotionally unhealthy. Second, a few adolescents reported less beneficial strategies for coping with their symptoms, such as isolating themselves and breaking things. When some adolescents experienced emotional disturbances, they isolated themselves and became preoccupied with thinking about their problems.

Third, a few suggestions were made regarding emotional, educational, biomedical, and financial support. As discussed in section 5.2.1, some adolescents suggested financial support and food to concentrate at school and adhere to ART, while others needed biomedical investigations to find the cause of, and solution to, their physical symptoms. Adolescents needed support to overcome stigma, cope with HIV and mental health symptoms and overcome challenges they encountered at home and school environments. Despite adolescents having no awareness of their mental disorders, they had ideas of what they felt would be beneficial to them. In this study, some adolescents only wanted to be counselled and supported by close family to overcome their distress, which is closely related to other research findings where patients with mental disorders preferred comfort from family members and other adults (Steidtmann et al., 2012, Martorell-Poveda et al., 2015). Other research also reports on the different needs of people with HIV/AIDS and how they got support. Research also documents successful interventions that have helped to keep adolescents with HIV in school longer (Baird et al., 2010, Ssewamala et al., 2009). Atwine et al. (2005) reported that interventions aiming at improving material support alone are not enough to overcome the challenges faced by HIV/AIDS orphans. Mental health interventions are required alongside material support to reduce emotional suffering and the burden of disease experienced by adolescents infected with HIV.

5.4 Implications for policy, practice and further research

This study points out issues that require urgent attention in adolescents with mental disorders and HIV in Uganda. There are a number of opportunities to address these issues at the policy and practice levels. Additionally, there remain gaps in knowledge and evidence regarding the mental health of HIV-positive adolescents and effective interventions for this vulnerable group. At the policy level, the Ministry of Health in Uganda should endeavor to move the mental health policy forward from the draft form it has been in for decades (Kigozi et al., 2010) to tackle mental health needs in HIV care (Munderi et al., 2012). Lack of policy on mental health is a form of injustice to the populations that need mental health services. Leibson et al. (2001) also reports on the high cost of health care where there is a mental disorder involved versus care without mental disorders. Low income countries are characteristic of low budgets for mental health care with smaller numbers of professionals compared to the multitude of those in need of mental health services. The levels of poverty and hopelessness also make societies more vulnerable to mental disorders (Ganasen et al., 2008, Patel et al., 2007, Lund et al., 2010). Furthermore, there should be policy provisions for young people growing up with HIV to reduce their vulnerability to mental disorders.

Various government departments could be involved in addressing this problem. Since mental health is being integrated into primary health care, the ministry of health should ensure deployment of trained mental health personnel at government health centers to promote mental health treatment and education. Mental health personnel would help raise awareness amongst fellow healthcare personnel and patients and also avail appropriate care (Ganasen et al., 2008). On the other hand, HIV care services are predominantly provided by non-governmental organizations in Uganda that require support to integrate mental health services in their work. This may include training of HIV care staff on child and adolescent mental health to enable them to screen and detect mental disorders early in their clients (Ovuga et al., 2007, Kigozi, 2007). This would then enable proper treatment and referrals.

In the education sector, the Ministry of Education should make provision for mental health literacy in schools and a curriculum on child and adolescent mental health during teacher training. Increase in mental health literacy would increase help seeking in schools. (See section 5.4.1 below for more on mental health literacy.) Teachers could identify scholars with mental health challenges and bring caregivers of adolescents on board to enable proper referral and early treatment for mental disorders. All forms of violence in schools should also be brought to an end to make schools safe for all scholars. Some research in Uganda documents successful interventions of preventing violence in schools and improving education outcomes (Devries et al., 2013a), while other research was able to make a positive change in the lives of school-going adolescents through education and financial safety nets (Ssewamala et al., 2009). Such an intervention would enable adolescents to meet some of the needs as they advance their lives into adulthood with hope of meeting their life goals. Psychosocial support to adolescents and children should not stop in HIV care, but also extend to school environments to help them overcome negative mental health outcomes with support through life challenges they experience (Cluver et al., 2012b).

Interventions for various aspects identified in this study could be conducted in society, community/school, healthcare or family settings. I will discuss the following focus areas: (i) mental health literacy, (ii) mental disorder diagnosis, effective treatment and the provision of psychosocial support.

5.4.1 Mental health literacy

Adolescents are growing up with mental disorders with no awareness about their disorders and the possible forms of treatment that may enable them to overcome their mental health symptoms. In this study, people around the adolescents seemed not to recognize their symptoms based on the adolescent reports, suggesting low mental health literacy in the community. Kelly et al. (2007) indicates that mental

health literacy improves help seeking in adolescents and their carers, thus improving mental health literacy is an important target for interventions in various contexts. In health care, health workers' mental health literacy could enable effective interventions in line with mental health needs of the populations they serve. Mental health literacy interventions for health workers to identify common mental disorders in primary health care, should be prioritized in HIV care as this is the first step to implementing effective screening for, and treatment of mental disorders (Ganasen et al., 2008).

In community, school and other settings, interventions can be designed to improve mental health literacy and help seeking for mental disorders. An article reviewing literature on mental health literacy promotion indicates that teachers should be in position to identify mental difficulties of their students and also to make sure that the care received is what is required (Whitley et al., 2013, Jorm et al., 2010). This may be made possible by including mental health literacy in the teacher training curriculum.

5.4.2 Mental disorder diagnosis, effective treatment and psychosocial support

There is a need to accurately identify and effectively treat mental disorders in HIV infected adolescents. Freeman et al. (2005) recommended that HIV care services make use of existing counselors and other health workers in providing mental health care, by given additional training and appropriate materials, and in collaboration with mental health professionals. These health workers would be in a position to treat and create awareness of the existing burden of mental disorders. Mental health interventions in HIV care will lead to further advantages such as improved ART adherence since mental disorders lead to poor adherence and poor quality of life due to disease burden (Freeman et al., 2005, Mannheimer et al., 2005). This is particularly relevant for HIV care services in limited resource settings such as Uganda. Successful strategies to implement interventions in primary health care, such as the PRIME project and others that involved the community to implement the intervention, are also reported in Uganda (Nanyonjo et al., 2012, Innocent, 2007, Lund et al., 2012). While the PRIME project focuses on mental health care, others have targeted other diseases, providing valuable lessons for mental health researchers and practitioners. For example, one study used village health teams (VHTs) to identify health needs of the community in their efforts to narrow treatment gaps in primary health care. Two VHTs from each village were trained to diagnose, treat (malaria, diarrhea and pneumonia), follow up and carry out health education to prevent diseases (Nanyonjo et al., 2012, Innocent, 2007). A similar approach has been used in Nepal, whereby community members are trained to identify people with possible mental disorders and encourage them to seek help from local clinics (Jordans et al., 2015). This kind of intervention may be useful if extended in the community for mental health literacy, mental health needs and referral of adolescents for mental

health care and management. This may help improve knowledge and help seeking for mental disorders in HIV infected adolescents both in and out of the school settings.

Mental health practice contains important interventions that are advantageous in HIV care to improve adherence to lifelong ART and cope with HIV disease. Non-pharmacological interventions support existing biomedical interventions and include cognitive behavioral therapy, motivational counseling and group therapy (Freeman et al., 2005). A number of such mental health interventions have been shown to be effective in African primary health care (Lund et al., 2012, Chibanda, 2017), however intervention is needed in settings other than healthcare facilities. A recent press release about mental health service situation at Butabika national referral mental hospital in Uganda, called for the revival of counselling in schools and religious institutions to handle some mental health problems early (Sunday Vision, December 2016). Additionally, effective interventions have been initiated in school settings (Ssewamala et al., 2009), and results from this study highlight the importance of intervening in these settings. Moreover, the mental health of the caregivers also needs to be addressed. Caregivers need support socially, emotionally and financially to reduce risks of mental health symptoms, promote their own good health in order to care for their young charges (Abaasa et al., 2008, Li et al., 2010). It is important that interventions also support caregivers through the challenges they experience in parenting these adolescents as they are often older adults and challenged with poverty (Karimli et al., 2012, Seeley et al., 1993).

Households already affected by HIV/AIDS and increased care burdens for orphans being fostered may face challenges to seek help for mental health due to poor economic status leading to continued disease burden (Karimli et al., 2012, DeLaMora et al., 2006, Ganasen et al., 2008). To contextualize this, HIV infected people in Uganda mostly depend on donor funds to access HIV treatment and hardly afford daily basic needs as documented (Bukusuba et al., 2007, Tsai et al., 2011, Tsai et al., 2012, Weiser et al., 2010). The HIV epidemic has drained communities of resourceful people, leaving many children and adolescents in poverty with some taking on the 'head of household' role (Evans, 2011). Adolescents are growing up in poverty without resources which they can fall back on when they need treatment or to plan for the future (Evans, 2011, Ssewamala et al., 2009). Adolescents growing up with HIV need support to manage life challenges that make them vulnerable to mental disorders. Economic empowerment interventions aiming at enhancing asset ownership to improve mental health risk factors should be replicated in adolescents infected with HIV and being challenged with mental disorders (Ssewamala et al., 2009).

5.5 Study limitations

There are several limitations of this study to be considered. First, was the adolescents' lack of awareness about mental disorders they were diagnosed with. This hindered in-depth narration of their EMs for mental health such as the nature of their disorders, causes and treatment seeking. A few adolescents could not relate to the vignettes. This could have been because they needed their diagnosis to be reviewed or had limited insight into mental disorders. Each child diagnosed with a mental disorder was supposed to have an appointment with a psychiatrist to confirm their mental disorder, thus they would have had some discussion regarding their symptoms with a specialist. Since mental health literacy is low in the general population in Uganda these adolescents who had not seen a specialist were not able to see their symptoms as being linked to a possible disorder. However, the adolescents were able to describe emotional problems and these data provide insight into the experiences of HIV-positive adolescents.

Second, adolescents in the urban setting were not so accessible. Their contacts were often inactive and unavailable, hence the failure to contact them during the study duration. Of those who were available, the caregivers were sometimes busy and unable to find time to come with them to the HIV clinic. This limitation highlights a vulnerable group of adolescents who either did not return for follow up, or who did not have a caregiver that could accompany them to study visits. These hard to reach adolescents may have been more vulnerable to mental disorders than those who attended the clinic. Future research could seek to actively engage this group.

Third, this was a small qualitative study recruiting participants enrolled in a larger study. Being a research participant may have affected their responses as they had had other contacts with study staff in addition to these qualitative interviews. Furthermore, the sample size was small, and data may not be representative of all HIV infected adolescents in Uganda. This small study has given an insight into the mental health EMs of HIV-infected adolescents using a small sample size that may not be representative of all adolescents with HIV and mental disorders nationwide. There is need for more qualitative studies recruiting HIV infected adolescents from different cultural backgrounds of Uganda that are representative of the different ethnicities in Uganda.

Fourth, translation of the mental health vocabulary into the local language (Luganda) and translation of participant responses into English could have affected some meaning inadvertently during translation. Future studies need to take into account to have professional translations of mental health technical language to enable solicit EMs from different cultures.

5.6 Conclusion

While this study set out to examine explanatory models in HIV infected adolescents with mental disorders to inform policy and practice, there was limited understanding of the mental disorders among the adolescent participants. HIV infected adolescents suffer a great deal of psychological distress and violence due to poor functioning with no awareness of the causes and the need to seek help. Negative life events and challenges they experience frequently make them more vulnerable to mental disorders. There is an urgent need for interventions in HIV care targeting adolescents to enable them overcome these challenges and improve their quality of life. There is also need for empowerment with knowledge about mental disorders through mental health literacy programs to improve interpersonal relationships in schools and the adolescents' home for better mental health and ability to recognize mental disorders early for help seeking. Treatment of mental disorders lead to improved wellbeing and quality of life in young people with chronic illness.

There are a number of opportunities to intervene in policy and in practice. A myriad of evidence-based interventions is reported in the literature, yet few have been tested in Uganda. Such interventions should not only be implemented at the HIV care clinic level, but also at the broader community level, including interventions in school, faith-based and civil society settings. To support such interventions, more research on EMs for mental disorders should be done across cultures in Uganda to improve accuracy in diagnosis and effective treatment provision. Further research could focus on the validation of mental health screening tools in HIV care. Interventions could target improving mental health literacy in these settings which could reduce mental health stigma and improve mental health help seeking. Healthcare interventions could address healthcare worker mental health literacy, screening, diagnosis and treatment. Additionally, psychosocial interventions supporting adolescents in HIV care, as well as their caregivers, should be considered. In addition to addressing their mental health symptoms, the importance of life challenges in the lives of HIV infected adolescents should not be neglected as it plays a big role in affecting their mental health wellbeing and future prospects. Early interventions are vital to improve the wellbeing of these adolescents to allow them to grow into healthy adults who are able to contribute to their communities.

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APPENDICES

Appendix One: Adolescent information leaflet and assent form

UNIVERSITY OF CAPE TOWN



Alan J Flisher Centre for Public Mental Health

Department of Psychiatry and Mental Health

46 Sawkins Road,

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Cape Town, South Africa

TITLE OF THE RESEARCH PROJECT: A QUALITATIVE STUDY OF EXPLANATORY MODELS OF MENTAL HEALTH AND THEIR IMPACT ON EVERY DAY LIFE IN ADOLESCENTS IN RURAL AND URBAN UGANDA

Okunonyereza ku ngeri obulwadde bw'obwonga gye bunnyonnyolwamu era n'engeri gye bukosaamu obulamu mu bavubuka okuva mu byalo ne mu kibuga mu Uganda

RESEARCHERS NAME(S): WINIFRED NALUKENGE

Akoze okunonyereza: Winifred Nalukenge

ADDRESS: MEDICAL RESEARCH COUNCIL/UVRI UNIT ON AIDS RESEARCH IN UGANDA, P.O. BOX 49, ENTEBBE.

CONTACT NUMBER: 0782330884

Okumutuukirira: 0782330884

Introduction: We are asking you to take part in a research study. The purpose of this study is to find how adolescents understand and explain emotional and behavioural problems. This study is part of a Master's study at the University of Cape Town. You qualify to take part in this study because you are an adolescent between 12 and 17 years of age. We hope to find 20 adolescents to take part in this study.

Ennyanjula: Tukasaba obeere omu kubetabye mu kunonyereza kuno. Ekigendererwa ky'okunonyereza kuno kwe kuzuula engeri abavubuka gyebategeeramu era ne bwe bannyonnyola ebizibu ebigwa mu empisa ne neyisa. Okunonyereza kuno kitundu by'okusoma

eddaala erya masita mu ttendekero lya yunivasite e Cape Town. Osaanidde okwetaba mu kunoonyereza kuno lwakuba oli muvubuka ali wakati w'emyaka 12 ne 17 egy'obukulu. Tsubiria okuyingiza abavubuka 20 mu kunoonyereza kuno.

What is this research project all about?

We want to know about the experiences of the adolescents. While adolescents grow up, some are affected by some events in their lives, while others are not affected. We would also want to find out about what you think of the things that *may make young people feel sad or worried*.

Okunoonyereza kuno kukwata kuki?

Twagala okumanya biki abavubuka byebayitamu. Abavubuka nga bakula, abamu bakosebwa embeera gye bayitamu mu bulamu bwabwe, ate nga abalala tebakosebwa. Era twandiyagadde okumanya biki by'olwooza ku nsonga eziretera abavubuka okuba abenyamivu oba abeeralikirivu.

Why have I been invited to take part in this research project?

You have been invited to participate in this study because you are an adolescent between 12 and 17 years, in the districts of Masaka and Kampala.

Lwaki mpitiddwa okwetaba mu kunoonyereza kuno?

Oyitiddwa okwetaba mu kunoonyereza kuno lwakuba oli muvubuka ali wakati w'emyaka 12 ne 17, era ng'obeera mu disitulikiti y'e Masaka oba e Kampala.

Who is doing the research?

This research is being conducted by Winifred Nalukenge who works with Medical Research Council in Masaka and Kampala.

Ani akoze okunoonyereza kuno?

Okunnoyereza kuno kukoledwa Winifred Nalukenge akola n'ekitongole kya Medical Research Council e Masaka ne Kampala.

What will happen to me in this study?

If you do take part in the study you would meet a researcher for an interview. The interview will be like a conversation, and will last for about an hour. You will be asked questions about your feelings and life experiences. These questions *may make you to feel shy or embarrassed*; you are free not to answer any questions that you are not comfortable with. You can stop the interview at any time, without having to explain why. There are no wrong or right answers. Leaving the study or not answering some of the questions will *not stop you from getting treatment* at the clinic.

The interview will take place somewhere that you feel comfortable, probably at the clinic in a private room. We would like to audio record these interviews, if you are comfortable with this. All recordings in the study *will be kept safely away from other people. No one else will see or*

know about what you have said in the interview. We will then write down all your answers and your name will not be kept with these answers. The recording will then be destroyed.

Kiki ekinantuukako mu kunoonyereza kuno?

Bw'onetaba mu kunoonyereza kuno, oja kuisinkana akola okunonyereza kuno akubuuze abibuuzo. Ebibuuzo bija uba mu ngeri ya mbooji, era bija kutwala essaawa nga emu. Oja kubuuzibwa ebibuuzo ebikwata ku newulirayo awamu ne by'oyiseemu. Ebibuuzo bino biyiza okukwasa ensanyi oba okukuswaza; oli wa ddembe obutaddamu bibuuzo by'owulira nti toli mwetegefu kuddamu. Oyinza okuyimiriza okubuuzibwa ebibuuzo obudde bwonna, awatali kunyonyola lwaki. Tewlai kyonaddemu kinaatwalibwa nit kikyamu oba kituufu. Okuva mu kunonyereza oba obutaddamu bibuuzo ebimu tekijja kusazaamu bujanjabi bw'ofuna ku ddwaliro.

Okubuuzibwa ebibuuzo kuja kukolebwa awantu w'owulirira eddembe, nga ku ddwairo mu kasenge akekusifu. Twandyagadde okukwata ebibuuzo bino ku katambi, bwoba nga tokirinaako buzibu. Amawulire gonna aganakwatibwa ku katambi mu kunoonyereza gajja ku kuumibwa abantu abalala webatatuuka. Tewali mulala ajja kulaba oba ajja kumanya byoyogeddo mu kubuuzibwa ebibuuzo. Tujja kuwandiika byonna byonaaba otugambye era erinyalyo terijja ku kuumibwa kumu n'ebyo byonnaba oyogedde. Era obutambi bujja kusiimulwa.

Can anything bad happen to me?

The researcher may ask you some very personal questions about your life. You may find it embarrassing or difficult to talk about your life experiences. This may make you feel shy or uncomfortable. If this happens, the researcher is well trained to offer immediate support for *feelings of sadness or worry* that may arise.

Nyinza okutuusibwao obulabe bwonna?

Akola okunoonyereza ayinza okukubuuza ebibuuzo ebiukwata ku bulamubwo. Oyinza okwesanga nga kino kikuswaza oba nga kizibuwala okwogera ku by'oyiseemu mu bulamu. Kino kiyinza okukusonyiwaza oba obutakuwuliza bulungi. Kino bwekinabaawo, akola okunonyereza mutendeke bulungi okusobola okukkanya mu ebyo ebikunakuwaza oba okukweralikiriza ebiyinza okugwawo.

Can anything good happen to me?

You may find this an opportunity to talk about your experiences of growing up to be a good thing. Results of this study may help other young adolescents cope with *difficult* situations that they face. In case you want to talk to a counsellor or clinician, they will be available after the interview.

Kirungi ki ekiyinza okuva mu kwetaba kwange mu kunoonyereza?

Guno guyinza okuba nga mukisa mulungi okukusobozesa okwogera ku byewayitamu ng'okula. Ebinaava mu kunoonyereza kuno biyinza okuyamba abavubuka abalala okusoboa okugumira embeera enzibu zebayitamu. Singa oba oyagala okwogera n'omulungamy oba omusawo, baja kubaawo oluvanyuma lwokubuuzibwa ebibuuzo.

We will give you money for transport and for your time spent in the interview. No other money will be paid to anyone for being in this study.

Tujja kukuwa sente zentambula era n’olwobuddebwo mu kubuuzibwa ebibuuzo. Tewali sente ndala zijja kuwebwa muntu yenna olw’okwetaba mu kunoonyereza kuno.

Will anyone know I am in the study?

To keep what you say secret and for other people not to be able to identify that you are the one who said it, we are not going to use your names, but special numbers will be given in the study. Information that you share with us will only be seen by the researcher and supervisors. All information about you will be stored under key and lock and only accessed by the researcher. We will use the information for study purposes; *some of the things we will discuss will be talked about at some meetings and will also be written in some books about health.* Your name and contact details will not be in these talks and reports.

Waliwo anamanya nti netabye mu kunoonyereza kuno?

Okukuuma by’otugambye nga byakyama era n’abantu abalala obutasobola kumanya nti gwe eyabyogedde, tetugenda kukozeza mannya gonna, okujjako enaamba enakuwebwa mu kunoonyereza kuno. Amawulire gonatuwa gajja kulabwa anoonyereza yeka awamu n’abamukulira mu kunoonyereza kuno. Amawulire gona agakukwatako gajja kukuumbwa awagalwa era nga akoze okunoonyereza yekka yajja okuba nga agalabako. Amawulire gajja kukozezebwa ku kunoonyereza kwokka; ebimu ku bye tunaakubaganyaako ebirowoozo bijja kwogerwako mu nkungaana era bijja kuwandiikibwa ne mu bitabo by’obulamu. Amannyago ne ebikukwatako tebijja kwogerwako mu nkungaana zino ne alipoota.

The only exception to ***what you say remaining secret*** is if you tell us something that makes us worried about you or another young person’s safety, such as physical harm or neglect. If we have to tell someone else, we will talk to you about it first.

Ensonga eyinza obutakuumisa byotugambye nga bya kyama; singa otubuulira ensonga yonna nekitweralikiriza eri gwe oba muto munno omulala yenna ku bulamu bwabwe nga okutulugunyizibwa oba okulagajjalibwa. Bwetuba nga tulina okubuulira omuntu omulala yenna, tujja kusooka tukikugambeko.



Who to contact with questions:

If you have any questions about the study please contact the researcher, Winifred Nalukenge, on mobile no. 0782330884 or the research supervisor Dr. Claire van der Westhuizen from the University of Cape Town on email: clairevdwest@gmail.com.

Ani gwenkubira nga nina ebibuuzo?

Bw’oba olina ekibuuzo kyonna ku kunoonyereza kuno, oyinza okutuukirira akoze okunoonyereza kuno, Winifred Nalukenge ku ssimu 0782330884 oba Dr. Eugene Kinyanda ku ssimu 0788461950 okuva mu kitongole kya Medical Research Council/UVRI e Entebbe.

If you are unhappy or have **anything that worries you about being in** the study, please feel free to contact Shuretta Thomas at the Faculty of Health Sciences Human Research Ethics Committee by Telephone: (021) 406 6492; fax: (021) 406 6411; or email: Shuretta.Thomas@uct.ac.za.

Bwoba nga toli musanyufu oba nga waliwo ensonga yonna ekwerarikiriza mu kunoonyereza kuno, oli wa ddembe okukubira Shuretta Thomas ku ttendekero ly'eby'obulamu na amateeka agogobererwa ku ssimu (021) 406 6492; fax: (021) 406 6411 oba ku Shuretta.Thomas@uct.ac.za. Oba Dr. Eugene Kinyanda ku ssimu: 0788461950 mu kitongole kya MRC Entebbe.

What if I do not want to do this?

You are free to decide whether to take part or not, even if your caregiver agrees that you should participate. If you decide to take part you can still leave the study any time without **being blamed in any way**. You can choose not to answer certain questions and still remain in the study. If you decide to take part you will be given this information sheet to keep and we will ask you to sign an assent and consent form with your caregiver.

Ate bwemba saagala kwetabamu?

Oli wa ddembe okusalawo okwetabamu oba obutetabaamu, akulabirira ne bwasalawo nti olina okwetabamu. Bw'osalawo okwetabamu, ojja kuba okyali wa ddembe okuva mu kunoonyereza obudde bwonna awatali kuvunaanibwa mu ngeri yonna. Oyinza okusalawo obutaddamu bibuuzo ebimu naye era n'osigala mu kunoonyereza. Bw'osalawo okwetaba mu kunoonyereza kuno, ojja kuwebwa olupapula luno okuli amawulire olutereke era tujja ku kusaba okuteeka omukono ku lupapula olulala awamu n'akulabirira okulaga nti mukkirizza.

Do you understand this research and are you willing to take part in it?

Okunoonyereza kuno okutegedde era oli mwetegefu okukwetabamu?

Yee

Nedda

Has the researcher answered all your questions?

Akola okunoonyereza azzeemu ebibuuzo byo byonna?

Yee

Nedda

Do you understand that you can STOP being in the study at any time?

Okitegedde nti osobola okvu mu kunoonyereza kuno obudde bwonna?

Yee

Nedda

Signature of Child

Date

Omukono gw'omuvubuka

Ennaku z'omwezi

Appendix Two: Caregiver information leaflet and consent form
UNIVERSITY OF CAPE TOWN



Alan J Flisher Centre for Public Mental Health
Department of Psychiatry and Mental Health

46 Sawkins Road,
Rondebosch, 7700

Cape Town, South Africa

TITLE OF THE RESEARCH PROJECT: A QUALITATIVE STUDY OF EXPLANATORY MODELS OF MENTAL HEALTH AND THEIR IMPACT ON EVERY DAY LIFE IN ADOLESCENTS IN RURAL AND URBAN UGANDA.

Omutwe ogunoonyerezebwako: okunoonyereza mu bulambulukufu engeri abavubuka abalina akawuka gye bannyonyolamu obikwata ku bulamu bw'obwongo okuva mu bitundu bye kibuga ne byalo mu Uganda.

RESEARCHERS NAME(S): WINIFRED NALUKENGE

Akoze okunoonyereza: Winifred Nalukenge

ADDRESS: MEDICAL RESEARCH COUNCIL/UVRI UNIT ON AIDS RESEARCH IN UGANDA, P.O. BOX 49, ENTEBBE.

Ava: mu MEDICAL RESEARCH COUNCIL/UVRI UNIT ON AIDS RESEARCH IN UGANDA, P.O. BOX 49, ENTEBBE.

CONTACT NUMBER: 0782330884

Essimu: 0782330884

Introduction: We are asking your adolescent child to take part in a research study. The purpose of this study is to find how adolescents understand and explain emotional and behavioral problems. This study is part of a Master's study at the University of Cape Town. Your adolescent child qualifies to take part in this study if she/he is 12-17 years of age. We hope to find 24 adolescents to part take in this study.

Enyanjula: tusaba omwana wo oyo avubuse okwetaba mu kunoonyereza. Ekgendererwa ky'okunoonyereza kwe kuzuula engeri abavubuka gye bannyonyolamu ebikwata ku buzibu obuli mu ngeri gyebeyisaamu, gye balaga essanyu awamu n' okunakuwala. Okunoonyereza kuno kukoledwa nga ekitundu ku musomo gwa Masters ku University ye Cape Town. Omwanawo avubuse alina ebisaanyizo okwetaba mu kunoonyereza kuno singa aba aweza emyaka 12-17 egy'obukulu. Tusubira okufuna abavubuka 24 betabe mu kunoonyereza kuno.

What is this research project all about?

We want to know about the experiences of the adolescents. While adolescents grow up, some are affected by some events in their lives, while others are not affected. We would also want to find out about what they think of the things that challenge emotional well-being.

Okunoonyereza kuno kukwata kuki?

Twagala okumanya abaana abavubuse bye bayiseemu. Abaana nga bavubuka, abamu batawanyizibwa embeera zebayitamu ate abalala tebatawanyizibwa. Era twandiyagadde okumanya biki ebitaataganya/ebisomooza endowozaa zabwe.

Why has your child been invited to take part in this research project?

Your adolescent child has been invited to participate in the study because he/she is between 12-17 years of age in the districts of Masaka and Kampala.

Lwaki omwanawo avubuse ayitiddwa okwetaba mu kunonyereza kuno?

Omwanawo avubuse ayitiddwa okwetaba mu kunoonyereza kuno olwensonga nti ali wakati we myaka 12-17 egy'obukulu era ng'ava mu disitulikiti ye Masaka oba e Kampala.

Who is doing the research?

This research is being conducted done by Winifred Nalukenge who works with Medical Research Council in Masaka and Kampala.

Ani okoze okunoonyereza?

Okunoonyereza kuno kukoledwa Winifred Nalukenge akolera mu kitongole kya Medical Research Council e Masaka ne Kampala.

What will happen to your adolescent child in this study?

If you agree for your adolescent child to take part in the study they would meet a researcher for an interview. The interview will be like a conversation, and will last for about an hour. The adolescent will be asked questions about his/her his feelings and life experiences. These questions may be sensitive to your adolescent child; they will be free not to answer any questions that they are not comfortable with. There are no wrong or right answers. Leaving the study or not answering some questions will not affect the care the adolescent receives from the clinic. The interview will take place somewhere that you feel comfortable, probably at the clinic in a private room. We would like to audio record these interviews, if you are comfortable with this. All recordings in the study will be kept confidential. We will then write down your child's responses to the questions and their names will not be kept with these answers. The recording will then be destroyed.

Kiki ekinaatuuka ku mwanawo avubuse mu kunoonyereza kuno?

Singa okiriza omwanawo avubuse okwetaba mu kunoonyereza kuno, ajja kuisinkana okola okunonyereza amubuze ebibuuzo. Okubuuzibwa ebibuuzo kujja kuba mu ngeri ya mbooji, era nga kujja kutwala essaawa nga emu. Omuvubuka ajja kubuuzibwa ebibuuzo ebikwata ku ngeri gya alagamu essanyu awamu ne nnaku era ne byayiseemu mu bulamu. Ebibuuzo bino biyinja okwesiwaza omuvubukawo; ajja kuba wa ddembe obutaanukula bibuuzo bya wulira nga tayagal kwanukula. Tewali kiddibwamu kyetutwala nti kye kituufu oba kikyamu. Okuva mu kunoonyereza oba obutaddamu bibuuzo tekijja kukosa bujanjabi omuvubuka oyo bwafuna okuva ku ddwaliro.

Okubuuzibwa ebibuuzo kujja kukolebwa wanawulira eddembe gamba nga ku ddwaliro mukasenge awatali bantu balala. Twandyagadde okukwata ebibuuzo bino ku katambi, bwoba nga kino tokirinaako buzibu. Ebina kwatibw ku katambi tujja ku bikuuma nga bya kyama. Oluvanyuma, tujja kuwandiika omuvubuka by'anaaba azeemu era erinnya lye terijja kukuumibwa wamu nabyo. Awo akatambi kasiimulwe.

Can anything bad happen to my adolescent child if they participate?

The researcher may ask your adolescent child some very personal questions about his/her life. Your child may find it embarrassing or difficult to talk about his/her life experiences. This may make him feel shy or uncomfortable. If this happens, the researcher is well trained to offer immediate support for emotional issues that may arise.

Waliwo ekibi kyonna ekiyinja okutuuka ku mwana avubuse singa yetaba mu kunoonyereza? Anoonnyereza ayinza okubuuzo omuvubukawo ebibuuzo nga bya munda ddala kubulamubwe. Omwanawo ayinza okwesanga nga kisonyiwaza oba nga kizibu okwogera ku bayiseemu mu bulamubwe. Kino kiyinza okumukwasa ensanyi oba obutamuwuliza bulungi. Kino bwekinabaawo, anoonnyereza mutendeke bulungi okuzza embeera yonna eba etuseewo mu nteeko.

Can anything good happen to my child?

This may be an opportunity for your adolescent child to talk about his/her experiences of growing up to be a good thing. Results of this study may help other young adolescents cope with challenging situations that they face. In case your child wants to talk to a counsellor or clinician, they will be available after the interview.

Waliwo ekirungi kyonna ekiyinja okubaawo?

Guno guyinza okuba omukisa eri omuvubukawo okwogera okwogera ku byayiseemu nga akula. Ebinaava mu kunoonyereza kuno biyinja okuyamba abavubuka abalala okusobola okuyita mu mbeera esomooza gyebayitamu. Singa omuvubukawo yetaaga okwogera n'omulungamya oba omusawo, bajja kubaawo oluvanyuma lw'okubuuzibwa ebibuuzo.

Travel expenses and time spent during the interview will be reimbursed. There will be no other compensation for participation in this study.

Sente z'entambula n'obudde n'obudde bw'omazze mu kubuuzibwa bijja kukuddizibwa. Tewaja kubaawo kusalwa kulala kwonna mu kunoonyereza kuno.

Will anyone know my adolescent child is participating in the study?

For the sake of confidentiality, we are not going to use your names, but special numbers will be given in the study. Information that you share with us will only be seen by the researcher and supervisors. All information about your child will be stored under key and lock and only accessed by the researcher. We will use the information for study purposes and some study results may be presented at conferences and also published in journals. The names of your adolescent child will not be in these talks and reports.

Waliwo omulala ayinza okumanya nti omuvubuka wange yetabye mu kunoonyereza?

Okusobola okukuuma ebinaava mu kubuuzibwa nga bya kyama, amanya tegajja kukozebwa, okujjako enaamba eyejnauwol ejja okuwebwa mu kunnoonyereza kuno. Amawulire gonna ganatuwa gajja kulabibwako anoonyereza awamu nabalondoola engeri gyakolamu okunoonyereza. Amawulire gonna agakwata ku mwanawo gajja kuterekebwa awagalwa n'ekisumuluzo nga anoonyereza yekka yaggulawo. Amawulire gajja kukozebwa ku nsonga zakunoonyereza era ne bimu biyinda okwogerwako mu nkungaana era n'okuwandiikibwa mu bitabo. Amannya g'omuvubukawo tegajja kw'ogerwako mu nkungaana ne mu lipoota.

The only exception to the information of your child being kept confidential is if he/she tells us something that makes us worried about him/her or another young person's safety, such as physical harm or neglect. If we have to tell someone else, we will talk to you and your child about it first.

Ekiyinda ekubaawo amawulire negatakuumibwa nga kyama, singa tumanya ensonga etweralikiiriza ku bulamu bw'omuvubuka yenna nga okutuusibwako obulabe oba okulagajjalirwa. Bwtuba nga tulina okubuulirako omuntu omulala yenna, tujja kusooka kwogerako nawe n'omuvubukawo.



Who to Contact with Questions:

If you have any questions about the study please contact the researcher, Winifred Nalukenge, on mobile no. 0782330884 or the research supervisor Dr. Claire van der Westhuizen from the University of Cape Town on email: clairevdwest@gmail.com.

Ani gwentuukirira nga nina ebibuuzo?

Singa olina ebibuuzo byonna ebikwata ku kunoonyereza, tuukirira anoonyereza, Winifred Nalukenge, ku ssimu 0782330884 oba awabula ku ngeri okunoonyereza gye kukolebwamu Dr. Claire Westhuizen okuva mu ttendekero lya University ye Cape Town ku: clairevdwest@gmail.com bw'oba toli mumativu oba ng'olina ensonga yonna gye wemulugunyaako, tuukulira Shuretta Thomas ku Faculty ya Health Sciences Human Research Ethics Committee ku ssimu (021) 406 6492; fax: (021) 406 6411; oba ku Shurett.Thomas@uct.ac.za oba kubira Dr. Eugene Kinyanda ku ssimu 0788461950 okuva mu kitongole kya Medical Research Council Entebbe.

If you are unhappy or have concerns about participating in the study, please feel free to contact Shuretta Thomas at the Faculty of Health Sciences Human Research Ethics Committee by Telephone: (021) 406 6492; fax: (021) 406 6411; or email: (Shurett.Thomas@uct.ac.za).

What if I do not want my child to do this?

You are free to decide whether your child takes part or not. If you decide that your child takes part he/she can still withdraw from the study any time without any negative consequences. He/she can choose not to answer certain questions and still remain in the study. If you decide for your child to take part you will be given this information sheet to keep and be asked to sign consent form and an assent form with the adolescent.

Ate bwemba nga saagala mwana wange yetabe mu kunoonyereza kuno?

Oli wa ddembe okusalawo oba omwanwo yetaba mu kunoonyereza kuno oba nedda. Bw'osalawo nti omwanawo yetabemu, era asigala nga wa ddembe okuva mu kunoonyereza obudde bwonna awatali buzibu bwonna. Ayinza okusalawo okusalawo obutayanukula bibuuzo era naasigala mu kunoonyereza. Bw'osalawo omwanawo yetabe mu kunoonyereza uno, ojja kuwebwa olupapula lw'amawulire luno olutereke era oteekeko omukono era n'omwanawo naye ateekeko omukono.

DECLARATION BY CAREGIVER

By signing below, I agree for my adolescent child to take part in a research study entitled: a qualitative study of explanatory models of mental health in adolescents in rural and urban Uganda.

Nteddeko omukono, nze nzikiriza omwana wange omuvubuka wange okwetaba mu kunoonyereza okuyitiddwa: okunoonyereza ku ngeri abavubuka gyebannyonyolamu obulwadde bwe mitwe mu byalo ne bibuga bye Uganda.

I declare that:

Njatula nti:

- I have read the attached information leaflet and it is written in a language with which I am fluent and comfortable.
- **Nsomye amawulire agakwata ku kunoonyereza era gawandiikiddwa lwentegeera obulungi.**
- I have had a chance to ask questions and all my questions have been adequately answered.
- **Nfunye omukisa okubuuza ebibuuzo era ebibuuzo byange byonna biddiddwamu bulungi ddala.**
- I understand that my child taking part in this study is **voluntary** and I have not been pressurised to make the decision.

- **Ntegedde nti okwetaba kw’omwana wange mu kunoonyereza kuno kwakyeyagalire era sikakiddwa kukola kusalawo kuno.**
- My adolescent child may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- **Omwana wange ono asobola okuva mu kunoonyereza obudde bwonna era nga tajja kutanzibwa oba kujolongwa mu ngeri yonna.**
- My adolescent child may be asked to leave the study before it has finished, if the researcher feels it is in my child’s best interests, or if he/she does not follow the study plan, as agreed to.
- **Omwana wange asobola okuva mu kunoonyereza nga tekunaggwa, singa anoonyereza awulira nti kiyamba mwana wange oba nga omwana wange tagoberedde nteekateeka akunoonyereza nga bweyakiriziganyizibwako.**
- All issues related to privacy and the confidentiality and use of the information my child will provide have been explained to our satisfaction.
- **Ensonga zonna ezikwata ku kukuuma ebyama n’enkokesa y’amawulire omwana wange ganawaayo ennyonyoddwa netumatira.**

Signed at (place) on (date) 201.

Omukono guterreddwako mu kifo ennaku z’omwezi nga 2016

.....

Signature of Caregiver

Omukono gw’alabirira omwana

SIGNATURE OF INVESTIGATOR

Omukono gw’akoze okunoonyereza

I declare that I explained the information given in this document to _____ [name of the participant] [He/she] was encouraged and given ample time to ask me any questions. This conversation was conducted in [Luganda] and no translator was used.

Nkakasa nti nyinnyonyodde amawulire agawereddwa mu kiwandiiko kino eri Yasabiddwa era nawebwa obudde obumala okubuuza ebibuuzo. Ebibuuzo bino bya buuziddwa mu Luganda era tewali muvunuzi yakozeseddwa.

Signature of Investigator

Date

Omukono g'wakoze okunoonyereza

Ennaku z'omwezi

Appendix Three: In-depth interview schedule

Thank you for accepting to participate in this study. My name is Winifred Nalukenge, I would like to request you to answer some questions and also to have them recorded onto a digital recorder. What you answer is going to be very useful in this study, and it will be kept confidential. Your name will not be used anywhere. An identifier will be used instead of your name. I request that we record this interview so that I can listen to it later and have it written out to enable analysis. After I have done this, I will destroy the recording and I will not use your name on the typed pages. You are free to not answer the questions that you do not feel comfortable about.

A. Socio-demographics

1. How old are you?
2. What is your religion?
3. Do you go to school? If yes, in which class are you?
4. Who are you currently staying with?
 - a) If not staying with parents, how did it happen you are not staying with them?

B. HIV issues

- a) How did you learn about your HIV status? (Probe: at what age did you first get to know about your HIV status?)
- b) Do you know anyone else in your family having HIV? If yes, how did you get to know about it?
- c) Are you on any HIV treatment? If yes, tell me about your experience with the treatment.

Probes:

- i. How has ART helped you?
- ii. What challenges have you faced while on ART?
- iii. Have you faced any hardships with ART? If yes, tell me about them.

C. Mental health

Introduce a vignette related to the adolescent's mental disorder diagnosis and encourage them to talk about their own emotional experiences using the questions below.

- a) What do you think is happening in the story I have just shared with you?

- b) Do any of the things happening in the story remind you of your own experiences? If yes, tell me about your experiences (if participant does not find any symptom that is related to his/her own experience, ask them if they recall what they talked about with the doctor to get them talk about their experiences). (Note down the words they use to describe their “symptoms”, and use these words for the rest of the interview)
- c) How did it start?
- d) What do you think caused your experiences?
- e) Do you think the problem in any way indicates that it is an illness? What is it called?
- f) Why do you think it started when it did?

Probe: Was there any big change or problem in your life at that time or just before?

- g) What did you do when you realized you were having the problem?
- h) How do/did people in your family/community react to the problem?
- i) What do you fear most about having these feelings?
- j) What are the main problems that your experience causes for you? What makes it better? What makes it worse?
- k) What kind of treatment or help would you like to receive?

Probes: where do you think the treatment/help can be found? Do you think anyone would help you? Do you think anyone at home or school would help you? How would they help you with the feelings you experience?

- l) What would you like to be different after getting help?
- m) Tell me about the things that make you unhappy, sad, stressed or worried. Probes:
 - i) Tell me about your life at school
 - ii) Tell me about your home environment.
 - iii) Tell me about your life at home?
 - iii) Do you have any problem that is a result of you having HIV?

NB: for the responses in i, ii, iii above, also ask:

- a) How did that make you feel?
 - b) What did you do when you felt like that?
 - i. What made you feel better?
 - ii. What made you feel worse?
- D. Is there anything else you find important that we have not talked about?

Appendix Four: Vignettes

Boys' vignettes

Depression

John is a 12-year-old boy who was born with HIV/AIDS. Both his parents are alive but sick most of the time. Because his parents are sick most of the time they cannot work and hence the family is poor. They can only afford to have one meal a day and during the school terms he is frequently sent home for lack of school fees. The last six months have been particularly difficult for him, he has been sick most of the time, he has been feeling weak and as a result his school performance has been poor. Three weeks ago began feeling sad all the time, crying over small things. He feels he has no appetite, has poor sleep and wishes he was dead.

John mulenzi wa myaka 12 era yazalibwa n'akawua ka siliimu. Bakadde be bombi balamu naye emirundi egisinga baba balwadde. Olwensonga nti bakadde be babab balwadde ebbanga lyonna, tebasobola kukola era y'ensonga lwaki amaka gabwe maavu. Kyebasobola kwe kulya omulundi gumu buli lunnaku era mu budde bw'essomero, John azzibwa awaka olw'obutaba na bisale bya ssomero. Emyezi omukaaga egiyise gibadde mizibu gyali, abadde mulwadde obudde obusinga, abadde awulira nga mugonvu era ekyavaamu naba nga akola bubi ku ssomero. Yatandika okuwulira nga ssi musanyufu obudde obusinga, nga n'obuntu obutono bu mukaabya. Awulira nga tayagala kulya, teyebaka bulungi, era yegomba nti singa oba afa.

Anxiety

Tito is a 17-year-old boy living with HIV/AIDS. He joined secondary school and reports increasing stress. He has been performing well in school but since he joined secondary, it has not been easy for him. His grades are going low. He is afraid of asking questions in class with fear that he might ask something 'stupid' and get laughed at. He avoids meeting with his class teachers and other school staff. He experiences difficulty when there are discussions because he cannot easily hide unlike during classroom time. His mouth dries up and his heart pumps faster when he thinks about asking any questions. He now keeps more to himself, and is feeling unhappy. He has also started missing classes.

Tito mulenzi wa myaka 17 era alina akawuka ka siliimu. Yatandika okusoma mu siniya era agamba nti Abadde akola bulungi ku ssomero naye okuva lwe yagenda mu siniya, tebibadde byangu gyali. Emiwendo gyafuna gyeyongera okukka. Atywa okubuuza ebibuuza mu kibiina nti oba oluusi yalibuuza ekintu eky'obusiru nebamusekerera. Yewala okusinkana abasomesa bekibiina kye awamu n'abasomesa abalala. Afuna obuzibu bwe wabaayo okukubaganya ebirowoozo kuba awo aba tasobola kwekweka nga bwe guba mu budde bwe kibiina. Kati abeera yeka obudde obusinga, era awulira nga ssi musanyufu. Era kati atandise okwewala okugenda mu kibiina.

Attention deficit hyperactivity disorder

Job is a 13-year-old boy who despite being HIV positive generally grew up well. Job finds it hard to sit still and is often in trouble with people who say he doesn't listen well. His teacher at school is often frustrated with him for making careless mistakes and he is often told off for not concentrating during lessons. Even at home, his aunt shouts at him for not finishing things she asked him to do.

Job mulenzi wa myaka 13 nga newankubadde alina akawuka akaleeta siliimu, yakuzibwa bulungi ddala. Job alina obuzibu nti tasobola kutuula wamu era afuna obuzibu n’abantu abalala abagamba nti tawuliriza bulungi. Omusomesa we mu kibiina taba mu sanyufu naye olw’okukola ensobi eziteetagisa era batera okumukambuwalira olw’obutasaayo mwoyo mu kibiina. Ne bwaba awaka, senga we amubogolera olw’obutamaliriza mirimu giba gimuwereeddwa okukola.

Girls’ vignettes

Depression

Joana is a 12 year old girl who was born with HIV/AIDS. Both her parents are alive but sick most of the time. Because her parents are sick most of the time they cannot work and hence the family is poor. They can only afford to have one meal a day and during the school terms she is frequently sent home for lack of school fees. The last six months have been particularly difficult for her, she has been sick most of the time, she has been feeling weak and as a result her school performance has been poor. Three weeks ago she began feeling sad all the time, crying over small things. She feels she has no appetite, has poor sleep and wishes she was dead.

Joana muwala wa myaka 12 era yazalibwa n’akawua ka siliimu. Bakadde be bombi balamu naye emirundi egisinga baba balwadde. Olwensonga nti bakadde be babab balwadde ebbanga lyonna, tebasobola kukola era y’ensonga lwaki amaka gabwe maavu. Kyebasobola kwe kulya omulundi gumu buli lunnaku era mu budde bw’essomero, John azzibwa awaka olw’obutaba na bisale bya ssomero. Emyezi omukaaga egiyise gibadde mizibu gyali, abadde mulwadde obudde obusinga, abadde awulira nga mugonvu era ekyavaamu naba nga akola bubi ku ssomero. Yatandika okuwulira nga ssi musanyufu obudde obusinga, nga n’obuntu obutono bu mukaabya. Awulira nga tayagala kulya, teyebaka bulungi, era yegomba nti singa oba afa.

Anxiety

Tendo is a 17 year old and is living with HIV/AIDS. She joined secondary school and reports increasing stress. She has been performing well in school but since she joined secondary, it has not been easy for her. Her grades are going low. She is afraid of asking questions in class with fear that she might ask something ‘stupid’ and get laughed at. She avoids meeting with his class teachers and other school staff. She experiences difficulty when there are discussions because she cannot easily hide unlike during classroom time. Her mouth dries up and her heart pumps faster when she thinks about asking any questions. She now keeps more to herself, and is feeling unhappy. She has also started missing classes.

Tendo muwala wa myaka 17 era alina akawuka ka siliimu. Yatandika okusoma mu siniya era agamba nti abadde akola bulungi ku ssomero naye okuva lwe yagenda mu siniya, tebibadde byangu gyali. Emiwendo gyafuna gyeyongera okukka. Atywa okubuuza ebibuuzo mu kibiina nti oba oluusi yalibuuzo ekintu eky’obusiru nebamusekerera. Yewala okusinkana abasomesa bekibiina kye awamu n’abasomesa abalala. Afuna obuzibu bwe wabaayo okukubaganya ebirowoozo kuba awo aba tasobola kwekweka nga bwe guba mu budde bwe kibiina. Kati abeera yeka obudde obusinga, era awulira nga ssi musanyufu. Era kati atandise okwewala okugenda mu kibiina.

Attention deficit hyperactivity disorder

Jane is a 13-year-old girl who despite being HIV positive generally grew up well. Jane finds it hard to sit still and is often in trouble with people who say she doesn't listen well. Her teacher at school is often frustrated with her for making careless mistakes and she is often told off for not concentrating during lessons. Even at home, her aunt shouts at her for not finishing things she asked Jane to do.

Jane muwala wa myaka 13 nga newankubadde alina akawuka akaleeta siliimu, yakuzibwa bulungi ddala. Jane alina obuzibu nti tasobola kutuula wamu era afuna obuzibu n'abantu abalala abagamba nti tawuliriza bulungi. Omusomesa we mu kibiina taba mu sanyufu naye olw'okukola ensobi eziteetagisa era batera okumukambuwalira olw'obutasaayo mwoyo mu kibiina. Ne bwaba awaka, senga we amubogolera olw'obutamaliriza mirimu giba gimuwereddwa okukola.