COMMON MENTAL DISORDERS AMONG ADOLESCENTS ACCESSING HIV TREATMENT IN CAPE TOWN, SOUTH AFRICA

By

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Declaration

I, *Bulelwa Mtukushe* hereby declare that this thesis is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being or is to be submitted for another degree in this or any other university.

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Abstract

Background: At the present time, data on the prevalence of common mental disorders (CMD) among adolescents living with HIV (ALHIV) in South Africa (SA) is limited. Studies that exist focus mainly on HIV-infected adults with mental health problems besides a few studies investigating depression and anxiety in children and adolescents living in SA. Research on the mental health of this vulnerable population remains very limited. Therefore, this study aims to address this gap by assessing the prevalence of CMD among adolescents living with HIV in SA; and determining the factors associated with CMD among this vulnerable population.

Specific objectives: Specific objectives included, assessing the CMD among adolescents accessing ARV treatment; and determining factors associated with CMD among adolescents accessing HIV treatment.

Methods: 121 Participants were recruited into the study through convenience sampling and interviewed. To be included in the study, participants had to be 10 to 19 years old; have knowledge of their own HIV-positive status; and presently on HIV treatment. Participants over 18 years were excluded if they did not provide informed consent and those under 18 were excluded if parent consent or adolescent assent was not obtained. Interviews with participants were conducted by study research assistants using a survey questionnaire which included the following mental health measures; Beck Depression Inventory for youth (BDI-Y), Beck Anxiety Inventory for youth (BAI-Y). Data collection for the study took place at two HIV treatment clinics in Cape Town, Groote Schuur hospital and Kuyasa clinic. Two logistic regression models were developed. Unadjusted and adjusted associations between socio-demographics, SES, food insecurity, alcohol use, years child known status and the presence of anxiety and depression were explored through logistic regression. Age, gender and variables that were significant in the unadjusted associations were included in the adjusted logistical regression models. Significance was set at $p<0.05$.

Results: Four main findings emerged from the current study: 13.2% of participants were at risk for anxiety and 13.2% were at risk for depression; 6.6% participants were at risk for both anxiety and depression; the only variable associated with anxiety was socio-economic status and this was only significant in the unadjusted model; and the only variable associated with

depression was highest level of schooling completed (i.e. currently in high school/completed high school) and this was significant in both unadjusted and adjusted models. Overall, adolescents with a higher educational level were less likely to develop depressive symptoms (adjusted model: OR=0.10, 95% CI 0.02-0.68).

Conclusion: The present study assessed the prevalence of CMD, including determining the factors associated with CMD among adolescents accessing HIV treatment in Cape Town. Findings revealed that participants were at risk for anxiety, depression and comorbid anxiety and depression. Only highest level of schooling completed was found to be a protective factor against depression for this vulnerable population. Based on these findings, considerations for improving mental health outcomes for this population should include, screening for mental health conditions in ARV clinics, early identification and treatment of mental health problems, and evidence-based mental health counselling.

List of abbreviations

CMD: common mental disorders

HIV: human immunodeficiency virus 1

PLHIV: people living with HIV

ALHIV: adolescents living with HIV

PMCTC: prevention of mother to child transmission

HIC: high income countries

LMIC: low-and-middle income countries

RLC: resource-limited communities

SSA: Sub-Saharan Africa

SA: South Africa

ART: anti-retroviral therapy

ARV: anti-retroviral

PHIV: Perinatal HIV

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CHAPTER ONE : INTRODUCTION

The Human Immunodeficiency Virus-1 (HIV) epidemic has emerged as a major global public health issue. It has developed into one of many other leading causes of mortality and burden globally in the past few years (Ortblad, Lozano, & Murray, 2013). In 2019, an estimated 38 million people globally were infected with HIV (UNAIDS, 2020). Sub-Saharan Africa (SSA) remains the worst affected and research suggests that the majority of people (25.7 million) living with HIV reside in this region which forms part of low-and-middle-income countries (LMICs) (WHO, 2020). HIV affects people globally, across all ages, including adolescents.

Previous research shows that HIV is highly prevalent among adolescents. An estimated 21 million adolescents (age 10-19 years) were living with HIV in 2016; as well as 770 000 younger adolescents between the ages of 10-14 years old, and 1 million older adolescents in the age range of 15-19 years old. Approximately, 84% of adolescents were living in SSA (Slogrove et al., 2018). Additionally, of the adolescents living with HIV (ALHIV), some were either peri-natally infected, meaning they acquired HIV around the time of birth or through breastfeeding, or horizontally infected.

South Africa (SA) has made exceptional progress in the fight against HIV for ALHIV. This is noticeable in the efforts to eliminate mother to child transmission through interventions like prevention of transmission between mother and child, also known as Prevention of Mother To Child Transmission (PMTCT) which has substantially reduced the number of children born with HIV (Doherty, Chopra, Nsibande, & Mngoma, 2009). Adolescent access to anti-retroviral therapy (ART) is also another great milestone in the treatment and management of HIV in SA, and it has significantly improved the quality of life of ALHIV (Desmonde et al., 2018). As a result, children born with HIV are growing into adolescence in larger numbers, more especially in LMICs (Woollett, Cluver, Bandeira, & Brahmbhatt, 2017).

Although access to ART among this population can be viewed as a success, adherence to ART continues to be a challenge among ALHIV. For example, findings from a systematic review and meta-analysis of patient reporting barriers to adherence to ART revealed that forgetfulness, away from home, and change to daily routine were found as risk factors of non-adherence by ALHIV (Shubber et al., 2016). Another systematic review found that caregiver relationships, adherence strategies, child beliefs about medication were identified as

significant risk factors impacting on adherence (Hudelson & Cluver, 2015). ALHIV are not only faced with adherence challenges but mental health problems which are prevalent in this vulnerable population may contribute to poor adherence.

A few studies have investigated the prevalence of common mental disorders (CMD) among ALHIV. A systematic review by (Vreeman, McCoy, & Lee, 2017) found that the majority of these studies have been conducted in high income countries (HIC) and very few studies from LMICs. The review revealed that ALHIV in HIC generally have a lot of mental health challenges. Moreover, CMD such as depression and anxiety are highly prevalent among perinatally infected adolescents (PHIV) in HIC. For example, the prevalence rates of 24% for anxiety 25% for depression were reported (Vreeman et al., 2017)

Although there is limited evidence on the prevalence of CMD among ALHIV in LMICs, research in countries like Kenya and SA have investigated the mental health problems of ALHIV. For example, a cross-sectional study conducted in Kenya found that CMD that are most prevalent among ALHIV include major depression and anxiety disorders (Kamau, Kuria, Mathai, Atwoli, & Kangethe, 2012). Further, Oppositional Defiant Disorder (ODD), Attention Deficit Hyperactive Disorder (ADHD), and suicidality were also reported (Kamau et al., 2012). In SA, findings from a cross-sectional study that was done at five Paediatric clinics in Johannesburg show that depression and anxiety are highly prevalent among ALHIV, with a prevalence rate of 27% for both anxiety and depression (Woollett et al., 2017).

Several risk factors are reported in a few international and local studies that examined the mental health issues of adolescents. (Boyes, Cluver, Meinck, Casale, & Newnham, 2018; Flisher, Parry, Evans, Muller, & Lombard, 2003; Gentz, Calonge Romano, Martínez-Arias, & Ruiz-Casares, 2017; Lyon, D'Angelo, Schuman, Tipnis, & Mrazek, 2000; Pinto et al., 2014; Woollett et al., 2017). For instance, an integrative review that examined risk factors associated with mental health issues in adolescents, in Brazil shows that there are diverse risk factors associated with adolescent mental health issues, ranging from the individual level (intrapersonal), family level (proximal) and the broader social level (distal) (Pinto et al., 2014). Individual level risk factors were characterized by feeling lonely, self-harm, low self-esteem; including alcohol and substance abuse, to mention a few (Pinto et al., 2014). Family level risk factors included child abuse, neglect, domestic violence, low emotional support and

parental substance abuse. Social factors associated with CMD included school drop-out, gang involvement, poverty, bullying, institutionalisation as well as community violence (Pinto et al., 2014). In addition, evidence from a study which investigated the psychiatric diagnoses in adolescents seropositive for HIV in Washington, DC revealed that ALHIV, with at least one CMD also have a higher prevalence (59%) of substance use (Lyon et al., 2000). Other evidence shows that teenagers with emotional and mental health problems, often use alcohol or drugs to help them deal with the pain (www.childmind.org).

At the present time, very little is known about the prevalence of CMD among HIV infected adolescents in South Africa. This is so partly because Section 71 of the South National Health Act 61 of 2003 requires parental or legal guardian consent for all research involving children under the age of 18 (Tsey, 2017). In addition, in resource limited communities (RLC), a number of studies that exist focus mainly on HIV-infected adults with mental health challenges, as a result research on the mental health problems of ALHIV is very limited (Rao, Sagar, Kabra, & Lodha, 2007; Vreeman et al., 2017).

We were able to identify a few studies investigating CMD among this vulnerable population in SA (Boyes et al., 2018; West et al., 2019; Woollett et al., 2017). For example, one study that investigated possible risks associated with mental health problems in HIV-positive adolescents accessing treatment in Johannesburg found that depression and anxiety were the most prevalent CMD among ALHIV, with a prevalence of 27% for both disorders (Woollett et al., 2017). Another study that investigated correlates of internalising and externalising symptoms associated with mental health in South African ALHIV, at a health district in the Eastern Cape found that depression and anxiety were highly prevalent among this vulnerable population (Boyes et al., 2018). Therefore, given the lack of available research in this area, further understanding about the factors associated with CMD among adolescents living with HIV is warranted in SA. The proposed study will address this gap.

1.1 Aim

The aim is to assess CMD and factors associated with CMD among adolescents accessing HIV treatment and care in Cape Town, South Africa.

1.2 Specific objectives

1. To assess CMD among adolescents accessing ARV treatment.
2. To determine factors associated with CMD among adolescents accessing HIV treatment.

1.3 Thesis Outline

Chapter 2 offers a review of local and global literature on the prevalence rates and risk factors associated with CMD. Chapter 3 describes the methodology used when gathering data to meet the study's objectives. The results of the study are reported in Chapter 4, and Chapter 5 provides the discussion of results, recommendations for future studies and conclusion.

CHAPTER TWO: LITERATURE REVIEW

2.0 Introduction

This chapter will describe the available literature on the prevalence of HIV among adolescents. The role of HIV treatment in HIV-infected adolescents will also be discussed and highlighting the risk factors for non-adherence to ART. International, as well as local prevalence rates of CMD among HIV-infected adolescents will be discussed, drawing special attention to the risk factors associated with CMD among this vulnerable population. The risk factors will be further explained by making use of the socio-ecological framework to illustrate the interaction between the individual level factors, family level factors and social level factors.

2.1 HIV prevalence among the general population

In 2019, an estimated 38 million people globally were living with HIV, with 1.7 million new infections (UNAIDS, 2020). Of the 38 million PLHIV, 36.2 million were adults, and 1.8 million were children younger than 15 years. An estimated 690 000 people died of AIDS-related causes in the same year (UNAIDS, 2020). Further, regional data for 2019 by WHO, shows that of the 38 million PLHIV, 3.7 million were residing in America, 3.7 million in South East Asia, 2.5 million in Europe, 1.9 million in Western Pacific. Unfortunately, a majority of people (25.7 million) living with HIV reside in Africa (WHO, 2020).

SSA remains the worst affected region. The prevalence rates of the epidemic continue to vary greatly between regions located in SSA (UNAIDS, 2020). For example, Eastern and Southern Africa have a significant number of PLHIV in comparison to Western and Central Africa. In Eastern and Southern Africa alone, it was estimated that there were 20.7 million people living with HIV in 2019 (UNAIDS, 2020). The prevalence also varies across countries in the Southern African region. Lesotho, for instance had an estimated 340 000 PLHIV, 11 000 new infections and 4 800 AIDS related deaths. On the other hand, in Botswana there was an estimated 380 000 of PLHIV, 9 500 new infections and 5000 AIDS related deaths. In Namibia there were 210 000 PLHIV, 6 900 new infections, and 3 000 AIDS related deaths

reported in 2019. Swaziland had 200 000 PLHIV, 4 500 were new infections and 2 300 were AIDS related deaths.
In 2019, SA had an estimated 7 500 000 PLHIV, with 200 000 new infections and 72 000 people who died of AIDS related illnesses (UNAIDS, 2020). In 2012, the SA national HIV prevalence, incidence and behaviour survey, estimated that 12.2 % of the population were HIV-positive. The top four provinces with a high prevalence included Kwa-Zulu Natal, Mpumalanga, Free State and North West, with Western Cape, Northern Cape and Limpopo having the lowest prevalence (Shisana et al., 2014).

2.2 HIV prevalence among children and adolescents

Children and adolescents are also vulnerable to HIV. Research indicates that HIV-infected children and adolescents fall into two well-defined populations based on how the virus is acquired. First, some are born with the disease through mother to child transmission (meaning around the time of birth or through breastfeeding). This type of infection is also known as vertical transmission or perinatal infection. Others acquire HIV horizontally, that is either by transfusion of blood products or by risk behaviours which include sexual activity and intravenous drug use (Martinez, Chakraborty, & AIDS, 2014). Cases of children born with the disease were common in the early days of the HIV era but have since declined dramatically with the successful prevention of mother to child transmission programs also known as Prevention of Mother to Child Transmission (PMTCT) (Haberer & Mellins, 2009).

PMTCT interventions such as ARV prophylaxis have remarkably reduced the risk of vertical or perinatal transmission, particularly in SSA. In SA, PMTCT has been a high priority and PMTCT interventions have been implemented since 2002 with much success (Doherty, Chopra, Nsibande, & Mngoma, 2009). Despite the progress made to curb perinatal or vertical transmission of HIV, horizontal transmission remains a great challenge among adolescents, and is known as one of the factors contributing to the increased rate of new infections in Southern Africa (Delva & Abdool Karim, 2014).

Research suggests that HIV transmission in SSA occurs mainly through sexual intercourse and engaging in risky sexual behaviours. This includes early sexual intercourse initiation, having multiple partners and inconsistent condom use (Doherty et al., 2009; Fearon, Wiggins, Pettifor, & Hargreaves, 2015). A systematic review and meta-analysis conducted in SSA

among ALHIV found that, among sexually active adolescents living with HIV, risk-taking including early sexual intercourse initiation and unprotected sex is a common phenomenon and has been associated with poor adherence (Ssewanyana, Mwangala, van Baar, Newton, & Abubakar, 2018). This review and meta-analyses included 14 studies conducted between 1990 and 2012 in SSA countries, the majority of which were conducted in SA (n=6) and in Uganda (n=4). Results from this review show that early sexual intercourse initiation among ALHIV was reported in 5 studies. Two of these studies reported 25.5 % and 42.1% of the ALHIV having early sexual intercourse at the age of 15 or less. With regards to unprotected sex or current non-use of condoms among ALHIV, 9 studies reported a prevalence of 59.8% and this was considered a high prevalence.

In SSA, sexual risk behaviour in ALHIV has not only become a major concern, but it is an obstacle to the prevention and management of HIV. Adolescent years is a critical time where girls and boys commonly start engaging in a number of risky behaviours, including risky sexual behaviour and risky use of alcohol and other drugs. These behaviours put them at risk for unplanned pregnancies, unintentional injury or violence including getting infected with HIV (Ssewanyana et al., 2018).

Further interesting findings from a study by (Idele et al., 2014) on the epidemiology of HIV and AIDS among adolescents suggest that HIV prevalence among adolescent females is significantly higher compared to adolescent males (Idele et al., 2014). This is according to age specific prevalence data, which shows a clear sex difference by the age of 15 years. For example, a 2006-2007 national survey conducted in Swaziland, revealed that HIV prevalence begins to rise in adolescent girls by the age 15 to 19 years and is 5 times higher than in boys. A similar trend is also noticeable in SA, Botswana and Uganda (other countries with the highest HIV prevalence rates), where HIV prevalence also increases by age group (i.e. a low HIV prevalence in early childhood in both girls and boys, followed by a greater increase in prevalence with entry into adolescence among females compared to males) (Idele et al., 2014).

Adolescence is a stage of life where individuals have unique psychological, social and health needs (Adejumo, Malee, Ryscavage, Hunter, & Taiwo, 2015). Studies investigating the epidemiology of HIV and AIDS among adolescents have shown that the adolescent stage is a typical period of experimentation, new experiences and vulnerability (Idele et al., 2014).

Findings from a systematic review of 35 studies investigating the prevalence, risk factors and interventions to reduce sexual risk behaviours among 13,536 HIV-positive adolescents and youth (10-24 years old) in SSA indicate high rates of unprotected sex (Toska et al., 2017). For example, 50% and 88% infection rates were reported on studies testing for biomarkers of sexually transmitted diseases like human papilloma virus (HPV). This high occurrence of sexual risk-taking was reported in adolescents younger than 19 years by most studies in this review. Findings also show that there was a significant variation in the prevalence of inconsistent condom use although most studies found that between one-third and half of the participants reported unprotected sex during their recent sexual encounter. These prevalence rates were similar to those reported by studies done in SA and other countries in SSA (Toska et al., 2017).

Risk-taking among young people can be linked to a number of factors. For instance, those who live in socio-economically deprived communities are likely to engage in sexual risk behaviours due to a poor education background coupled with limited employment opportunities (Dellar, Waxman, & Abdool Karim, 2015). As a consequence, their decision to engage in unsafe sexual behaviour may be compromised and they may end up engaging in sex for money, gifts or favours (Mabaso et al., 2018). Limited education also has implications on their knowledge of sexual and reproductive processes including services available to them, such as access to ART programmes (Dellar et al., 2015). Other studies conducted with young people have also shown that social, demographic and behavioural factors play a role in putting adolescents more at risk of acquiring HIV among adolescents from different settings in SSA (Mabaso et al., 2018).

2.3 HIV treatment among adolescents

ARV treatment continues to play a key role in preventing the progression of HIV to AIDS among ALHIV. The provision of ART was a challenge more than a decade ago as they were only available in developed countries. This was mainly due to the high cost of drugs. At the time, ARVs were not offered free of charge, and appropriate infra-structure at health facilities was needed to roll out the treatment programme. Therefore, only rich resource countries could afford to provide ART to people living with HIV, despite the low HIV prevalence found in these countries, and countries with the greatest need had limited access to ART (Taylor, 2018). With HIV remaining untreated for some patients, 50% peri-natally infected

children (PHIV) died before the age of two years (Brahmbhatt et al., 2006) and others who survived had advanced HIV disease during adolescence (Ferrand et al., 2007).
Free access to ART has dramatically changed the lives of many PLHIV who reside in LMICs. The provision of ART in resource limited countries has become more affordable since 2001, with access to generic drugs, private donations, including the establishment of the United Nations Global Fund to fight AIDS, Tubercolosis (TB) and Malaria. This move was driven by the Millenium Declaration in 2000 (Murray, 2014). Since then, countries such as SA have managed to develop polices and implemented a plan to provide ART free of charge to patients with symptomatic HIV disease who receive their treatment in public health clinics and hospitals (Nachega et al., 2004).

Since the introduction of ART, the number of PLHIV accessing treatment has increased significantly. In 2015, 17 million people were receiving ART globally (Heestermans, Browne, Aitken, Vervoort, & Klipstein-Grobusch, 2016). The improvement in people's quality of life, including the successful dissemination of HIV treatment, were brought about by early efforts and strategies introduced by the WHO in 2010, whereby ART was recommended to all HIV-infected children under 2 years. This recommendation was further extended in 2013, with the initiation of ART to children under 5 years irrespective of clinical stage or CD4 count. As a result of these recommendations, a revision to the guidelines to recommend ART regardless of age, clinical or immunological criteria came into effect in 2015 (Desmonde et al., 2018). With improved access and quality of services, there is an improvement of quality of life of PLHIV and HIV has been transformed into a chronic manageable disease (Amberbir, Woldemichael, Getachew, Girma, & Deribe, 2008).

Further strategies to fight the HIV/AIDS epidemic have recently emerged. First, the 90-90-90 targets for 2020 that were launched in 2014 by the Joint United Nations Programme on HIV and AIDS (UNAIDS) played a key role in upgrading access to ART. These targets aim to successfully diagnose 90% of all people living with HIV, delivering ART to 90% of those infected and attaining viral suppression for 90% of those accessing treatment (Levi et al., 2016). Second, in line with the 90-90-90 targets, there are 2020 super-fast-track targets that are primarily focused on supporting children and adolescents by eradicating HIV transmission between mother and child, which will result in the reduction of newly infected children by 40 000 per year by 2018 and 20 000 by 2020. These targets also aim to reduce the number of new infections among adolescents and young women to fewer than 100 000 per

year by 2020, and more importantly, provide HIV treatment to children between the ages of 0 to 14 years and adolescents aged 15 to19 by 2020 (UNICEF, 2017).

ART are prescribed for all people infected with HIV to promote viral suppression, which in turn increases their CD4 count. However, to achieve viral suppression, at least 95% adherence is recommended (Croome, Ahluwalia, Hughes, & Abas, 2017).

Previous studies investigating adherence to ART among adolescents show that adherence is particularly challenging for this age group, yet research findings reveal that the success of ART for HIV infection is, for the most part, determined by adherence (Bärnighausen et al., 2011). A systematic review examining interventions to improve ART adherence among adolescents in LMICs found that different methods were used to determine adherence. These methods were separated into biological measures and subjective measures. Biological measures were composed of CD4 counts, ART concentrations in hair samples, and viral load. Subjective measures contained pill counts conducted by clinic staff to measure the number of pills remaining compared to the number of doses to be taken over specified time period (Ridgeway et al., 2018). Another systematic review that examined factors impacting ART adherence in adolescents, in SSA found that adherence to ART was measured by self-reports in six studies, including pill counts in one study. Good adherence to ART was defined as greater than 95%; and 95% of those who were interviewed reported poor adherence sometime in their lives (Ammon, Mason, & Corkery, 2018).

Although, the gold standard measure of adherence to ART remains unclear (Gulick, 2006), the recent WHO guidelines recommend viral load tests (i.e. the physiological method) as a strategy to monitor ART effectiveness (Bijker et al., 2017). Other assessment strategies that are not well investigated in research studies of ART adherence in children include drug resistance, increasing viral load and decreasing CD4 count. These are often referred to as signs of non-adherence (Simoni et al., 2007)

2.4 Risk factors for non-adherence to ART among adolescents

Risk factors for non-adherence among those taking ART are well documented (Shubber et al., 2016), including among adolescents (Shubber et al., 2016; Simoni et al., 2007). They relate primarily to medication factors (i.e. complexity of the regimen, precise dosing times, side effects etc), patient factors (i.e. child unawareness of own HIV status), caregiver and family factors (i.e. more concern about hiding child's HIV status) and clinical environment (i.e. patient-relationship with service provider). In addition, families exposed to poverty, with limited resources often face discrimination, family disruptions, substance abuse and more importantly stigma, which is greater towards people living with HIV/AIDS than those with other chronic illnesses. Although studies have shown that these factors can impact adherence to ART, one of the main risk factors highlighted in the literature relates to adolescent mental health (Lall, Lim, Khairuddin, & Kamarulzaman, 2015).

2.5 Mental health of adolescents living with HIV

Many international studies have examined the prevalence of mental health problems among ALHIV. A 2013 systematic review by (Mellins & Malee, 2013) found that, globally, CMD, as well as attention deficit hyperactive disorder (ADHD), are highly prevalent among ALHIV. This systematic review included 38 articles and most studies were conducted in the US and Europe. Using the Behaviour Assessment System for Children (2nd edition), Child Behaviour Checklist (CBCL), Diagnostic Interview Schedule for Children (DISC-IV), Child and Adolescent Symptom Inventory-4R (CASI-4R), the prevalence rates of 24% for anxiety and 25% for depression and 29% for ADHD were reported in this systematic review. In addition, a 2017 narrative review by (Vreeman et al., 2017) found that globally among 7-17-year-old ALHIV, the prevalence rates of CMD range between 21 to 25%. This narrative review included 10 articles from studies conducted in HIC and LMICs, although the majority of studies were US-based. Using the Centre for Epidemiological Studies (CES-D), Reynold's Adolescent Depression Scale (RAD), Children's Depression Inventory (CDI), Beck Depression Inventory (BDI-11), Children's Depression Revised Scale (CDRS-R), they found that the anxiety and depression were highly prevalent among ALHIV in both HIC and LMICs. Further, a cross-sectional study that was conducted in Washington, a district of Columbia in the United States by (Lyon et al., 2000) and made use of a convenience sample of adolescents seropositive for HIV (N=34) aged 16-24 years, attending a Primary care urban

adolescent clinic. The type of measures used to evaluate the type of CMD in the current study included the Structured Clinical Interview for DSM-IV (SCID-P) and medical record review. The findings showed that depression (68%) was highly prevalent among these adolescents.

SSA countries generally have limited data on the prevalence of CMD among ALHIV. A systematic review by (Vreeman et al., 2017) found that research concerning the mental health of this vulnerable population significantly lags behind that of adults, especially in RLC. However, studies investigating the mental health of ALHIV have been conducted in countries such as Kenya and Rwanda (Betancourt et al., 2014; Kamau et al., 2012). In Kenya, a cross-sectional descriptive study was conducted in a purposive sample of HIV-infected children and adolescents (N=162) aged 6-18 years attending a Lea Toto Comprehensive Care Clinics for paediatric HIV management (Kamau et al., 2012). Using the MINI international Interview for children and adolescents (MINI-Kid), the study found that major depression (17.8%) and social phobia (12.8%) were highly prevalent among these adolescents. Furthermore, a case control study conducted in Rwanda made use of a stratified sample of 218 HIV-positive, 228 HIV-affected (children with an HIV-infected caregiver or who had a parent who died due to complications of AIDS) and 237 HIV-unaffected (children known not to have HIV themselves or in their family) adolescents (N=683) aged 10-17 years attending district hospitals at Rwinkwavu and Kireheng (Betancourt et al., 2014). Based on the Mini International Neuropsychiatric Interview for Children (MINI-Kid), Center for Epidemiologic Studies Depression Scale for Children (CESDC), Youth Self-Report (YSR) Internalizing Subscale, the study found that depression and anxiety were more prevalent in HIV-positive compared with HIV-unaffected adolescents.

In SA, a few studies have investigated the prevalence of CMD among youth with HIV. For example, (Woollett et al., 2017) used a convenience sample of 343 HIV-positive adolescents aged 13-19 attending one of five paediatric clinics in Johannesburg. Overall, the study found that 27% of the sample had experienced depression (using the 10-tem Child Depression Inventory Short form), anxiety (using the Revised Children's Manifest Anxiety scale) or PTSD (using the Child PTSD Checklist) and 24% of them reported suicidality and seventeen (5%) reported attempting suicide in the past month. Boyes et al., 2018 conducted a cross-sectional study in a random sample of 1060 HIV-positive adolescents aged 10-19 years attending Adolescent ART clinics in the Eastern Cape. Overall, results showed that

depression, anxiety, PTSD and conduct problems were prevalent among this group of adolescents when using the Child Depression Inventory-Short Form Revised Children's Manifest Anxiety Scale, Child PTSD Checklist and Strengths and Difficulties Questionnaire. More findings on the mental health of ALHIV are presented in a cross-sectional study conducted by (West et al., 2019) at Witkoppen primary care clinic in Johannesburg, in a random sample of 278 ALHIV aged 9-19. Using the Revised Children's Manifest Anxiety scale -14 item version, they highlighted anxiety (8.9%) as the most prevalent CMD among this population.

Although existing research indicate that anxiety and depression are generally considered very common disorders seen among children and adolescents irrespective of their HIV status (Cortina, Sodha, Fazel, & Ramchandani, 2012; Scharko, 2006), recent findings from a systematic review of mental health challenges among ALHIV show that CMD are even more prevalent among PHIV adolescents. This finding suggests a need to understand what the risk factors are for CMD commonly found among ALHIV.

2.6 Risk factors for mental health disorders among adolescents living with HIV

A few studies have investigated the risk factors of CMD, specifically among ALHIV. International studies conducted in the US and Europe have shown that mental health disorders in HIV-infected adolescents are significantly influenced by multiple factors (Mellins & Malee, 2013; Vreeman et al., 2017). For example, a systematic review by (Mellins & Malee, 2013) found that the significant risk factors for CMD in this population included age, child health status, worse cognitive function, stressful life events, parental health and mental health and neighborhood disorder. Another systematic review by (Vreeman et al., 2017) revealed that gender, disclosure of HIV illness, social support and stigma were significant risk factors for mental health problems.

In SSA, a few cross-sectional studies have looked at the risk factors for mental health in ALHIV (Betancourt et al., 2014; Gentz et al., 2017). The findings of a cross-sectional study by (Gentz et al., 2017) done in Namibia among ALHIV aged 12-18 years revealed that gender, disclosure of HIV illness, social support and stigma played a significant role in influencing the mental health of this vulnerable population. Moreover, in the Rwanda case

control study (Betancourt et al., 2014) found that daily hardships, harsh punishment, death of a caregiver, stigma were significant risk factor for mental health problems in ALHIV.

In SA, data on risk factors for CMD is very limited. However, at the present time, there are four cross-sectional studies that investigated the risk factors for CMD among ALHIV (Boyes et al., 2018; Flisher et al., 2003; West et al., 2019; Woollett et al., 2017). First, (Woollett et al., 2017), in their analysis, found that the significant risk factors for CMD in this population included gender, peer violence, hunger, being inappropriately touched and being hit. Second, a study by (Boyes et al., 2018) revealed that the significant risk factors in this population were bullying victimisation, self-efficacy, and parenting. Third, a cross-sectional study by West et al., 2019 found that age, orphanhood, social support, knowledge of HIV status were significant risk factors in ALHIV. Finally, a study by Flisher et al., 2003 revealed that socio-demographic variables, HIV, and characteristics related to sexual risk and comorbid mental health and behavioural health factors were associated with substance use behaviours (Flisher et al., 2003).

Study findings on significant risk factors associated with CMD vary. It is of concern that studies conducted in HIC and Africa, in particular consistently report stigma as the significant risk factor for CMD (Betancourt et al., 2014; Gentz et al., 2017; Vreeman et al., 2017). In South Africa, peer violence/bullying victimisation, and substance use are reported as significant risk factors (Boyes et al., 2018; Flisher et al., 2003; Woollett et al., 2017).

2.7 Socio-Ecological Framework

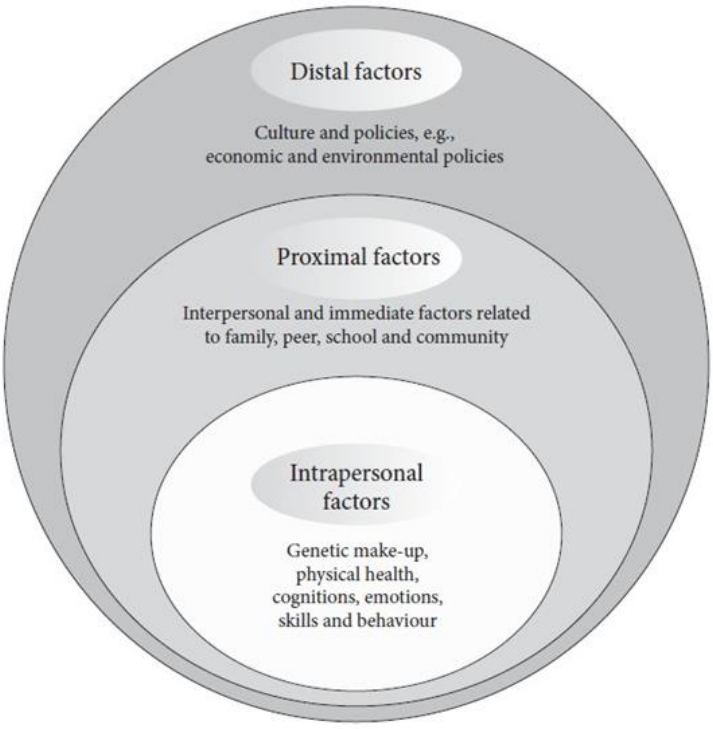
Socio-ecological (SE) frameworks are becoming more widely used in health behaviour research (Elder et al., 2006). The framework in figure 1 below displays the complex interaction between the intrapersonal (individual) factors, proximal (family) factors and distal (societal) factors. It further provides a broader understanding to various factors that can put certain groups at risk for mental health problems or protect them from being vulnerable to mental health problems. The overlapping rings in this framework illustrate how factors at one level may influence factors at another level (Kilanowski, 2017).

In line with the SE framework below, Pinto et al (2014) report the risk factors most commonly associated with mental health issues in adolescents according to three broad areas:

the individual level (intrapersonal), the family level (proximal), and the broader social level (distal) (Pinto et al., 2014). Individual level risk factors included biological risk factors, issues such as low self-esteem, self-harm, feeling lonely, and alcohol and substance abuse, to mention a few. Family level risk factors included domestic violence, neglect, child abuse, low emotional support, and parental substance abuse. There were also social factors associated with CMD, including gang involvement, school dropout, bullying, poverty, institutionalisation, and community violence.

Findings reported by most studies looking at risk factors associated with mental health problems among ALHIV (Boyes et al., 2018; Woollett et al., 2017) clearly show evidence of interplay between the individual level, the family level, and the social level. Existing literature shows that the application of this framework has proven to be useful in the treatment and prevention of depression in several countries around the world (Lakhan, 2013).

Figure: 1



2.8 Concluding paragraph

A detailed outline of the prevalence and risk factors associated with CMD was the main point of discussion in this chapter. Findings from published articles that were reviewed from HICs and LMICs provided more evidence regarding countries that have the highest prevalence of CMD. Sadly, CMD are more prevalent in LMICs (Vreeman et al., 2017). The prevalence of CMD is also reported to be elevated in ALHIV (Lyon et al., 2000). This is reported consistently across most papers that were reviewed (Boyes et al., 2018; Malee et al., 2011).With regard to risk factors commonly associated with mental health problems among ALHIV, some studies have reported similar findings. Risk factors that stand out from studies conducted both in HICs and LMICs include stigma and peer violence/bullying victimisation, followed by gender. Research shows there are multiple factors that can put this vulnerable population at risk for mental health problems such as intrapersonal factors, proximal factors and distal factors. An integrative review by (Pinto et al., 2014) was able to explain this through the application of the socio-ecological framework, a model that is more widely used in health behaviour research.

Many previous studies have indicated that CMD are more prevalent in LMICs, and highlighting stigma and peer violence/bullying victimisation and gender as significant risk factors. However, it appears that proximal (family) factors were not found as significant risk factors in these studies. Therefore, it would be interesting to find out what other risk factors impact adolescent mental health in the current study

CHAPTER THREE: METHODS

3.0 Introduction

This chapter outlines the study design that was employed in the study to investigate common mental health disorders among adolescents accessing treatment and care at Groote Schuur hospital and Kuyasa clinic in Cape Town, South Africa. Study setting, participants, procedure, data collection measures, data analysis and ethical considerations are also described.

3.1 Study design

This is a quantitative cross-sectional study that was nested within a larger study exploring the Conditional economic incentives for improving adolescent adherence to HIV treatment in the Department of Psychiatry and Mental Health at the University of Cape Town (UCT). The larger study was titled ”Conditional economic incentives for improving adolescent adherence to HIV treatment in South Africa”. The study used a mixed methods design comprised of qualitative interviews and a discrete choice experiment “DCE” to explore youth-centered preferences for ART adherence programs in South Africa. The overall study was conducted during 2017–2019 in South Africa’s Western Cape Province. All study procedures were approved by ethics committees at Brown University (Institutional Review Board, IRB/ IAA#16–19) and University of Cape Town (Protocol #HREC 368/2016).
Participants were recruited into the study through convenience sampling and interviewed. The sampling procedure used in this study was guided by the larger study.

3.2 Setting

The data collection for the study took place at two HIV treatment clinics in Cape Town where our team was currently doing some interviews for the main study. The two clinics were identified in the main study to ensure sufficient sample size. These included Groote Schuur hospitals and Kuyasa clinic.

Groote Schuur hospital

Groote Schuur hospital (GSH) is a tertiary government funded teaching hospital that was established in 1938. The hospital is in Observatory just a few kilometres from the University of Cape Town. Groote Schuur is staffed by well trained and experienced individuals who play a typical role of mentoring medical students who are completing their clinical training. As a tertiary hospital, Groote Schuur offers an acceptable standard of care to all patients, and patients are only admitted to the facility through referrals from the Primary and Secondary health care facilities.

The clinical services provided by the hospital include an outpatient HIV treatment ward (G26) for adolescents living with HIV. Only children and adolescents who are currently GSH patients receive treatment for HIV in this ward on Wednesdays (younger adolescents aged 7-13 years old) and Thursdays (older adolescents aged 14-19 years old). This ward was used for recruitment and data collection for this study. The ward is staffed with a qualified and experienced team of clinicians such as Psychiatrists, Psychologists, Nurses and HIV Lay Counsellors.

Kuyasa Clinic

Kuyasa clinic is a primary health care facility located at Kuyasa in the Khayelitsha sub district. Khayelitsha is a partially informal township, on the Cape Flats, in the City of Cape Town. Kuyasa clinic facility is run by the City of Cape Town. It provides several clinical services to meet the needs of the surrounding community. These include anti-retroviral services, basic antenatal care, child health, family planning, general HIV care, STI assessment and treatment, HIV testing TB assessment and treatment. Adolescents can access HIV treatment in this clinic from Monday to Friday. Support groups with adolescents mainly take place on Fridays. They are organised into different clubs and run by trained HIV counsellors.

3.3 Participants

Participants were recruited from the Adolescent HIV treatment clinics located in the G26 ward at GSH and Kuyasa Clinic in Khayelitsha. To be included in the study, participants had

to meet the following inclusion criteria: 1) 10-19 years old, 2) Knowledge of their own HIV-positive status and 3) presently on HIV treatment. Participants over 18 years were excluded if they did not provide informed consent and those under 18 were excluded if parent consent and adolescent assent was not obtained. The sample size of the study was guided by the larger study which is N=200 adolescents. However, for this study, the sample size was N=121 because recruitment was slow, potentially delaying the submission of this thesis.

3.4 Procedure

The recruitment of participants for the study was done as part of a larger study. G-power was used to calculate the sample size for a multivariate logistic regression analysis. The alpha was set at 0.05 and desired power at 0.80. The estimated sample size is 175 participants. Unfortunately, due to time and budgetary constraints only 121 participated in the current study.

While adolescents were waiting to be attended to by the clinicians in the waiting room, the research assistants approached the parent/caregiver (if present) and adolescent. The research assistants first explained the study to both patient and parent/caregiver. If the parent/caregiver gave permission for child to participate in the study by signing the consent form and the child was also willing to participate, the child was then asked to complete the brief screener for eligibility, as described above, using an audio computer assisted self-interview software (ACASI).

Eligible adolescents aged 10 to 17 whose caregivers were present and were willing to participate provided a signed assent (Appendix A) and parental/caregiver consent (Appendix B) to participate in the study. For these participants, the survey interview was conducted immediately. The older adolescents between the ages 18 to 19 signed their consent (Appendix C) for their own participation in the study.

In situations where the caregiver/parent was not present, the adolescent was asked to provide parent/caregiver contact details and was sent home with the parental consent form. In this instance, the researcher then made a telephonic follow-up with the parent/caregiver of the adolescent to explain the study and the consent process. If the parent/caregiver gave permission for the adolescent to participate in the study, an interview with the adolescent was

scheduled at a mutually convenient time. The study required that all adolescents under age 18 (minors) be accompanied by their parents to the study sites at the time of data collection. The parent/caregiver and the adolescent were asked to present the signed consent and assent forms upon their arrival at the study site before the survey interview took place.

All interviews were conducted in English or IsiXhosa in a private room at GSH and at Kuyasa clinic. The survey took approximately 30-45 minutes to complete. Each participant received R50 in the form of a Pick n Pay voucher.

3.5 MEASURES

Information on socio-demographic characteristics and 3 measures pertaining to depression, anxiety, and alcohol use were included in the survey to meet the aims and objectives of the study (Appendix D and Appendix E):

Socio-demographic variables

In this questionnaire, questions pertaining to sex, education race, language, and work were obtained. Living conditions questions were also included, covering aspects such as, main source of water for household use (for example, piped water (including in dwelling, yard, community tap or no piped water, assets (for example, refrigerator, electric/gas stove, vacuum cleaner, washing machine, computer, satellite television, DVD player, motorcar, television, radio, landline telephone or cell-phone), food security (for example, does your household ever run out of money to buy food?, do you ever cut the size of meals or skip meals because there is not enough money for food?, do you ever eat less than you should because there is not enough money for food?) and household size (for example, How many children 17 years or younger live in your household?). Socio economic status (SES) was calculated by summing up all the assets and food insecurity was calculated by summing up all insecurity variables.

Beck Youth Inventories-Second Edition (BYI-2)

The Beck Youth Inventories (BYI-2) consists of 5 self-report subscales and was used to assess the child's own experience of anxiety, anger, depression, disruptive behaviour and

self-concept in this study (Beck, Beck, J., Jolly, J., and Steer, R, 2005). The Becks inventories are intended for use with children and adolescents from 7 to 18 years of age. Each subscale includes 20 statements on a 4-point Likert scale that children use to describe how frequently each statement applies to them. For the present study, two of the five subscales were used, namely Beck Depression Inventory (BDI-Y) and Beck Anxiety Inventory (BAI-Y). The BDI-Y measured sadness, negative thoughts about one's self and future and bodily symptoms associated with depression. For example, one of the items on the scale reads: *I think that my life is bad* followed by the scoring of each item done as follows: (0=*Never, 1=Sometimes, 2=Often, 3=Always*). The Beck Anxiety Inventory (BAI-Y) measured fearfulness, worry and bodily symptoms indicating anxiety. On this scale a statement asks: *I worry people might tease me.* Each statement is rated 0-3 and scoring for the inventories is done by adding up all the raw as follows: *(0=Never, 1=Sometimes, 2=Often, 3=Always).* Raw scores are then translated into T-scores assigned by age and gender. The interpretation of the T-scores for both sub-scales is done as follows: (55 or less=average, 55-59=mildly elevated, 60-69=moderately elevated, 70+= extremely elevated). For this study, participants who scored between 55 or less were categorised as "no risk" while participants who scored between 55 to 70+ were categorised as "at risk" for anxiety and depression. The authors of the scale have reported good reliability and validity for each of the subscales (Beck, 2005). They reported an internal consistency coefficient for all inventories ranging from 0.86 to 0.96 when using the Cronbach's coefficient alpha method for each norm group, and test reliability correlation co-efficient ranging from 0.74 to 0.93. The rationale for using the Beck Depression and Anxiety inventories in this study was based on the fact that these mental health measures were identified and used in the larger study. These subscales have also been successfully used, but not validated in the South African context (Hoare et al., 2019; Seedat, Nyamai, Njenga, Vythilingum, & Stein, 2004; Ward, Flisher, Zissis, Muller, & Lombard, 2004). Although the Becks depression and anxiety measures have not been validated with adolescent populations in South Africa, they have been used in a number of published studies in this population. For example, the Beck youth inventories was used successfully in a study that examined mental health and functional competence in the Cape Town Adolescent Antiretroviral Cohort (Hoare et al., 2019). Additionally, they have also been validated in adult populations in SA. For example, the Beck Anxiety Inventory (BAI) was validated in a sample of South Africans living with HIV, by determining the performance of the items and also identifying the factor structure of the BAI. (Kagee, Coetzee, Saal, & Nel, 2015). Another South African study validated the Beck Depression Inventory (BDI) by evaluating the

factorial validity of the scale among a sample of university students (Makhubela & Mashegoane, 2016)

In the current study, the Becks Depression and Anxiety inventories that were used as mental health measures, were already translated into isiXhosa. The BAI-Y and BDI-Y scales were available to participants both in English and IsiXhosa, and participants were free to participate in the language of their choice.

3.6 Data Analysis

Statistical Package for Social Science (SPSS) version 25 was used to analyse the data. Descriptive statistics (means, standard deviations and frequency analysis) were presented. Unadjusted and adjusted associations between socio-demographics, SES, food insecurity, alcohol use, years known status and the presence of depression and anxiety were explored through logistic regression models. Age, gender and variables that were significant in the unadjusted associations were included in the adjusted logistical regression models. Significance was set at $p<0.05$.

3.7 Ethical considerations

Ethical approval for the study was sought from the University of Cape Town Human Research Ethics committee (REF: 702/2018). The study was nested within a larger study exploring the Conditional economic incentives for improving adolescent adherence to HIV treatment which already had ethical approval from the UCT Human Research Ethics Committee (REF: 368/2016). The main study obtained approval from the Department of Health and City of Cape Town to recruit from the clinics. Parental informed consent and assent were obtained for 10-17 years old adolescents, and an informed consent was obtained for adolescents aged 18-19. Participants were made aware that their participation was completely voluntary. They could stop participating at any time with no penalty and they could also refuse to answer any question.

3.7.1 Privacy and confidentiality

Every effort was made to keep all demographic information, and any other identifying data collected strictly confidential. We collected data in a private room via an audio computer-

assisted self-interview software (ACASI). Only the study team had access to participant information stored in the database secured in encrypted cloud. Participant information was only identified by a unique study number.

3.7.2 Description of risks and benefits

There were only minor risks attached to this study. For participants who experienced emotional reactions, including participants with extremely elevated symptoms of depression, anxiety, A/Prof Jacqueline Hoare was available for consultation on site, telephonically, including referrals for psychological services. Of the 121 participants who were interviewed, none of them required a referral. There were no direct benefits for participating in this study. Participants were reimbursed with a R50 Pick n Pay voucher and a snack. Transportation was also provided.

CHAPTER FOUR: RESULTS

4.0 Introduction

This chapter will provide study results. The first section focusses on describing the socio-demographic and mental health characteristics of the sample. It is followed by a presentation of the unadjusted and adjusted associations between anxiety and depression, as dependent variables, and socio-demographic factors.

4.1 Socio-demographic characteristics of the sample

A total of 121 adolescents (112 from GSH and 9 from Kuyasa clinic), 60 females and 61 males were recruited into the study. Although our target was 175, recruitment was slow potentially delaying the submission of this thesis. However, given that many of the variables were not significant in the unadjusted models, this probably made little impact on the findings. This has also been highlighted in the limitations. As we move towards a publication, we will have our sample size.

The mean age of the study participants was 15.14 (SD=2.13). Most participants 120 (99.2%) were Black African. Many of them 117, (96.7%), were attending either primary or high school/completed high school, with nearly half 59 (48.7%) currently in high school or having completed high school. Interestingly, there were 33 females (55.0%) and 26 males (42.6%) who were currently attending high school/completed high school. There were 112 (92,6%) Xhosa- speaking participants, and 9 participants (7.4%) who indicated other languages. The mean score of 9.40 (SD=1.88) for socio-economic status (SES) was calculated for all participants. The mean scores for males were 9.26 (SD=1.89) and 9.55 (SD=1.87) for females. The food insecurity mean score of the total sample was 1.38 (SD=1.20) and the mean scores for males was 1.48 (SD=1.23) and 1.28 (SD=1.17) for females. The number of years child known HIV status was also computed and the results showed an average score of 5.46 (SD=3.50). Males had an average score of 5.70 (SD=3.68) and females had an average score of 5.19 (SD=3.30) (Table 2).

Table 1: Summary of socio-demographic characteristics

	Total Sample **N=121 (100%)**	Male **N= 61 (50.4%)**	Female **N=60 (49.6%)**	**p**
Age: m (sd**)**	15.14 (2.12)	15.11(2.16)	15.18 (2.10)	0.860
Population group				
Black African	120 (99.20)	60 (98.40)	60 (100.00)	N/A
Other	1 (0.80)	1 (1.60)	0 (0.00)	
Highest school completed				
Currently in primary school	58 (47.90)	33 (54.10)	25 (41.70)	0.491
Currently in high school/completed	59 (48.80)	26 (42.60)	33 (55.00)	
Language				
IsiXhosa	112 (92.60)	57 (93.40)	57 (95.00)	0.710
Other	9 (7.50)	4 (6.60)	3 (5.10)	
Years known HIV status: m (sd**)**	5.46. (3.50)	5.70 (3.68)	5.19 (3.30)	0.430
SES[a] m (sd)	9.40 (1.87)	9.26 (1.88)	9.55 (1.87)	0.402
Food insecurity[b] m (sd)	1.38 (1.19)	1.48 (1.23)	1.28 (1.16)	0.381

Notes: a: composite socio-economic status

score b: composite food insecurity score.

4.2 Mental health characteristics of the sample

Most participants did not report elevated levels for either anxiety or depression. With regards to anxiety, the average score for anxiety for the total sample was 46.17 (SD=8.39). There were 16 participants (13.2%) who were at risk for anxiety (Table 2**).** Of the 16 participants, 5 had mildly elevated anxiety symptoms, 9 had moderately elevated anxiety symptoms and 2 had extremely elevated anxiety symptoms. In total, 10 males (16.4%) and 6 females (10.0%) had symptoms of anxiety. Of the 44 adolescents between the ages of 10-14, 6.8% reported symptoms of anxiety, while 16.9% of the 77 adolescents between the ages of 15-19 reported symptoms of anxiety,

With regards to depression, the average depression score for the total sample was 46.02 (SD= 8.68). There were 16 participants (13.2%) who were at risk for depression (Table 2). Of the 16 participants, 9 had mildly elevated depression symptoms, 5 had moderately elevated

depression symptoms and 2 had extremely elevated depression symptoms. In total, 10 females (16.7%) and 6 males (9.8%) had symptoms of depression. Of the 44 adolescents between the ages of 10-14, 11% reported symptoms of depression, while 14.3% of the 77 adolescents between the ages of 15-19 reported symptoms of depression.

Comorbidity scores for anxiety and depression were calculated. Four males (6.6%) as well as 4 females (6.7%) were at risk for anxiety and depression.

Table 2: Summary of mental health characteristics

	Total Sample	Male	Female	
	N=121 (100%)	**N= 61 (50.4%)**	**N=60 (49.6%)**	**p**
Anxiety: m (sd)	46.17 (8.39)	46.97 (8.32)	45.35 (8.45)	0.291
No	105 (86.80)	51 (83.60)	54 (90.00)	
Yes	16 (13.20)	10 (16.40)	6 (10.00)	
Depression: m (sd)	46.01 (8.68)	45.86 (8.65)	46.16 (8.78)	0.851
No	105 (86.80)	55 (90.20)	50 (83.30)	
Yes	16 (13.20)	6 (9.80)	10 (16.70)	
Comorbidity (depression and anxiety)				
No	113 (93.40)	57 (93.40)	56 (93.30)	
Yes	8 (6.60)	4 (6.60)	4 (6.70)	

4.3 Results for unadjusted and adjusted associations between socio-demographic factors and anxiety among adolescents

The investigation into the unadjusted and adjusted odds ratio (ORs) between participant socio-demographic factors and anxiety are displayed in Table 3 below. Among all the socio-demographic factors that were investigated, including gender, age, highest school completed, language, SES, food insecurity, alcohol use, years known status, only socio-economic status (SES) was significant (OR= 0.74, 95% CI 0.56-0.99). However, in the adjusted model, SES was no longer significant (OR=0.76, 95% CI 0.57-1.02).

Table 3: Unadjusted and Adjusted Associations between socio-demographic factors and anxiety among adolescents

	%, Yes	**%, No**	**Unadjusted OR (95% CI)**	**Adjusted OR (95% CI)**
Variable	**N=16**	**N=105**	**Anxiety**	

Gender				
Female	6 (37.50)	54 (51.40)	1.00	1.00
Male	10 (62.50)	51 (48.60)	1.77 (0.60-5.21)	1.68 (0.55-5.10)
Age m (sd)	15.81 (2.48)	15.04 (2.06)	1.19 (0.92-1.55)	1.17 (0.90 - 1.52)
Highest school completed				
Currently in primary school	5 (31.30)	53 (50.50)		
Currently in high school/completed	11 (68.80)	48 (45.70)	2.43 (0.79-7.50)	
Language				
IsiXhosa	14 (87.50)	98 (93.30)	1.00	
Other	2 (12.50)	7 (6.70)	0.50 (0.09-2.66)	
SES m (sd)	8.50 (2.68)	9.54 (1.70)	0.74 (0.56-0.99)*	0.76 (0.57-1.02)
Food insecurity m (sd)	1.13 (1.10)	1.42 (1.22)	0.81 (0.52-1.27)	
Alcohol use problems				
No	13 (81.30)	83 (79.00)		
Yes	3 (18.80)	22 (21.00)		
Years known status m (sd)	4.88 (2.83)	5.55 (3.60)	0.94 (0.81-1.11)	

***P<0.05**

4.4 Results for unadjusted and adjusted associations between socio-demographic factors and depression among adolescents

Investigations into unadjusted and adjusted odds ratio (ORs) between participant socio-demographic factors and depression are presented in Table 4 below. Among all the socio-demographic factors that were investigated, only highest school completed (i.e. currently in high school/completed high school) had an association with depression in the unadjusted model (OR=3.45, 95% CI 1.04-11.41), and in the adjusted model (OR=0.10, 95% CI 0.02-0.68). Participants in high school were 0.10 less likely to screen positive for depression (n=12, 75.0%) compared to those in primary school (n=4, 25.0%)

Table 4: Unadjusted and Adjusted Associations between socio-demographic factors and depression among adolescents

Variable	%, Yes N=16	%, No N=105	Unadjusted OR (95% CI) Depression	Adjusted OR (95% CI)
Gender				
Female	10 (62.50)	50 (47.60)	1.00	1.00
Male	6 (37.50)	55 (52.40)	0.55 (0.19-1.61)	0.67 (0.22-2.07)
Age m (sd)	15.38 (2.33)	15.11 (2.10)	1.10 (0.83-1.36)	0.72 (0.48-1.10)
Highest school completed				
Currently in primary school	4 (25.00)	54 (51.40)	1.00	1.00

Currently in high school/completed	12 (75.00)	47 (44.80)	3.45 (1.04-11.41)*	0.10 (0.02-0.68)*
Language				
IsiXhosa	15 (93.80)	97 (92.40)	1.00	
Other	1 (6.30)	8 (7.60)	0.81 (0.94-6.93)	
SES m (sd)	9.00 (2.81)	9.47 (1.70)	0.88 (0.67-1.16)	
Food insecurity m (sd)	0.88 (0.96)		0.65 (0.40-1.05)	
Alcohol use problems				
No	14 (87.50)	82 (78.10	1.00	
Yes	2 (12.50)	23 (21.90)	1.96 (0.42-9.27)	
Years known status m (sd)	5.67 (3.98)	5.43 (3.44)	1.02 (0.88-1.19)	

***P<0.05**

CHAPTER 5: DISCUSSION

5.0 Introduction

This study examined the prevalence of CMD, and factors associated with CMD among adolescents accessing HIV treatment and care in Cape Town, South Africa. The following main findings emerged: 13.2% of the participants were at risk for anxiety and 13.2% were at risk for depression; 6.6% of participants were at risk for both anxiety and depression; the only variable associated with anxiety was socio-economic status and this was only significant in the unadjusted model; and the only variable associated with depression was highest level of schooling completed (i.e. currently in high school/completed high school) and this was significant in both unadjusted and adjusted models. These findings are discussed in detail in this chapter in relation to the previous literature. Thereafter, the strengths and limitations are highlighted. Finally, this chapter concludes by highlighting implications and recommendations for future practice, policy and research.

5.1 Main findings

5.1.1 Prevalence of depression and anxiety among adolescents living with HIV

The current study found that 13.2% of adolescent participants were at risk for anxiety and 13.2% were at risk for depression in the sample of 121 participants aged 10 to 19 years old. Compared to other studies conducted globally and in SA, this prevalence is comparably average. For example, a systematic review that predominately included studies from Europe and the United States collated 38 studies that reported on the mental health of youth living with perinatal HIV infection. Using Conner's Parent Rating Scale (CPRS-48), Behaviour Assessment System for Children (2nd edition), Child Behaviour Checklist (CBCL), Diagnostic Interview Schedule for Children (DISC-IV), and Child and Adolescent Symptom Inventory-4R (CASI-4R), results revealed an average prevalence of 24% for anxiety and 25% for depression across studies (Mellins & Malee, 2013).

In SA, a cross-sectional study conducted by (Woollett et al., 2017), using a sample of 343 HIV-positive adolescents, found that 27% screened positive for both anxiety and depression

according to the 10-item Child Depression Inventory Short form and Revised Children's Manifest Anxiety scale. In addition, (Boyes et al., 2018) conducted a cross-sectional study in a random sample of 1060 HIV-positive adolescents, and results showed that depression and anxiety were prevalent among this group of adolescents when using the Child Depression Inventory Short Form and Revised Children's Manifest Anxiety Scale. Findings from a cross-sectional study conducted by (West et al., 2019) in a random sample of 278 ALHIV showed a prevalence of 8.9 % for anxiety, according to the Revised Children's Manifest Anxiety scale - 14 item version. The studies conducted in SA have shown substantial variations in prevalence of CMD among ALHIV and may not be a true reflection of the prevalence of depression and anxiety in this population. There are a number of explanations for this.

First, the present study used two subscales of the Beck Youth Inventories (BYI-2) which include the Beck Anxiety Inventory for Youth (BAI-Y) and Beck Depression Inventory for Youth (BDI-Y) to screen for anxiety and depression among ALHIV. The Beck Youth Inventories (second edition) is a newly revised test that uses the same principles as the widely used scales of depression, anxiety, hopelessness and suicide ideation. As highlighted in chapter 3, these subscales have previously been used successfully in other studies with ALHIV in SA (Hoare et al., 2019), and have also shown to be reliable and valid in adult populations in South Africa (Kagee, Coetzee, Saal, & Nel, 2015; Makhubela & Mashegoane, 2016).Unfortunately, reliability and validity data for these youth inventories are not currently available for the South African context.

Second, the variation in prevalence could be due to how the screening and diagnostic tools were administered. In the present study, the BDI-Y and BAI-Y were completed by self-report. Each self-report questionnaire was completed individually with all study participants in a private room. Older adolescents completed the questionnaires themselves with minimal assistance from the study research assistants. For some younger adolescents, the study research assistants verbally administered the questionnaires only when requested by the participant. The presence of fieldworkers during administration could have potentially pushed some participants to exaggerate their answers or to provide more socially acceptable answers, or participants may have felt embarrassed to reveal more personal details about themselves. Such biases may have affected the study results.

Third, this study cannot claim a true prevalence as convenience sampling methods were used. A convenience sample of adolescents was recruited using study research assistants who approached potential participants in a clinic waiting room. The key advantage of convenience sampling is that it is cheap, efficient and simple to implement. However, the key disadvantage of convenience is that it lacks clear generalisability (Jager, Putnick, & Bornstein, 2017). Moreover, convenience sampling makes it impossible to generalise the results of the survey to the population as a whole. Selection bias, or the possibility of under- or over-representation of the population creating biased results, are some of the reasons why some people choose to participate, and others refuse (Jager et al., 2017; Taherdoost, 2016).

Finally, participants for this study were recruited from Groote Schuur Hospital, which offers specialised paediatric ARV services with a qualified and experienced team of clinicians such as psychiatrists, psychologists, nurses and HIV lay counsellors. Many of these adolescents may have been exposed to significant mental health support since they started attending this clinic from early childhood. There are a number of strategies that members of the multi-disciplinary team may have used to prevent the onset of CMD among this vulnerable population. First, the multi-disciplinary team are well trained to create a safe and non-judgemental environment to patients, which can promote opportunities for the formation of positive relationships between clinicians and patients as well as among the adolescents. Second, many of the adolescents receiving care and treatment at G26 ward knew their HIV status and were participating in support groups which are facilitated by lay counsellors. Support groups provide vital HIV information and may have also promoted peer support among this vulnerable group. The role of support groups for ALHIV was explored in a study that was conducted in Zimbabwe among HIV-perinatally infected children and the authors found that support groups provide a safe social space for learning, obtaining HIV information, gaining self-esteem and reducing the burden of psychological care on caregivers and health care workers (Mupambireyi, Bernays, Bwakura-Dangarembizi, & Cowan, 2014). Knowing one's HIV status among young people is also associated with positive thoughts about their future, an element which was found to be protective against mental health problems in a study that was conducted in an HIV clinic in Harare, Zimbabwe among PHIV adolescents (Kidia et al., 2014).

5.1.2 Comorbid depression and anxiety

The current study found that 6.6% of the participants were at risk for both anxiety and depression. In relation to studies conducted internationally and other African countries, this comorbidity rate is comparably low. For example, a systematic review that examined the prevalence of comorbid depression and anxiety among children and adolescents in the United States and United Kingdom revealed than more than 95% of children with a major depressive disorder had a comorbid diagnosis, with the highest rates for anxiety disorders, when using the Child Behaviour Checklist (CBCL) (Melton, Croarkin, Strawn, & McClintock., 2016).

Studies done in other African countries also reported higher rates of comorbid disorders than those found in the current study. A study that investigated the prevalence and pattern of psychiatric disorders in HIV-infected children and adolescents in Kenya found that 25.9% of the participants met the diagnostic criteria of more than one psychiatric disorder, with anxiety disorders and major depression being the most common diagnoses (Kamau et al., 2012) Similarly, a study conducted in SA that examined the mental health of South African adolescents living with HIV found that 11.5 % of adolescents had one or more mental health conditions, with depression and anxiety being the most prevalent disorders (West et al., 2019).

Evidence shows that comorbidity presents itself in different forms, resulting in variations in comorbid rates. For example, in youth with anxiety, rates of comorbid depressive disorders are generally lower ranging from 10% to 15%, while among youth with depression, anxiety disorders are the most common comorbid mental health disorders ranging from 25% to 50% (Axelson & Birmaher, 2001).

There are a number of explanations that have been provided for the variations in comorbid rates of anxiety and depression in children and adolescents. First, youth with anxiety often present with very mild symptoms of depression which may not be detected when using screening or diagnostic tools (Van Voorhees, Melkonian, Marko, Humensky, & Fogel, 2010). Second, anxiety develops at an earlier age (Fichter, Quadflieg, Fischer, & Kohlboeck, 2010) and is generally more common in childhood, while depression is more prevalent among adolescents (Seligman & Ollendick, 1998), and therefore the level of comorbidity may vary

based on age. Third, rates of comorbid anxiety and depression may also vary based on gender, as other studies have found that anxiety and depressive disorders are more prevalent among girls than boys (Costello, Mustillo, Erkanli, Keeler, & Angold, 2003; Leikanger, Ingul, & Larsson, 2012). Similar findings were also reported in a study that examined the risks for mental health problems in HIV-positive adolescents in which girls scored significantly higher for anxiety and depression compared to boys (Woollett et al., 2017). Finally, evidence from other studies suggests that although a mood disorder may develop before anxiety, in children and adolescents it is common for anxiety to precede depression (Seligman & Ollendick, 1998). Further research is required to explore this low prevalence of comorbid anxiety and depression, probably in a larger sample.

5.1.3 Association between socio-economic status and anxiety

The present study found that socio-economic status (SES) was the only variable significantly associated with anxiety, but only in the unadjusted model, and no association was found in the adjusted model. This finding is inconsistent with what other studies have found. For example, evidence from previous studies shows that children of lower SES face significant challenges such as poverty, conflict, parental unemployment and larger family sizes, all of which are associated with increased mental distress (Foster & Williamson, 2000). Further, previous research indicates that poverty is the main challenge for many families that are affected with HIV in Africa (Abubakar et al., 2016). Based on previous literature, further investigation is warranted.

5.1.4 Association between educational level and depression

The current study found that among all the socio-demographic factors investigated, highest school level completed was significantly associated with depression. This negative relationship suggested that, as education increases, the likelihood of developing depressive symptoms decreases.

The current findings support previous studies which have reported on the protective effects of higher levels of education on depression (Bauldry, 2015). However, evidence shows that these protective effects may differ across population subgroups suggesting that people from poor backgrounds may benefit more from high levels of education in terms of financial

security than individuals from advantaged backgrounds (Brand & Xie, 2010). Other studies have also shown that a higher educational level does not only offer some degree of protection against depression, but it is also associated with better health outcomes (Bjelland et al., 2008). Similarly, a study that examined the epidemiology of major depression in the general population in SA found that subjects with higher levels of education (i.e. Grade 8-11) were less likely to experience major depressive episodes (Tomlinson, Grimsrud, Stein, Williams, & Myer, 2009).

These findings should be interpreted in the context of the multiple influences experienced at the individual, family and societal level (Stewart, McKenry, Rudd, & Gavazzi, 1994). At the individual level, previous studies have found that people who have achieved a high level of education are able to succeed, their overall wellbeing is improved, and they present with lower levels of depression (Bjelland et al., 2008; Mirowsky & Ross, 1998). At the family level, studies have found that parental involvement in education may serve a critical role in enhancing academic achievement and developing adolescent mental health (Wang & Sheikh-Khalil, 2014). At the societal level, one study found that fewer depressive symptoms were reported in adolescents with strong attachments to a school setting (Tandon, Solomon, & Society, 2009). Unfortunately, given this study utilised secondary data to explore risk factors of mental health problems, these factors were not included.

5.2 Study limitations

The present study had several limitations therefore the findings should be interpreted with caution. First, the study had a relatively small sample size with most participants recruited in a health care facility that offers specialised paediatric ARV services. This may have contributed to the average prevalence found for anxiety and depression among ALHIV in this study. Second, the design of the study was cross-sectional therefore making it difficult to conclude any causal direction of the associations found. Third, the study used a convenience sampling method which makes it difficult to generalise the results of the survey to the population. Fourth, the mental health measures used in the current study are currently not validated for the South African context. Finally, the number of years on treatment and care was not collected at either of the health care facilities.

5.3 Implications and recommendations for future practice

The current study findings highlight the CMD that are highly prevalent among ALHIV, including the comorbidity rate, and the influence of socio-demographic factors on the mental health outcomes of this vulnerable population. Based on these findings, some future recommendations are proposed. These include:

1. Screening for mental health conditions should be given a priority in ARV clinics.
2. Additional training should be provided to healthcare workers, including nurses and HIV lay counsellors, in identifying and treating CMD among ALHIV they are working with.
3. Training lay HIV counsellors to provide evidence-based mental health counselling, in addition to basic HIV counselling and support groups for ALHIV, is essential.
4. Given that most mental health conditions have their origin during childhood and adolescence, early identification of CMD and mental health counselling could be useful in addressing the problem of untreated mental health conditions in the adolescent population.

These recommendations could be used to complement the already existing micro-level HIV, mental health and life skills programmes offered to the HIV adolescent population at Groote Schuur hospital. They include support groups facilitated by HIV counsellors, mental health life skills programme called “Better Together” that is facilitated by a team of psychologists and psychiatrists. The rates of CMD are lower in this cohort because they have access to these services. More data and a larger sample are needed to start looking at interventions tailored for HIV adolescent mental health.

5.4 Concluding remarks

In conclusion, this was a quantitative study that assessed the prevalence of CMD, including determining the factors associated with CMD among adolescents accessing HIV treatment in Cape Town. The current study found that the participants were at risk for anxiety, depression,

and comorbid anxiety and depression. Regarding the factors associated with CMD, only highest level of schooling completed was found to be a protective factor against depression for this vulnerable population. Based on these findings, considerations for improving mental health outcomes for this population should include screening for mental health conditions in ARV clinics, early identification and treatment of mental health problems, and providing evidence-based mental health counselling.

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www.childmind.org.

APPENDICES

APPENDIX A: Youth Assent form

Conditional Economic Incentives for Improving Adolescent Adherence to HIV Treatment YOUTH Assent Form for Survey (Aim 3)
Version: 8 September 2017

Note to research staff: Only children for whom you have received a written signed adult consent form can participate in the informed assent process.
Study Implementers: University of Cape Town (South Africa) & Brown University School (USA) **Study Sponsors:** U.S. National Institute of Allergy and Infectious Diseases
Principal Investigators: Dr. Jacqueline Hoare & Dr. Omar Galárraga
Co-Investigators: Dr. Caroline Kuo & Dr. Abigail Harrison

Introduction

We would like to ask for your permission to take part in a study. The goal of this study is to find out what people think about using economic incentives to help HIV positive young people adhere to treatment. By economic incentives, we mean monetary rewards such as cash, a voucher, etc. that can be received if there are improvements in health (in this case adherence to taking treatment as prescribed). Before you can make an informed decision about taking part, you should understand the possible risks and benefits. This process is called informed assent. This informed assent document will give you an idea of what will take place during the study.

Why is this study being done?

People living with HIV can take medication to treat HIV. Young people under 18 years of age may face challenges in taking medication as prescribed. We want to understand people's opinions of giving young people an economic incentive to help young people take HIV treatment medication as prescribed. We will speak to people living with HIV as well as those not living with HIV.

Your participation is voluntary.

Your decision to provide consent is voluntary. If you provide assent, your decision to participate is voluntary. You can stop participating at any time with no penalty. You can refuse to answer any question. This does not affect benefits from clinics or social services.

Study procedures

Survey participants will do the following:

a. Fill out a completely **ANONYMOUS** survey (~50 short questions) that gathers general information on youth background (e.g., age, gender, population group, language, etc.); and opinions of HIV; knowledge; and behaviors that may impact adherence for young people. Then we will ask questions to help us design a future economic incentive program to improve adherence by asking about opinions of the best incentive amount, delivery schedule, site, etc.
b. Participants will receive R50 in the form of a voucher to compensate for their time (20-30 minutes).

Risks of participating

Possible risks

The survey covers sensitive topics such as HIV and medication. We do not ask about personal HIV or medication use, we only ask about these topics generally. You have the right of not answering any question that makes you feel uncomfortable.

How will we minimize these risks?

We will collect data ANONYMOUSLY in a private area directly into survey devices so that participants can be very honest. We will not ask you about your own experiences, but only about your general opinions. The survey will be identified only by study number.

Confidentiality

Every effort will be made to keep personal information confidential. Individually identifiable personal information (name, address, phone number) will not be linked in any way to the survey responses. We will not share information about anything disclosed to our research team unless in a case of imminent risk to self or others and legally mandated reporting requirements as outlined by South Africa's Children's Act. The research team may not be able to keep confidential, information about known or reasonably suspected incidents of deliberate neglect or physical, sexual or emotional abuse of a child. If a researcher is given such information, he or she may report it to the authorities such as

child welfare or the police. Your records may be reviewed by the sponsor of the study (US National Institutes of Health (NIH), US NIAID) and their representatives, Brown University of University of Cape Town Institutional ethical committees, and study staff.

Benefits

There may not be direct benefits from being in this study. Young people may benefit from this study later. The information gathered during this study may help to inform a new strategy for helping young people adhere to medication.

What happens if you do not want to take part?

Participants can stop taking part in the study at any time. There will be no penalty if participants choose not to participate or withdraw from the study. If the researcher feels it is in participant's best interest, they may end study participation at any time.

Persons to contact for problems or questions

If you have questions on the study, you can talk to anyone on our research team including the Principal Investigators: Dr. Jacqueline Hoare +27 (0) 21 404 2174 or Dr. Omar Galárraga omar_Galárraga@brown.edu +1 401 863 2331. The ongoing ethical conduct of the study remains the responsibility of the principal investigators. If you have any complaints about participation in this study, or would like more information about the rules for research studies, or the rights of people who take part in those studies, you may contact anonymously if you wish, in the Brown University Research Protections Office at +1 (401) 863-3050 or toll-free at +1 (866) 309-2095. Similarly, the University of Cape Town Faculty of Health Sciences Human Research Ethics Committee can be contacted on 021 406 6338 in case participants have any questions regarding their rights and welfare as research subjects on the study.

DO YOU UNDERSTAND WHAT I HAVE TOLD YOU AND YOU AGREE TO PARTICIPATE IN THE BRIEF SURVEY?

☐ Yes ☐ No

_____ _____

Signature Date

IF PARTICIPANT CANNOT SIGN THEIR NAME, A WITNESS WILL VERIFY THE DOCUMENTATION WITH A WRITTEN "MARK."

_____ _____

Signature of witness Date

I CERTIFY THAT I HAVE EXPLAINED THE NATURE AND PURPOSE, PROCEDURES AND THE POSSIBLE RISK AND POTENTIAL BENEFITS OF THIS RESEARCH STUDY.

_____ _____

Signature of researcher Date

APPENDIX: B Parental Consent Form

Conditional Economic Incentives for Improving Adolescent Adherence to HIV Treatment ADULT Consent Form Giving PERMISSION for Children to Choose Participation

Consent Form for Survey (Aim 3)

Version: September 2017

Study Implementers: University of Cape Town (South Africa) & Brown University School (USA) **Study Sponsors:** U.S. National Institute of Allergy and Infectious Diseases
Principal Investigators: Dr. Jacqueline Hoare & Dr. Omar Galárraga
Co-Investigators: Dr. Caroline Kuo & Dr. Abigail Harrison

Introduction

We would like to ask permission to invite your child to take part in a study. The goal of this study is to find out what people think about using economic incentives to help HIV positive young people adhere to treatment. By economic incentives, we mean monetary rewards such as cash, a voucher, etc. that can be received if there are improvements in health (in this case adherence to taking treatment as prescribed). Before you can make an informed decision about whether we can invite your child into the study, you should understand the possible risks and benefits. This process is called informed consent. This informed consent document will give you an idea of what will take place during the study.

Who should provide consent?

The following adults can provide consent: (1) the *parent* (including adoptive parents); (2) if no parent, the *guardian* (either court-appointed OR as indicated by the parent in a Will); (3) if no guardian, a *foster parent*; (4) if no foster parent, a *caregiver* (any person other than a parent or guardian, who cares for a child); (5) and if the child is from a child-headed household with no supervisory adult, a *trusted adult nominated by the minor*.

Why is this study being done?

People living with HIV can take medication to treat HIV. Young people under 18 years of age may face challenges in taking medication as prescribed. We want to

understand people's opinions of giving young people an economic incentive to help young people take HIV treatment medication as prescribed. We will speak to people living with HIV as well as those not living with HIV.

Your participation is voluntary.

Your decision to provide consent is voluntary. If you provide consent, your child's decision to participate is voluntary. Your child can stop participating at any time with no penalty. Your child can refuse to answer any question. This does not affect benefits from clinics or social services.

Study procedures

Survey participants will do the following:

a. Fill out a completely **ANONYMOUS** questionnaire (~50 short questions) that gathers information on background (e.g., age, gender, population group, language, etc.); and opinions on HIV knowledge; and behaviors that may impact adherence for young people. Then a survey (10 questions) will be used to help us design a future economic incentive program to improve adherence by asking about opinions of the best incentive amount, delivery schedule, site, etc.

b. Participants will receive R50 in the form of a voucher to compensate for their time (20-30 minutes).

c.We will review the study procedures with your child and ask if they want to be a part of the study. If he or she decides to be part of the study, they will provide their written assent.

Risks of participating

Possible risks

The survey covers sensitive topics such as HIV and medication. Survey questions about some of these topics can be uncomfortable. Children have the right of not answering any question that makes them feel uncomfortable.

How will we minimize these risks?

We will collect data ANONYMOUSLY in a private area directly into survey devices so that participants can be very honest. We will not ask the child about their experiences, but only about general opinions. The survey will be identified only by a study number, not by name.

Confidentiality

Every effort will be made to keep personal information confidential. Individually identifiable personal information (name, address, phone number) will not be linked in any way to the survey responses. We will not share information about anything disclosed to our research team unless in a case of imminent risk to self or others and legally mandated reporting requirements as outlined by South Africa's Children's Act. The research team may not be able to keep confidential, information about known or reasonably suspected incidents of deliberate neglect or physical, sexual or emotional abuse of a child. If a researcher is given such information, he or she may report it to the authorities such as child welfare or the police. Your records may be reviewed by the sponsor of the study (US National Institutes of Health (NIH), US NIAID) and their representatives, Brown University of University of Cape Town Institutional ethical committees, and study staff.

Benefits

There may not be direct benefits from being in this study. Young people may benefit from this study later. The information gathered during this study may help to inform a new strategy for helping young people adhere to medication.

What happens if you do not want to take part?

Participants can stop taking part in the study at any time. There will be no penalty if participants choose not to participate or withdraw from the study. If the researcher feels it is in participant's best interest, they may end study participation at any time.

Persons to contact for problems or questions

If you have questions on the study, you can talk to anyone on our research team including the Principal Investigators: Dr. Jacqueline Hoare +27 (0) 21 404 2174 or Dr. Omar Galárraga omar_Galárraga@brown.edu +1 401 863 2331. The ongoing ethical conduct of the study remains the responsibility of the principal investigators. If your child has any complaints about participation in this study, or would like more information about the rules for research studies, or the rights of people who take part in those studies, you may contact anonymously if you wish, in the Brown University Research Protections Office at +1 (401) 863-3050 or toll-free at +1 (866) 309-2095. Similarly, the University of Cape Town Faculty of Health Sciences Human Research Ethics Committee can be contacted on 021 406 6338 in case participants have any questions regarding their rights and welfare as

research subjects on the study.

I AGREE FOR MY CHILD TO CHOOSE WHETHER TO PARTICIPATE IN THE SURVEY

☐ **Yes** ☐ **No**

_____ _____

Signature Date

IF PARTICIPANT CANNOT SIGN THEIR NAME, A WITNESS WILL VERIFY THE DOCUMENTATION WITH A WRITTEN "MARK."

_____ _____

Signature of witness Date

I CERTIFY THAT I HAVE EXPLAINED THE NATURE AND PURPOSE, PROCEDURES AND THE POSSIBLE RISK AND POTENTIAL BENEFITS OF THIS RESEARCH STUDY.

_____ _____

Signature of researcher Date

APPENDIX: C Adult Consent Form for Own Participation

Conditional Economic Incentives for Improving Adolescent Adherence to HIV Treatment ADULT Consent Form for OWN Participation

Consent Form for Survey ((Aim 3)

Version: September 2017

Study Implementers: University of Cape Town (South Africa) & Brown University School (USA)

Study Sponsors: U.S. National Institute of Allergy and Infectious Diseases

Principal Investigators : Dr. Jacqueline Hoare & Dr. Omar Galárraga

Co-Investigators: Dr. Caroline Kuo & Dr. Abigail Harrison

Introduction

We would like to ask for your permission to take part in a study. The goal of this study is to find out what people think about using economic incentives to help HIV positive young people adhere to treatment. By economic incentives, we mean monetary rewards such as cash, a voucher, etc. that can be received if there are improvements in health (in this case adherence to taking treatment as prescribed). Before you can make an informed decision about taking part, you should understand the possible risks and benefits. This process is called informed consent. This informed consent document will give you an idea of what will take place during the study.

Why is this study being done?

People living with HIV can take medication to treat HIV. Young people under 18 years of age may face challenges in taking medication as prescribed. We want to understand people's opinions of giving young people an economic incentive to help young people take HIV treatment medication as prescribed. We will speak to people living with HIV as well as those not living with HIV.

Your participation is voluntary.

Your decision to provide consent is voluntary. If you provide consent, your decision to participate is voluntary. You can stop participating at any time with no penalty. You can refuse to answer any question. This does not affect benefits from clinics or social services.

Study procedures

Survey participants will do the following:

a. Fill out a brief questionnaire that gathers information on background (e.g., age, gender, population group, language, etc.); HIV status and stigma; adherence knowledge; and family factors that impact young people's adherence. Then a survey will be used to help us design a future economic incentive program to improve adherence by asking about opinions of the best incentive amount, delivery schedule, site, etc.
b. Participants will receive R50 in the form of a voucher.

Risks of participating

Possible risks

We talk about sensitive topics such as HIV, relationships, medication, and sex. Speaking about some of these topics can be uncomfortable.

How will we minimize these risks?

We will collect data in a private area so that participants can speak without being overheard. When the digitally recorded interview is transcribed, only first names or fictional names will be used, and all names will be replaced by an ID number. The survey will also be identified only by an ID number, not by name.

Confidentiality

Every effort will be made to keep personal information confidential. Individually identifiable personal information (name, address, phone number) will not be used in any publication about this study. We will not share information about anything disclosed to our research team unless in a case of imminent risk to self or others and legally mandated reporting requirements as outlined by South Africa's Children's Act. The research team may not be able to keep confidential, information about known or reasonably suspected incidents of deliberate neglect or physical, sexual or emotional abuse of a child. If a researcher is given such information, he or she may report it to the authorities such as child welfare or the police. Your records may be reviewed by the sponsor of the study (US National Institutes of Health (NIH), US NIAID) and their representatives, Brown University of University of Cape Town Institutional ethical committees, and study staff

Benefits

There may not be direct benefits from being in this study. Young people may benefit from this study later. The information gathered during this study may help to inform a new strategy for helping young people adhere to medication.

What happens if you do not want to take part?

Participants can stop taking part in the study at any time. There will be no penalty if participants choose not to participate or withdraw from the study. If the researcher feels it is in participant's best interest, they may end study participation at any time.

Persons to contact for problems or questions

If you have questions on the study, you can talk to anyone on our research team including the Principal Investigators: Dr. Jacqueline Hoare +27 (0) 21 404 2174 or Dr. Omar Galárraga omar_Galárraga@brown.edu +1 401 863 2331. The ongoing ethical conduct of the study remains the responsibility of the principal investigators. If you or your child have any complaints about participation in this study, or would like more information about the rules for research studies, or the rights of people who take part in those studies, you may contact anonymously if you wish, in the Brown University Research Protections Office at +1 (401) 863-3050 or toll-free at +1 (866) 309-2095. Similarly, the University of Cape Town Faculty of Health Sciences Human Research Ethics Committee can be contacted on 021 406 6338 in case participants have any questions regarding their rights and welfare as research subjects on the study.

I AGREE TO PARTICIPATE IN:

THE SURVEY ☐ Yes ☐ No

_____ _____

Signature Date

IF PARTICIPANT CANNOT SIGN THEIR NAME, A WITNESS WILL VERIFY THE DOCUMENTATION WITH A WRITTEN "MARK."

_____ _____

Signature of witness Date

I CERTIFY THAT I HAVE EXPLAINED THE NATURE AND PURPOSE, PROCEDURES AND THE POSSIBLE RISK AND POTENTIAL BENEFITS OF THIS RESEARCH STUDY.

_____ _____

Signature of researcher Date

APPENDIX D: CEI Aim3 Adolescent Survey

Concept

Question ID	Question	Answer
1	[PriorSubject] Interviewer, did this adolescent participate in Aim 1? If yes, please use the same ID# as previously assigned. If no, follow ID# assignment rules.	<1> Yes <0> No <9> Don't know
2	[ARIN] Interviewer to fill. Assign a unique research ID number (RIN) for each participant as they participate in each stage of the study. Enter Research ID #:	
3	[ANIHDATE] Date of Interview:	
4	[ASTARTTIME] Start Time of Interview:	
5	Interviewer: Take a picture of the signed assent or consent document.	

TEEN: Demographics

Question ID	Question	Answer
6	[ANIHIRBSEX] Would you define your sex as. . . (male, female)?	<0> female <1> male **<2> transsexual or intersex**
7	[ASCHOOLCOMPLETION/AEDUCATIONO] What is the highest level of education that you have completed?	<0> No schooling <1> Grade 0 <2> Grade 1/Sub A <3> Grade 2/Sub B

		<4> Grade 3/Std 1/ABET 1 <5> Grade 4/Std 2 <6> Grade 5/Std 3/ABET 2 <7> Grade 6/Std 4 <8> Grade 7/Std 5/ABET 3 <9> Grade 8/Std 6/Form 1 <10> Grade 9/Std 7/Form 2/ABET 4 <11> Grade 10/Std 8/Form 3 <12> Grade 11/Std 9/Form 4 <13> Grade 12/Std 10/Form 5 <15> Other [enter response]:
8	[ANIHRACE] How would you define your population group?	<0> Black African <1> Coloured <2> Indian or Asian <3> White <4> Other
9	[ALANGUAGE/ALANGUAGEO] What language do you speak mostly at home?	<1> IsiXhosa <2> Afrikaans <3> English <4> Other [enter response]:
10	[AWORK] Are you currently working?	<1> No, I am too young to work

		<2> No, I am unemployed <3> Yes, I work part time <4> Yes, I work full time
11	[AWATER] What is your household's MAIN source of WATER for household use?	<1> Piped water (including in dwelling, yard, or community tap) <0> No piped water

TEEN: Assets, Food Security & Household size

Question ID	Question	Answer
12	[AASSETFRIDGE] Does your household own any of the following in working order? Refrigerator	<1> Yes <0> No
13	[AASSETSTOVE] Electric/gas stove	<1> Yes <0> No
14	[AASSETVACUUM] Vacuum cleaner	<1> Yes <0> No
15	[AASSETWASHMACHINE] Washing machine	<1> Yes <0> No
16	[AASSETCOMPUTER] Computer	<1> Yes <0> No
17	[AASSETSATTV] Satellite television	<1> Yes <0> No
18	[AASSETDVD] DVD player	<1> Yes <0> No
19	[AASSETCAR] Motorcar	<1> Yes <0> No
20	[AASSETTV] Television	<1> Yes <0> No
21	[AASSETRADIO] Radio	<1> Yes

		<0> No
22	[AASSETLANDPHONE] Landline/Telephone	<1> Yes <0> No
23	[AASSETCELLPHONE] Cell phone	<1> Yes <0> No
24	[AHOUSEFOODINSECURE1] Does your household ever run out of money to buy food?	<1> Yes <0> No
25	[AHOUSEFOODINSECURE3] Do you ever cut the size of meals or skip meals because there is not enough money for food?	<1> Yes <0> No
26	[AINDFOODINSECURE] Do you ever eat less than you should because there is not enough money for food?	<1> Yes <0> No
27	[ANBRCHILDREN] How many children 17 years or younger live in your household?	

ACACI Device Practice Questions

Question ID	Question	Answer
28	[ACACIQ1/APRACQ1OTH] One type of question asks you to choose one and only one response. For these questions, press the button on the screen for one response. This will automatically bring you to the next screen. For practice, please answer the following question. What is your favorite flavor of ice cream?	<1> Vanilla <2> Chocolate <3> Other

29	Another type of question allows you to choose more than one response. For these questions, press the button on the screen for all responses that apply to you. For practice, please answer the following question. What are your favorite animals? Choose all that apply:	[A_29_1] <1/0> Elephant [A_29_2] <1/0> Lion [A_29_3] <1/0> Giraffe [A_29_4] <1/0> Rhino
30	[ACACIQ3] Finally, other questions ask you to enter a response, such as the number of times you did something. For these, simply type in your answer and press Enter. If you don't know the exact number, that's OK. Just MAKE YOUR BEST GUESS. Meanwhile, if you don't want to answer a question of this kind, type 999 in the box. Please practice this now. How many times per week, on average, do you eat bananas?	

TEEN: Adherence

Question ID	Question	Answer
31	[AADHERENCEARV] How hard it for you take your ARV's in the way you are suppose to?	<1> Extremely hard <2> Very hard <3> Somewhat hard <4> Not very hard <5> Not hard at all

TEEN: Access

Question ID	Question	Answer
32	[ACLINICACCESS] How easy is it for you to access your HIV care?	<1> Very easy <2> Somewhat easy, sometimes difficult <3> Very difficult

TEEN: Clinical travel

Question ID	Question	Answer
33	[ACLINICTRAVEL] How long do you have to travel to get to your healthcare provider?	<1> less than 15 minutes <2> 15-30 minutes <3> 30 minutes to 1 hour <4> more than 1 hour

TEEN: HIV treatment knowledge

Question ID	Question	Answer
34	[AHIVTXKNOW1] The following questions are about HIV treatment. Please choose whether you think each statement if True or False CD4 count testing measures how many soldier cells we have in our blood that fight HIV.	<1> True <0> False <999> Not sure
35	[AHIVTXKNOW2] When a person is feeling healthy or their CD4 count is high it is okay for them to stop taking their HIV medication.	<1> True <0> False <999> Not sure
36	[AHIVTXKNOW3] When a person's CD4 count drops he/she	<1> True <0> False

	has fewer soldier cells to fight infections.	<999> Not sure
37	[AHIVTXKNOW4] Medication for HIV shoudl be taken every day at about the same time.	<1> True <0> False <999> Not sure
38	[AHIVTXKNOW5] Viral load tests measure how much HIV is in the blood.	<1> True <0> False <999> Not sure
39	[AHIVTXKNOW6] If the viral load is "undetectable", this means there is no virus left in the body.	<1> True <0> False <999> Not sure
40	[AHIVTXKNOW7] If we say tht the virus is "resistant" to a particular medicine that means that the medicine no longer works to lower or slow down the virus.	<1> True <0> False <999> Not sure
41	[AHIVTXKNOW8] The virus can become resistant if medication doses are missed.	<1> True <0> False <999> Not sure
42	[AHIVTXKNOW9] HIV can be passed from mother to child.	<1> True <0> False <999> Not sure

Thank you & Reimbursement

Question ID	Question	Answer
43	[AENDTIME] Enter end time.	
44	[AENDNOTE] Interviewer (do not read aloud): The survey is now over. Interviewer, please enter any notes below that may explain any unexpected issues. You must	

	press the checkmark at bottom right, to upload the survey.	

APPENDIX E: CEI Aim3 Adolescent Mental Health

Introduction

Question ID	Question	Answer
1	[PriorSubject] Interviewer, did this adolescent participate in Aim 1? If yes, please use the same ID# as previously assigned. If no, follow ID# assignment rules.	<1> Yes <0> No <9> Don't know
2	[ARIN] Interviewer to fill. Assign a unique research ID number (RIN) for each participant as they participate in each stage of the study. Enter Research ID #:	
3	[ANIHDATE] Date of Interview:	
4	[ASTARTTIME] Start Time of Interview:	

BAI-Y

Question ID	Question	Answer
15	[BAIY21] I worry someone might hurt me at school	<0> Never <1> Sometimes <2> Often <3> Always <9> Refused to answer
16	[BAIY22] My dreams scare me	<0> Never <1> Sometimes <2> Often <3> Always

		<9> Refused to answer
17	[BAIY23] I worry when I am at school	<0> Never <1> Sometimes <2> Often <3> Always <9> Refused to answer
18	[BAIY24] I think about scary things	<0> Never <1> Sometimes <2> Often <3> Always <9> Refused to answer
19	[BAIY25] I worry people might tease me	<0> Never <1> Sometimes <2> Often <3> Always <9> Refused to answer
20	[BAIY26] I am afraid that I will make mistakes	<0> Never <1> Sometimes <2> Often <3> Always <9> Refused to answer
21	[BAIY27] I get nervous	<0> Never <1> Sometimes <2> Often <3> Always <9> Refused to answer
22	[BAIY28] I am afraid I might get hurt	<0> Never <1> Sometimes <2> Often <3> Always <9> Refused to answer
23	[BAIY29] I worry I might get bad grades	<0> Never <1> Sometimes

		<2> Often <3> Always <9> Refused to answer
24	[BAIY30] I worry about the future	<0> Never <1> Sometimes <2> Often <3> Always <9> Refused to answer
25	[BAIY31] My hands shake	<0> Never <1> Sometimes <2> Often <3> Always <9> Refused to answer
26	[BAIY32] I worry I might go crazy	<0> Never <1> Sometimes <2> Often <3> Always <9> Refused to answer
27	[BAIY33] I worry people might get mad at me	<0> Never <1> Sometimes <2> Often <3> Always <9> Refused to answer
28	[BAIY34] I worry I might lose control	<0> Never <1> Sometimes <2> Often <3> Always <9> Refused to answer
29	[BAIY35] I worry	<0> Never <1> Sometimes <2> Often <3> Always <9> Refused to answer

30	[BAIY36] I have problems sleeping	<0> Never <1> Sometimes <2> Often <3> Always <9> Refused to answer
31	[BAIY37] My heart pounds	<0> Never <1> Sometimes <2> Often <3> Always <9> Refused to answer
32	[BAIY38] I get shaky	<0> Never <1> Sometimes <2> Often <3> Always <9> Refused to answer
33	[BAIY39] I am afraid that something bad might happen to me	<0> Never <1> Sometimes <2> Often <3> Always <9> Refused to answer
34	[BAIY40] I am afraid that I might get sick	<0> Never <1> Sometimes <2> Often <3> Always <9> Refused to answer

BDI-Y

Question ID	Question	Answer
35	[BDIY41] I think that my life is bad	<0> Never <1> Sometimes <2> Often <3> Always

		<9> Refused to answer
36	[BDIY42] I have trouble doing things	<0> Never <1> Sometimes <2> Often <3> Always <9> Refused to answer
37	[BDIY43] I feel that I am a bad person	<0> Never <1> Sometimes <2> Often <3> Always <9> Refused to answer
38	[BDIY44] I wish I were dead	<0> Never <1> Sometimes <2> Often <3> Always <9> Refused to answer
39	[BDIY45] I have trouble sleeping	<0> Never <1> Sometimes <2> Often <3> Always <9> Refused to answer
40	[BDIY46] I feel no one loves me	<0> Never <1> Sometimes <2> Often <3> Always <9> Refused to answer
41	[BDIY47] I think bad things happen because of me	<0> Never <1> Sometimes <2> Often <3> Always <9> Refused to answer
42	[BDIY48] I feel lonely	<0> Never <1> Sometimes

		<2> Often <3> Always <9> Refused to answer
43	[BDIY49] My stomach hurts	<0> Never <1> Sometimes <2> Often <3> Always <9> Refused to answer
44	[BDIY50] I feel like bad things happen to me	<0> Never <1> Sometimes <2> Often <3> Always <9> Refused to answer
45	[BDIY51] I feel like I am stupid	<0> Never <1> Sometimes <2> Often <3> Always <9> Refused to answer
46	[BDIY52] I feel sorry for myself	<0> Never <1> Sometimes <2> Often <3> Always <9> Refused to answer
47	[BDIY53] I think I do things bad	<0> Never <1> Sometimes <2> Often <3> Always <9> Refused to answer
48	[BDIY54] I feel bad about what I do	<0> Never <1> Sometimes <2> Often <3> Always <9> Refused to answer

49	[BDIY55] I hate myself	<0> Never <1> Sometimes <2> Often <3> Always <9> Refused to answer
50	[BDIY56] I want to be alone	<0> Never <1> Sometimes <2> Often <3> Always <9> Refused to answer
51	[BDIY57] I feel like crying	<0> Never <1> Sometimes <2> Often <3> Always <9> Refused to answer
52	[BDIY58] I feel sad	<0> Never <1> Sometimes <2> Often <3> Always <9> Refused to answer
53	[BDIY59] I feel empty inside	<0> Never <1> Sometimes <2> Often <3> Always <9> Refused to answer
54	[BDIY60] I think my life will be bad	<0> Never <1> Sometimes <2> Often <3> Always <9> Refused to answer

ADOLESCENT: Problem Alcohol Use

Question ID	Question	Answer
55	[BLCAUDITC1] We would like to ask you some questions about alcohol and drugs. We appreciate you answering honestly and sharing as much information with us as possible. How often do you have a drink containing alcohol?	<1> Never <2> Monthly or less <3> 2 - 4 times a month <4> 2 - 3 times a week <5> 4 or more times a week <6> Refuse to answer
56	[BLCAUDITC2] How many standard drinks containing alcohol do you have on a typical day?	<1> 1 or 2 <2> 3 or 4 <3> 5 or 6 <4> 7 to 9 <5> 10 or more <6> Refuse to answer
57	[BLCAUDITC3] How often do you have six or more drinks on one occasion?	<1> Never <2> Less than monthly <3> Monthly <4> Weekly <5> Daily or almost daily <6> Refuse to answer

Thank you

Question ID	Question	Answer
70	[AENDTIME] Enter end time.	
71	[AENDNOTE] Interviewer (do not read aloud): The survey is now over. Interviewer, please enter any notes below that may explain any unexpected issues. You must	

	press the checkmark at bottom right, to upload the survey.	