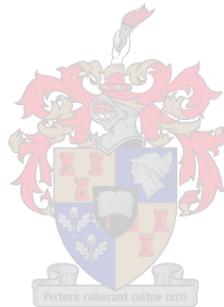


**The subjective experiences and perceptions of care among depressed adolescents
living with HIV attending a community adolescent HIV programme in Harare,
Zimbabwe**

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Thesis presented in fulfilment of the requirements for the Degree of Master of Philosophy
in Public Mental Health at Stellenbosch University

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Declaration

By submitting this thesis electronically, I declare that the entirety of the work contained therein is my own original work, that I am the authorship owner thereof (unless to the extent explicitly otherwise stated) and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

Signature:

Date: December 2016

Abstract

Introduction: Studies in Zimbabwe and elsewhere have found that adolescents with HIV are at risk of depression. Depression has a disabling effect on adolescents' quality of life, increases suicide risk and impacts on their adult lives. There is also evidence from Zimbabwe that depression affects HIV positive adolescents' adherence to antiretroviral medicines (ARVs). Sub-optimal adherence to ARVs results in virological replication and subsequent treatment failure. There are limited alternative treatment regimens available. High viral loads also increase the risk of HIV transmission to sexual partners and children. As HIV-related mortality rates rise in adolescents worldwide, evidence-based, adolescent-focused interventions which prevent and manage depression are urgently needed. If these services are to effectively meet adolescents' needs, it is necessary to understand their own experiences of depression and their perceptions of the care that they have received and need.

Methods: In-depth interviews were conducted with twenty-one HIV positive adolescents, 13-19 years old, diagnosed with major depressive disorder using DSM-V criteria. All participants were attending 'Zvandiri', a community programme for adolescents with HIV in Zimbabwe. The interviews were structured around a body mapping session, a creative arts technique. Participants were asked to create a painted map of their body to assist them in externalizing their somatic and emotional experiences. Verbal and visual data were collected from the interviews and body maps, then analysed thematically.

Results: Participants described a relational model of depression, attributing their experiences of depression to their relationships and interactions with significant people in their lives, primarily family members and peers. A sense of being different from others was common, both due to their HIV status and the impact HIV has had on their life circumstances. Participants described a longing to be important or to matter to the people in their lives. A sense of isolation and rejection was common, as well as grief and loss,

including ambiguous and anticipated loss. Participants' idioms of distress included 'thinking deeply' (*'kufungisisa'*), 'pain', darkness, 'stress' or a lack of hope and ambiguity for the future. Suicidal ideation was described, including slow suicide through poor adherence. Supportive factors were also relational, including the importance of supportive relatives and peers, clinic staff and psychosocial support programmes. Educational assistance and skills training for employment were also important. The results of this study suggest an ecological systems theoretical model for depression in adolescents with HIV, where characteristics at the microsystem level have the greatest influence on young person as they develop through childhood and adolescence. Body mapping was an effective, acceptable methodology for engaging adolescents in an exploration of their own narratives around depression. Participants described feeling relieved having shared experiences, emotions, life events and needs which they had not shared before.

Conclusions and Recommendations: An understanding of HIV positive adolescents' own narratives around depression can help to inform the development and integration of appropriate mental health interventions within HIV care and treatment programmes. Research is needed to validate culturally-sensitive diagnostic tools for depression in young people with HIV. An ecological systems framework should be adopted and utilised to strengthen community, family and peer-based interventions for the prevention and management of depression in adolescents with HIV. However, studies are needed to evaluate the effectiveness, acceptability and feasibility of such family and peer-led mental health interventions in preventing and managing depression and improving adherence to ARVs. This evidence must be disseminated to inform national and international policy and guidelines for adolescent HIV treatment and care.

Opsomming

Uittreksel Inleiding: Studies in Zimbabwe en elders het bevind dat adolessente wat gediagnoseer is met MIV 'n risiko is om depressie te ondervind. Depressie het 'n kreupele effek op adolessente se lewensgehalte, verhoog hulle risiko vir selfmoord en het 'n impak op hulle volwasse lewe. Daar is ook bewyse vanuit Zimbabwe dat depressie affekteer MIV-positiewe adolessente se meewerkendheid aan antiretrovirale medikasie (ARVs). Suboptimale meewerkendheid aan ARVs veroorsaak virologiese replikasie en daaropvolgende behandelingmislukking. Daar is beperkte alternatiewe behandeling regimens beskikbaar. 'n Hoë virale lading verhoog ook die risiko van MIV-oordrag na seksmaats en kinders. Soos die MIV-verwante sterftesyfer van adolessente wêreldwyd styg, is bewysgebaseerde ingryping wat op adolessente fokus, en wat depressie verhoed en beheer dringend nodig. Indien hierdie dienste die behoeftes van adolessente doeltreffend kan bevredig, is dit noodsaaklik om hulle eie ondervindinge van depressie te verstaan en hulle persepsie omtrent die sorg wat hulle ontvang het en benodig.

Metodes: Diepgaande onderhoude was gedoen met 21 MIV-positiewe adolessente tussen die ouderdomme van 13 tot 19jaar oud, wie gediagnoseer is met kliniese depressie gebaseer op DSM-V kriteria. Alle deelnemers het "Zvandiri" bygewoon, 'n gemeenskapsprogram vir adolessente wie MIV-positief is in Zimbabwe. Die onderhoude was gestruktureerd om 'n lyfkaart sessie wat 'n kreatiewe kuns tegniek is. Deelnemers was gevra om 'n geverfde kaart van hulle liggaam te maak sodat dit hulle help met die eksternalisering van hulle somatiese en emosionele ondervindinge. Mondeling en visuele data was ingesamel vanaf die onderhoude en lyfkaarte vir tematiese analisering.

Resultate: Deelnemers het 'n relasionele model van depressie beskryf wat toegeskryf was aan hulle ondervindinge van depressie in hulle verhoudinge en interaksie met belangrike mense in hulle lewe, en wie hoofsaaklik familielede en vriende is. Die gevoel om anders te voel in vergelyking met ander mense was algemeen, weens hulle MIV-status en die impak wat MIV gehad het op hulle lewensomstandighede. Deelnemers het beskryf hoe hulle verlang om belangrik te voel of om saak te maak vir die mense in hulle lewe. 'n Gevoel van isolasie en verwerping was algemeen, asook rou en verlies, insluitend dubbelsinnige en verwagte verlies. Deelnemers se idiome van nood het ingesluit "dink diep" (kufungisisa), "pyn", donkerte, "stres" of 'n gebrek aan hoop en dubbelsinnigheid oor die toekoms. Selfmoord denkbeeldvorming was beskryf, insluitend stadige selfmoord deur swak meewerkendheid. Ondersteuningsfaktore was ook relasioneel, insluitend die belangrikheid van ondersteuningsfamilielede en vriende,

kliniek personeel en psigososiale ondersteuningsprogramme. Opvoedkundige bystand en vaardigheidsopleiding vir indiensneming was ook belangrik. Die resultate van hierdie studie stel voor 'n ekologiese stelsels teoretiese model vir depressie in adolessente met MIV, waar karaktereienskappe by die mikrostelselsvlak die grootste invloed het op jongmense soos hulle ontwikkel deur kinderjare en adolessensie. Lyfkartering was 'n effektiewe, aanvaarbare metodologie vir die betrekking van adolessente in 'n ondersoek van hulle eie verhaal oor depressie. Deelnemers het 'n gevoel van verligting beskryf ná hulle ondervindinge, emosies, en lewensgebeurtenisse gedeel het, en behoeftes wat hulle nog nie voorheen gedeel het nie.

Gevolgtrekkings en Aanbevelings: 'n Begrip van MIV-positiewe adolessente se eie verhale rondom depressie kan help met die ontwikkeling en integrasie van toepaslike geestelikesondheidsingrypings binne MIV-sorg en behandelings programme. Navorsing word benodig met die geldigheidsbepaling van kultuursensitiewe diagnostiese instrumente vir depressie in jongmense wat gediagnoseer is met MIV. 'n Ekologiese stelselsraamwerk moet gebruik word vir die versterking van gemeenskap, familie, en portuurgebaseerdeingrypings, en vir die voorkoming en bestuur van depressie in adolessente wat gediagnoseer is met MIV. Studies word egter benodig om die doeltreffendheid, aanvaarbaarheid, en uitvoerbaarheid te evalueer soos die van die familie en poortuurgeleide geestelikesondheidsingryping, in die voorkoming en bestuur van depressie en verbetering van meewerkendheid aan ARVs. Hierdie bewyse moet meegedeel word om nasionale en internasionale beleid en riglyne vir adolessente MIV-behandeling en sorg.

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Over the past 11 years, my professional career has been driven by a deep concern and interest in the relationship between the mental health of adolescents with HIV and their clinical outcomes. This study has allowed me to further explore this area and I am sincerely grateful to the young people who participated in this study for so generously sharing their experiences of depression and the events in their lives. I now commit to working hard so that their experiences can be used to shape service delivery for adolescents with HIV across Zimbabwe and that this may also influence policy and guidelines worldwide.

I feel deeply privileged and thankful for the opportunity to be supervised by the vastly experienced Professor Kagee, who has patiently mentored, encouraged and guided me through this work. I have learned a tremendous amount which will assist me now and in the future. I sincerely hope that we can continue to study the field of adolescent HIV and mental health in the future.

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Dedications

This work is dedicated to all the children, adolescents and young people living with HIV who attend the Zvandiri programme in Zimbabwe. Thank you for inspiring me with your courage, resilience and determination over the past 11 years.

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List of Abbreviations

AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral therapy
ARVs	Antiretroviral medicines
HIV	Human Immunodeficiency Virus
mhGap	Mental Health Gap Action Programme
MoHCC	Ministry of Health and Child Care
PMTCT	Prevention of Mother to Child Transmission
WHO	World Health Organisation

Definitions

Adolescents are young people aged 10 -19 years old (WHO, 2013a)

Antiretroviral medicines (ARVs) are medicines which control HIV disease through suppressing the multiplication of the virus, thereby protecting the immune system (WHO, 2013b)

Mental disorders are clinically significant conditions characterised by changes in thinking, mood or behaviour associated with personal distress and impaired functioning (WHO, 2010)

Mental health is a state of wellbeing in which the individual realises his or her own abilities, copes with the normal stresses of life, works productively and fruitfully and is able to make a contribution to his or her own community (WHO, 2010)

Zvandiri is a Shona word meaning “As I am” and was used by adolescents living with HIV to name their community support programme in Harare, Zimbabwe (Jackson et al. 2015)

Chapter 1: Introduction

This study sought to explore the subjective experiences and perceptions of care among HIV positive adolescents with depression and attending the Zvandiri community programme in Harare, Zimbabwe.

1.1 Depression in adolescents with HIV

Depression is a common mental disorder which has a disabling effect on adolescents' quality of life and functioning, increases their risk of suicide and continues to impact on their lives as they grow up into adulthood. Of all mental disorders, depression is the most common in adolescents and is the largest contributor to the global burden of disease in this age group (Patton et al., 2012). Although there is a wealth of literature on depression in different groups of adolescents, there has been a significant lack of attention to depression in adolescents living with HIV. However, recent studies in Zimbabwe and elsewhere have found that adolescents with HIV are at risk of depression (Khan 2013; Patel et al. 2007, Mellins 2013).

1.1.1 Depression and quality of life in adolescents with HIV

Depression impacts on adolescents' normal development, quality of life, social and family functioning, school performance and suicide risk. However, there has been a lack of research to explore the experience, impact and manifestations of depression in adolescents with HIV. Adolescents with HIV already face overwhelming psychological and social stressors (Bernays et al. 2014a; Campbell et al. 2012; Kidia et al. 2014; Lowenthal et al. 2014; Mavhu et al. 2013; Parsons 2012; WHO 2013a). These include stressors associated with orphaning and recurrent change of households (Mavhu et al., 2013; Parsons, 2012), disclosure of HIV status (Kidia et al., 2014), recurrent illness and hospitalisation (Ferrand et al., 2007) and extended periods of absence from school and stigma and discrimination

(Mavhu et al., 2013). In addition, many HIV positive children are born with impaired immunity and suffer lung, heart and brain damage from an early age, develop hearing, visual and learning impairments, and have disfiguring skin conditions (Ferrand et al., 2010), further exacerbating their experience of stigma. In addition, as adolescents grow and develop a desire for relationships and families of their own, they face decisions around if, when and to whom to disclose their HIV status and concerns around preventing transmission of HIV to their partners and children (WHO, 2013a). These stressors may well increase the risk of adolescents to depression as well as exacerbating their experience of depression. Yet this needs further research.

1.1.2 Depression and HIV outcomes in adolescents with HIV

Depression has been shown to be associated with poor adherence to antiretroviral medicines (ARVs) in adolescents with HIV (Mavhu et al., 2013). Sub-optimal adherence to ARVs results in virological replication and subsequent treatment failure. Although studies have not been conducted to establish virologic suppression rates in adolescents on ART, programmatic data from facility and community programmes for adolescents with HIV in Harare, confirms rates of treatment failure between 30-40%, correlating with psychological distress and depression (personal communication with Makadzange, 2014; personal communication with Pascoe, 2014). In the event of treatment failure, there are limited alternative treatment regimens available for adolescents with HIV who require life-long treatment, increasing the risk of AIDS-related illness and death.

The negative impact of depression on adolescents' adherence to ARVs also has public health implications. Adolescents who are not virologically suppressed and are sexually active are at higher risk of transmitting HIV to their partners and infants. Furthermore, adolescents with HIV have often been heavily treated with ARVs throughout their lives and have multiple drug resistance, as confirmed by a study of HIV-perinatally infected young mothers in Harare, Zimbabwe (Mupambireyi et al, 2014). Therefore, non-adherent

adolescents are not only at risk of transmitting HIV but of transmitting HIV that is resistant to antiretroviral medicines.

1.2 The burden of adolescent HIV

HIV has had a devastating impact on children and adolescents worldwide. Of the 35 million people living with HIV, 3.2 million are children under 15 years of age and 2.1 million are adolescents aged 10-19 years (Joint United Nations Programme on HIV/AIDS (UNAIDS), 2014). 90% of the children living with HIV are in Sub-Saharan Africa. Over the past ten years, global efforts to scale up paediatric HIV prevention, treatment and care have had a substantial impact on the HIV pandemic in children. The acceleration of prevention of mother to child transmission (PMTCT) interventions has contributed to a 40% decline in the number of new HIV infections in children, from an estimated 400,000 in 2009 to an estimated 240,000 new infections in 2013 (WHO, 2014a). Furthermore, mortality rates amongst HIV-infected children have declined significantly due to increasing access to paediatric antiretroviral therapy (ART) (WHO UNAIDS UNICEF, 2010). Children born with HIV or infected since birth are now growing up into adolescence and adulthood and having children of their own (Lowenthal 2014; WHO 2013a).

Despite these advances, children and adolescents continue to lag behind adults in terms of access to HIV diagnostic services and antiretroviral treatment, with 76% of children with HIV who are eligible for ART not yet receiving treatment (Joint United Nations Programme on HIV/AIDS (UNAIDS), 2014). Adolescents in particular have now been recognized as neglected by the HIV response worldwide (Bernays et al., 2014a; WHO, 2013a) and HIV is now the second leading cause of death in adolescents, with 300 deaths every day (WHO, 2014b). Whilst the global number of HIV-related deaths decreased by 30% across all age groups between 2005 and 2012, HIV-related deaths among adolescents increased by 50% (UNAIDS, 2013). The increase in HIV-related deaths in adolescents is reported to be due to a range of factors including the poor prioritization of adolescents in national HIV plans,

inadequate provision of accessible and acceptable HIV testing and counselling (HTC) and treatment services and lack of support for adolescents to remain in care and adhere to antiretroviral therapy (ART) (WHO, 2013a). However, there has been minimal research into the determinants of HIV-related morbidity and mortality in the adolescent age group, including mental health, and a similar lack of evidence-based interventions to improve these outcomes.

1.3 The need for research

Despite the increasing evidence of depression in adolescents with HIV and the global concern around adherence challenges and HIV-related mortality in this age group, the mental health needs of this group have been largely neglected. There is a critical lack of research exploring the prevalence, manifestation, impact and management of depression in adolescents living with HIV. As HIV-related mortality rates continue to rise in adolescents worldwide, evidence-based, adolescent-focused interventions which prevent and manage depression are urgently needed. If these services are to effectively meet adolescents' needs, it is necessary to understand their own experiences of depression and their perceptions of the care that they have received and need.

1.4 Brief chapter overview

This thesis contains 6 chapters. In Chapter 1, I introduce the context for this study by giving an overview of the global burden of HIV in adolescents. I introduce psychosocial and mental health issues for this group of young people and highlight the current gap in mental health research in adolescents with HIV, before then stating my research aim and questions.

In chapter 2, I begin my literature review with an overview of mental illness in adolescents before then focusing on depression in this age group. I then describe the literature on depression and psychosocial stressors in adolescents with HIV. Finally, I present my

structured review of the literature focusing on the expressed experiences and perceptions of care of HIV positive adolescents with depression.

In Chapter 3, I describe my study design and methods, including my rationale for the use of body mapping as a participatory, qualitative data collection tool. I provide a description of the study site, study sample, data collection and analysis processes and ethical considerations for the study. In Chapter 4, I present the data from this qualitative research study before then going on to discuss the research findings in Chapter 5. I propose a theoretical framework for depression in adolescents with HIV and describe the implications of this study in future policy and practice. I complete my thesis in Chapter 6 with final conclusions and recommendations for future research, policy and programming.

1.5 Research Aim and Questions

Aim of the Research:

This research seeks to explore the subjective experiences and perceptions of care among HIV positive, depressed adolescents (13-19 years old) on antiretroviral therapy and attending a community programme for adolescents with HIV in Harare, Zimbabwe.

Research Questions:

Through this research study, I aim to answer the following questions:

1. What are the subjective experiences of depression among depressed adolescents living with HIV attending a community adolescent HIV programme in Harare, Zimbabwe?
2. What idioms of distress are used by depressed adolescents living with HIV attending a community adolescent HIV programme in Harare, Zimbabwe?

3. To what extent do depressed adolescents living with HIV attending a community adolescent HIV programme in Harare, Zimbabwe perceive that their experiences are being addressed by families, communities and service providers?

Chapter 2: Literature Review

2.1 Introduction

In this chapter, I begin by introducing the global burden of mental health disorders in adolescents. I review the existing literature on prevalence, risk factors and management of depression in adolescents. I then describe the literature on depression and psychosocial stressors in adolescents living with HIV. Finally, I describe my structured review of the available literature on the self-reported experiences of HIV positive adolescents with depression and their perceptions of care.

2.2 The global burden of mental health disorders in adolescents

There are 1.2 billion young people aged 10-19 years worldwide, representing one quarter of the world's population (UNICEF, 2011). The greatest proportion of young people are living in low and middle income countries due to the combination of high fertility rates and the success of child survival programmes (Sawyer et al., 2012; WHO, 2014b). Adolescents, defined as young people aged 10-19 years (WHO, 2013) often represent more than 20% of a country's population (Clifton & Hervish, 2013). The health, education and skills acquired during adolescence are critical both for adolescents' individual growth and development and contribution at family, community and national level, but also for societal and economic development in the future (Sawyer et al., 2012).

In comparison with other age groups, adolescence is typically considered to be a period of relatively good health, based on indicators of mortality, chronic disease burden and hospitalisations (Sawyer et al. 2012). Yet there is a significant burden of disease in this age group (Patton et al., 2012) arising from accidents, HIV, early pregnancy, unsafe abortions, risky behaviours such as tobacco consumption and drug use, violence and mental health issues (UNICEF, 2011).

Over the past two decades, the prevalence of mental health disorders in adolescents has increased and now represents the largest contribution to the burden of disease in young people (Gore et al., 2011). An estimated 20% of young people are now affected by a mental health disorder (UNICEF, 2011) with 75% of mental disorders presenting before the age of 24 years and 50% before 15 years (Kessler et al., 2005). In the 15-19 year old age group, depression is the largest contributor to the global burden of disease and in the 10-24 year old age group, self-inflicted injury is the second leading cause of death (Patton et al., 2014). Suicide is one of the three leading causes of mortality among people aged 15–35 years and neuropsychiatric disorders are the leading cause of disability in this age group (Gore et al., 2011). In a global community consultation with adolescents led by the World Health Organisation (WHO), the respondents identified mental health problems as the most important of all health problems affecting young people (WHO, 2014b).

In a review of mental health in adolescents and young people (Patel et al. 2007), the authors found that investigators have tended to focus on children and older adults, rather than young people, and that data are not stratified, making it difficult to determine prevalence of mental health disorders in this age group. Furthermore, there is very limited prevalence data from developing countries. However, from their review of a combination of studies from Australia, the Netherlands and the USA, they report that at least one out of four to five young people in the general population will experience at least one mental disorder in any given year. They also report that five of the ten disability affected life years (DALYs) in the 15-44 year old population are mental disorders and include unipolar depressive disorder, alcohol use disorders, self-inflicted injuries, schizophrenia and bipolar affective disorder. Furthermore, the authors report that many of the other leading causes of DALYs have mental health dimensions. For example, young people with mental disorders are at greater risk of contracting HIV than their peers without mental illness. In a review of studies on HIV/AIDS in young people, including psychosocial and psychiatric risk factors for acquiring HIV, adolescents and young people with mental illness were more likely to engage in high-risk

sexual behaviour and drug use than their peers without mental illness (Donenberg & Pao, 2005).

Mental health disorders impact on adolescents' development educational achievement due to impaired functioning, risk taking behaviours and vulnerability to other health challenges, in addition to impacting on social and economic status both during adolescence and in adulthood. There are both human rights and public health imperatives to ensure that mental health disorders in adolescents are diagnosed and treated effectively, in order to promote adolescents' normal development and to protect them from harm. The World Health Organisation has responded to the global burden of mental health conditions in adolescents and current gap in service provision in its Global Mental Health Action plan for 2013-20 (WHO 2013), which makes recommendations for the scale up of mental health services for adolescents.

2.3 Depression in adolescents

2.3.1 Prevalence, diagnosis and manifestations of depression in adolescents

Of all mental disorders, adolescents are most commonly affected by depression or anxiety. Depression, or unipolar depression, is a common mental disorder characterised by "*depressed mood, loss of interest or pleasure, decreased energy, feelings of guilt or low self-worth, disturbed sleep or appetite, and poor concentration*" (Marcus et al, 2012, page 1). Comorbidity between major depressive disorder and generalised anxiety disorder is also common in adolescents (Brady, 1992). Depressive symptoms may be chronic or recurrent and significantly impair an individual's functioning. As stated in section 2.2, depression is the largest contributor to the global burden of disease in 15-19 year olds (Patton et al., 2014). Although it is often reported that the highest burden of depression is in low and middle income countries, others state that there is insufficient evidence to confirm this increased rate due to the lack of research in low income countries (Thapar et al. 2012). A meta-

analysis in 2006 of 26 studies involving children born between 1965 and 1996 estimated the point prevalence of major depressive disorder in adolescents to be 5.6% (SE .3%). Rates were slightly higher among girls than boys (Costello et al. 2006). Although depression commonly presents in adolescence, it is often unrecognised and untreated at this time (Thapar et al. 2012) and is only addressed in adulthood having had a considerable impact on the individual's mental health, functioning and parenting (Kessler et al., 2012).

Depression is diagnosed using a standardised set of diagnostic criteria as set out in two main classification systems - the diagnostic statistical manual of mental disorders (DSM) (American Psychiatric Association, 2013) and the international classification of diseases-10 (ICD-10) (World Health Organisation, 2010). In the DSM version V (DSM-V), criteria for a diagnosis of major depressive disorder include having at least five of nine depressive symptoms for at least two weeks or more, of which one must be depressed mood, including irritability, or loss of interest in activities. Although the clinical and diagnostic features of depression are largely the same in adults and adolescents, the DSM criteria recognise that irritability may be more common than depressed mood in children and adolescents (American Psychiatric Association, 2013), in addition to disruptive behaviour, including tantrums (Thombs, Roseman, & Kloda, 2012). Anxiety and unexplained somatic symptoms are also common. In comparison with adults, depressed adolescents are reported to have more frequent suicide attempts and thoughts, particularly in teenage girls (Dodig-Curković, Curković, Radić, Degmečić, & Fileković, 2010).

The severity and frequency of symptoms determine whether depression is classified as mild, moderate or severe (American Psychiatric Association, 2013). Depression significantly impairs adolescents' ability to function at school or to cope with daily life. The average duration of a depressive episode is nine months (Hazell, 2002) and 70% of adolescents experience a subsequent depressive episode within 5 years, with symptoms recurring later in adulthood (Hazell 2002; Thaparet al. 2012). The literature describes depression as

contributing to a variety of negative outcomes in adolescents including behavioural problems, poor school achievement, early pregnancy, impaired social and family functioning in adolescence (Crivello, Morrow, & Wilson, 2013; Thapar et al., 2012a; Thapar, Collishaw, Potter, & Thapar, 2010), increased risk of obesity, smoking and substance misuse (Keenan-Miller, Hammen, & Brennan, 2007) and suicide (Thapar et al. 2012). In turn, depression has a considerable impact on adolescents' present and future morbidity and mortality.

2.3.2 Contributing factors for depression in adolescents

Depression results from a complex interaction of social, psychological and biological factors. Evidence suggests that genetic and biological factors, which then interact with environmental factors to modify the risk of depression, contribute to the development of depression (Patel et al. 2007).

The literature describes multifactorial causes for mental health disorders in young people. The highest risk factors for depression in adolescence are reported to be a family history of depression (Patel, Flisher, Hetrick, & McGorry, 2007; Thapar et al., 2012a) and exposure to psychosocial stress. Whereas not all adolescents will develop depression following acute stressful events and chronic adversity, those with an increased genetic risk may be more susceptible to the effects of those events, contributing to depression. In one paper, chronic, severe stressors that affect relationships with relatives, peers and social networks are reported to present the most significant psychosocial risk for depression (Thapar et al., 2012a). Others describe a strong association between poverty, social disadvantage, violence and child abuse, educational challenges and cultural factors (Patel, Flisher, Hetrick, & McGorry, 2007). War, displacement, orphanhood and HIV are also reported to contribute to the risk of depression in this age group, particularly where there has been chronic exposure or there is a family history of depression (Cluver et al. 2007; Patel et al. 2007).

2.3.3 Treatment for depression in adolescents

There have been significant advances in the management of depression in adolescents over the past two decades. Treatment typically involves pharmacotherapy and psychotherapy as the two main forms of treatment. However, the literature reports limitations in both methods. Whilst tricyclic antidepressants are effective in adults, a meta-analysis of the efficacy and acceptability of Selective serotonin reuptake inhibitors (SSRIs) versus tricyclic antidepressants (TCAs) in 7 – 25 year olds found the efficacy of SSRIs to be superior to TCA therapy. SSRIs were also better tolerated (Qin et al., 2014).

Although Serotonin Selective Reuptake Inhibitors (SSRIs) can be used in major depressive disorder, studies have demonstrated a risk of increased suicidality associated with the use of SSRIs in adolescents compared with a placebo group (Hetrick & McKenzie, 2012). The use of SSRIs is therefore restricted to the judicious use of Fluoxetine, in combination with psychotherapy. In cases of mild to moderate depression, psychotherapy is the first line of treatment. A variety of structured psychotherapies are used with adolescents with depression including cognitive behavioural therapy (CBT), behavioural, cognitive, interpersonal, problem solving, play and psychodynamic.

2.4 Depression in adolescents with HIV

2.4.1 Prevalence and risk factors for depression in adolescents with HIV

There is a dearth of evidence in the literature on the prevalence of depression in adolescents with HIV. Research studies have largely focused on the burden of HIV disease, biomedical outcomes and adherence to ART (Bandason et al., 2013; Bygrave et al., 2012; Ferrand et al., 2007; Kim, Gerver, Fidler, & Ward, 2014; Ryscavage, Anderson, Sutton, Reddy, & Taiwo, 2011; Shroufi et al., 2013). However, there is increasing awareness that genetic, biomedical, familial and environmental risks mean that they are at high risk of mental health

disorders, including depression (Mellins & Malee, 2013) and that there is a high burden of mental illness in this group of adolescents (Patel, Flisher, Hetrick & McGorry 2007; Malee et al. 2011). There is also evidence to suggest that youth living with perinatal HIV infection may be equally, if not more vulnerable to behavioural and emotional problems than comparison controls (Cluver et al., 2007).

An extensive review of 38 studies (Mellins & Malee, 2013) found that adolescents born with HIV following transmission of HIV infection from their mother experience emotional and behavioural problems, including psychiatric disorders, at higher than expected rates, often exceeding those of the general population and other high-risk groups. However, the review highlights the gap in research in to the specific role of HIV infection in contributing to mental health disorders as young people with HIV are commonly exposed to multiple risk factors associated with mental health disorders in other populations, including biomedical, genetic and environmental factors. The authors of the review also state that HIV and health status are not reliable predictors of mental health disorders in this age group, as multiple studies demonstrated factors of age, poor cognitive functioning, parental health and mental health, stressful life events and neighbourhood disorder as contributing factors for poor mental health outcomes. The authors report that there are therefore challenges in determining the aetiology of mental health disorders, including depression, in this age group (Mellins & Malee, 2013).

2.4.2 Psychosocial stressors in adolescents with HIV

The scale-up of HIV diagnostic services and antiretroviral therapy for children born with HIV has resulted in improved survival for perinatally HIV-infected children who are now growing up in to adolescence and adulthood. Yet despite the global success of antiretroviral treatment programmes and an overall decrease in AIDS-related deaths, mortality rates continue to increase in the adolescent age group (UNAIDS, 2013). Until recent years, this

emerging adolescent HIV epidemic has been largely unrecognised (Bernays, Jarrett, Kranzer, & Ferrand, 2014b; WHO, 2013a) but the alarming mortality rates in adolescents have now led to a surge of interest in this age group and a corresponding growth in research in this area. There is now growing awareness of the psychosocial determinants of health in this age group and their impact on morbidity and mortality in young people growing up with HIV, whether they were born with HIV or infected since birth.

It is now recognised that this group of young people living with HIV often face multiple, recurrent, sustained psychosocial stressors (WHO 2013b; Lowenthal et al. 2014) and that these impact on their HIV outcomes as well their mental health. They are commonly orphaned and have spent their childhood caring for sick relatives or are grieving for parents and siblings, with minimal attention to the impact of the multiple losses in their lives by families and communities (Parsons, 2012). They often live in extended families and are required to move between different households as they grow up (Mavhu et al., 2013; Willis et al., 2014) limiting the opportunities for benefiting from long-term stable family environments and disrupting schooling and peer networks. In addition, HIV positive children and adolescents often face considerable challenges in school due to stigma and discrimination, recurrent absenteeism due to ill health or clinic attendance and cognitive impairment (Lowenthal et al. 2014; Willis et al. 2014; Laughton et al. 2013), although more research is needed in this area.

Adolescents with HIV also continue to experience clinical complications, despite the roll out of antiretroviral therapy. A study in Harare, Zimbabwe found HIV to be the most common cause of adolescent hospitalisation due to opportunistic infections. There was also a high burden of chronic of paediatric HIV infection (Ferrand et al., 2010).

The impact of disclosure is traumatic in itself as young people are required to come to terms with their HIV status and mode of infection. Yet this trauma is commonly exacerbated by the

impact of late or accidental disclosure in an unstructured, unsupportive manner (Butler et al. 2009; Kidia et al. 2014; Lowenthal et al. 2014; Willis et al. 2014;). The need for long term medication and adherence to antiretroviral medicines, whilst trying to conceal their medication from relatives and peers, is an immense burden on young people and jeopardises optimal adherence (Mavhu et al., 2013). Furthermore, the implications of chronic skin infections, growth and developmental impairments and long term treatment toxicities presents further challenges for HIV positive young people (Ferrand et al. 2012; Lowenthal et al. 2014). Pubertal delay contributes to the stigma and discrimination they experience in their lives and cognitive impairments impact on school performance and the attainment of academic qualifications, further impacting on future employment and socioeconomic status.

The adolescent period is characterised by the need to associate and identify with peers. Yet adolescents with HIV are commonly dealing with a range of issues which separate them from their peers, compounded by the burden of secrecy around their HIV status and its impact on their lives. As adolescents grow and develop, their emerging sexuality and desire for relationships and families of their own contribute further emotional stress in their lives as they face decisions around disclosure of their HIV status to partners (WHO, 2013b).

2.4.3 The impact of depression and psychosocial stressors on ART adherence

Research from Harare, Zimbabwe has demonstrated that depression is associated with poor adherence to antiretroviral therapy in adolescents with HIV. There is also evidence to suggest that the wide range of psychosocial stressors which adolescents with HIV experience also impact on adherence to ART and adherence is well recognised to be challenging in the adolescent age group. Adherence in adolescents is affected by a wide range of factors including late disclosure, poor treatment literacy, the desire to conceal the medicines from others, side effects, religious and cultural perceptions of treatment, lack of support at home and forgetting to take the medicines (Bhana et al., 2014; Hosek, Harper, &

Domanico, 2005; Mavhu et al., 2013; Mupambireyi, Bernays, Bwakura-Dangarembizi, & Cowan, 2014; Willis et al., 2014).

Yet the effectiveness of antiretroviral therapy depends on high levels of adherence if virological suppression is to be achieved. Virological failure is increasingly common in adolescents (Nachega et al., 2009; Ryscavage et al., 2011), resulting in the need for 'second' and 'third line' treatment regimens. In most parts of the world, the availability of a range of treatment options is severely limited. However, an increasing number of adolescents report that despite a comprehensive understanding of the importance of ART and adherence, they are tired or bored of being on treatment and lack the motivation to adhere well (Personal communication, Africaid 2015). Whereas poor adherence to antiretroviral drugs results in inadequate viral suppression and subsequent treatment failure, these diverse, complex challenges threaten to override any therapeutic benefit of antiretroviral therapy if not adequately addressed. Despite the early studies in Harare, Zimbabwe, there has been a significant gap in other research to explore the impact of depression in HIV in this population.

2.4.4 The lived experiences of adolescents with HIV and depression

I conducted a structured review of the literature on the experiences of HIV positive adolescents with depression. I searched PubMed (2000 to current) and the search terms included experiences, depressive disorder, depression, adolescent and HIV. Only publications in English language were searched. Studies from all countries were included. Through this search, no studies were found on the lived experiences of depression in adolescents with HIV. I therefore widened the search to the lived experiences of HIV in adolescents. One study was found from Harare, Zimbabwe.

The study in Harare, Zimbabwe explored the lived experiences of adolescents with HIV and also highlighted the risk of depression in adolescents with HIV (Mavhu et al. 2013). In a cohort of 229 adolescents living with HIV, psychological well-being was poor with a median score on the Shona Symptom Questionnaire of 9/14. In this study, 63% of adolescents were at risk of depression and this correlated with poor adherence. Psychosocial stressors in this group included verbal abuse, stigma and discrimination. However, this study did not set out to explore adolescents' experiences of depression *per se*. Bearing in mind the lack of other studies, there is therefore a clear gap in the literature on the lived experiences of depression with HIV and depression.

In contrast to the lack of studies in adolescents, a few studies have been conducted to explore the way in which adults conceptualise and describe depression and its manifestation in their lives. One study in South Africa found that participants were more likely to report somatic symptoms because they attributed these symptoms to HIV or ARVs and therefore perceived them as medically relevant. Yet participants were less likely to disclose affective, cognitive, and behavioural symptoms due to their unfamiliarity with depression as a psychiatric disorder (Andersen, Kagee, O'Cleirigh, Safren, & Joska, 2014). Similarly, a study in Uganda found that adults attributed their depression to HIV and ARVs, specifically news of the HIV diagnosis, a fear of dying, and the potential socioeconomic consequences of their HIV infection on their family, ART side-effects and continued bad health. The concept of 'thinking too much' was commonly referred to (Okello et al., 2012)

2.4.5 The perceptions of care among HIV positive adolescents with depression

I conducted a second review of the literature on the perceptions of care among HIV positive adolescents with depression. Again, no studies were found. However, in the same study with HIV positive adolescents in Harare, Zimbabwe (Mavhu et al., 2013), participants confirmed that whilst support group attendance is helpful, they described the difficulties of coping with life outside of the support groups. Caregivers were perceived by adolescents to lack the knowledge and skills required to support them with adherence to ART or communications

around dating and relationships. Adolescents also described their caregivers as perceiving them to have no future. These perceptions were corroborated by caregivers of adolescents in the study when they described feeling ill-equipped to support the children in their care, including with adherence.

In response to the study findings in Harare, a peer-led psychosocial intervention was then developed for adolescents with HIV, known as the Community Adolescent Treatment Supporters (CATS) intervention. Young people living with HIV, 17-24 years old, are trained and mentored as peer counsellors and work within their own community and health facilities providing counselling and psychosocial support for their HIV positive peers. Whilst their primary role is to support adherence to ART, their daily interactions with their peers draws on elements of problem-solving, motivational interviewing and cognitive behavioural therapy and has been reported to have benefits for young people's broader psychosocial well-being, as well as adherence (Jackson et al. 2015). In addition to the CATS intervention, the study also led to the development of a 10-session caregiver intervention aimed at improving their skills and confidence to support their HIV positive adolescents. Programmatic evidence suggests these have been beneficial in improving communication, parenting and support for their adolescents.

The CATS intervention has also been found to improve self-reported adherence, psychosocial well-being and retention in care among adolescents with HIV, compared with adolescents receiving standard of care in a rural setting of Zimbabwe, Adolescents receiving the CATS intervention reported improved care and support from their caregivers and health workers (Willis et al, 2015). The CATS intervention has recently been described as a useful approach for the delivery of peer-led, mental health support for adolescents living with HIV (Kidia, Ndhlovu, Jombo, Abas, & Makadzange, 2015).

The CATS model and other programmes in different countries (Bhana et al., 2014; McKernan McKay et al., 2014) provide important evidence to support the role of community

mental health interventions for adolescents with HIV. However, further research into the role and effectiveness of mental health interventions for young people with HIV is now urgently needed bearing in mind the scale of the HIV epidemic, increasing mortality rates in this age group and the evidence of depression in this population. While significant advances have been made in the scale up of treatment programmes for children and adolescents with HIV, there has been a critical lack of attention to the integration of mental health services within HIV treatment and care.

2.5 Theoretical Framework for the study

This study sought to explore the subjective experiences and perceptions of care of HIV positive adolescents with depression. The research questions focus at the individual level, the adolescent, and then proceed to explore the adolescents' perceptions of the care they receive from caregivers, health workers and communities. This study was therefore based on Bronfenbrenner's ecological systems theory, a developmental psychology theory. In the ecological systems theory, human development is affected by the reaction between the person and their social relationships and world around them (Bronfenbrenner 1986). Bronfenbrenner proposes that the environment is divided into five levels: *the microsystem*, *the mesosystem*, *the exosystem*, *the macrosystem* and *the chronosystem*. The results from this study determined the way in each level of Bronfenbrenner's ecological systems theory influenced HIV positive adolescents' experiences of depression and their perceptions of the care they receive.

2.6 Conclusion

This literature review has demonstrated that despite the advances in the treatment of HIV, AIDS-related deaths continue to increase in the adolescent population. Although there is increasing evidence of the range and complexities of psychosocial stressors in this age group and their risk of developing mental health disorders, including depression, researchers have neglected to understand the way in which young people themselves perceive their

condition and the care they require. The World Health Organisation has called for the integration of mental health services within primary health care (World Health Organization, 2013). Furthermore, within its guidelines on Adolescent HIV, WHO calls for research in to the mental health needs of young people growing up with HIV (WHO, 2013a). This study sought to respond to that call and to inform future policy, programming and service delivery both in Zimbabwe and internationally, by exploring the subjective experiences and perceptions of care among HIV positive, depressed adolescents (13-19 years old) on antiretroviral therapy and attending a community programme for adolescents with HIV in Harare, Zimbabwe.

Chapter 3: Methods

3.1 Research Design

This qualitative, exploratory study took place over a twelve month period between July 2014 and June 2015.

3.1.1 Participants

Twenty-one adolescents living with HIV, 13-19 years old, with a diagnosis of major depressive disorder (MDD) were engaged by the researcher (NW) in a one-on-one in-depth interview focused around a body mapping session. Each interview lasted between 1 and 1.5 hours. The study participants were purposively recruited to the study from the Zvandiri community programme for children and adolescents living with HIV in Harare, Zimbabwe, following a diagnosis of MDD by a psychologist or psychiatrist. Each interview generated audio data from the verbal narrative and visual data from the body map.

3.1.2 Procedures

The Zvandiri programme provides community-based psychosocial support and health services for over 5,000 children and adolescents living with HIV in Zimbabwe (Jackson et al. 2015). As part of its standard monitoring for programme beneficiaries, the Zvandiri multidisciplinary team conducts routine clinical and psychosocial assessments for children and adolescents in the programme, which includes screening of adolescents for depression using the Shona Symptom Questionnaire (SSQ) (Patel, Simunyu, Gwanzura, Lewis, & Mann, 1997). Adolescents scoring ≥ 8 on this 12 point scale or with psychological concerns, are referred to the Zvandiri programme's resident psychologist or to a psychiatrist at the Child and Adolescent Psychiatric Unit at Parirenyatwa Hospital for clinical diagnostic assessment using DSM-V criteria (American Psychiatric Association, 2013). In addition, 55%

of adolescents registered in the Zvandiri programme receive their clinical care at Newlands Clinic in Harare where there is a resident psychologist who conducts psychological assessments, including for depression, as part of their routine care.

During the study period, the psychiatrist or psychologist introduced the study to each adolescent meeting the study inclusion criteria. Adolescents were informed that if they would like to find out more about participating in the research, that they could meet with the researcher who was available in the same building on the same day. In this way, adolescents were able to choose to present themselves to the researcher if they wished to learn more about the study and their right to confidentiality was not violated.

If the adolescent chose to present to the researcher, the study was then explained in full and the participant was invited to participate. If the adolescent did not choose to present himself to the researcher, this has in no way affected the continued care provided.

Purposive sampling was used for maximum variability. Although the researcher aimed to recruit an equal number of males and females to ensure equal gender representation, participants were recruited until thematic saturation - a situation where qualitative data collection reaches a point where no new constructs emerge (Bowen, 2008; Green & Thorogood, 2009; Ritchie & Lewis, 2003). A total of 11 males and 10 females were identified and recruited, with a total of 21 interviews conducted.

3.1.3 Inclusion and Exclusion Criteria

The inclusion and exclusion criterion were as follows:

Inclusion criteria: 13-19 years old, males and females who are HIV positive, diagnosed with major depressive disorder, signed informed consent from caregiver, signed assent from

adolescent and registered in Africaid's Zvandiri programme. Although adolescents are defined as 10-19 years (WHO, 2013a), this period is associated with profound physical and neurodevelopmental changes. In early adolescence, abstract and metaphorical thought is still developing (Sawyer et al., 2012). Whilst 10-12 year olds may be able to express themselves through body maps, they may not be as able to reflect on or describe what they have expressed, which is needed for the research.

Exclusion criteria: Did not meet inclusion criteria, did not obtain consent from caregiver, were not able to assent, were acutely unwell or had a serious mental disorder such as schizophrenia or were hospitalised.

3.1.4 Research Instruments

The aim of the research is to explore the subjective experiences and perceptions of care among HIV positive, depressed adolescents (13-19 years old) on antiretroviral therapy and attending a community programme for adolescents with HIV in Harare, Zimbabwe. In order to achieve this aim, a methodology was required which would safely and effectively engage young HIV positive research participants with depression in an exploratory process which would enable them to externalize their experiences of depression and perceptions of care. A participatory, qualitative approach was therefore chosen, drawing on narrative therapy with body mapping as the methodological tool for data collection.

Narrative therapy is a therapeutic process which encourages the storyteller to regain a sense of authorship and re-authorship of their own experiences in the telling and retelling of their own story (White & Epston, 1990), to see their experiences for what they are rather than as other people would have them believe them. In narrative therapy, storytelling provides the opportunity for a holistic exploration of the participant's experiences and provides a deeper insight in to the ways in which participants interpret and understand their

world. Narrative enquiry has been described as an effective means for understanding the complex individual experience of health and illness. It has also been suggested that storytelling offers greatest value where the human experience of illness is unknown or unexplored (Greenhalgh, 2001).

Body mapping is one participatory, therapeutic process which is based on narrative therapy. It is the process of creating body maps using drawing, painting or other art-based techniques to visually represent aspects of people's lives, their bodies and the world they live in (Gastaldo et al. 2012). It is a creative, therapeutic technique which combines bodily experience and visual artistic expression. In the body mapping process, an outline of the participant's body is produced by tracing around his or her body on a large sheet of paper. The participant is then guided through an exploratory process in which he/she uses colours, pictures, symbols and words to represent his lived experiences, in the way he/she perceives them. Body mapping provides a medium for the participant to externalize somatic and emotional experiences in a way that has meaning for him/her and to express their understanding in a way which best suits him/her (Solomon, 2002).

Body mapping has been used as a therapeutic tool for people living with HIV and AIDS (Brett-MacLean, 2009; Solomon, 2002). Similarly, drawings are used in psychology as a diagnostic or therapeutic approach, particularly with children. Art therapy has been shown to have a therapeutic effect in adolescents with depression (Riley, 2001) as this provides an effective, often less threatening medium for young people to express themselves. Although there is an increasing recognition of the importance of participatory research methodologies, particularly when research involves children and young people, no studies could be found in which body mapping has been used as a research methodology. However, body mapping does draw on narrative therapy which has been used effectively as a research methodology (Scott, Brett-MacLean, Archibald, & Hartling, 2013; Willis et al., 2014).

engage the participant in a deeper exploration and to elicit descriptive statements and symbolisations of experience and perceptions. I developed the interview guide in consultation with my supervisor, a psychiatrist based in Harare, and counsellors from the Zvandiri programme with experience in body mapping.

I also developed consent and assent forms which were translated into Shona, the participants' language. Although the sample size was not pre-defined as this was guided by thematic saturation, I anticipated that a minimum of 20 participants would be interviewed. All tools were therefore pre-tested with 2 participants, 10% of this anticipated minimum number. The tools were found to be both appropriate and acceptable to the participants and required no amendments.

3.2 Data

3.2.1 Methods of Data Collection

Data were collected at one research site, Zvandiri House training and support centre in Harare, Zimbabwe. As the interview was based around the body mapping session, two types of data were generated – audio data from the interview and visual data from the body map. Each interview was audio recorded with the participant's consent. A pseudonym was chosen by the participant and used throughout the interview in order to ensure anonymity and confidentiality. In addition, at the end of the interview and with the participant's consent, a photograph was taken of the body map and this generated the visual data.

Two Shona speaking research assistants assisted with data collection throughout the study period. Both assistants have extensive experience in participatory research methodologies with children and adolescents living with HIV. In addition, both research assistants are trained, experienced counsellors for children and adolescents with HIV so were well equipped to identify and manage participants in the event that they experienced

psychological distress during the research process. One research assistant was present during each interview to assist with field notes and practical issues associated with the body mapping itself, such as preparation of paints and water. In addition, in the event that the participants preferred to speak in Shona, the interview was led by one of the research assistants.

3.2.2 Data Analysis and Management

Each in-depth interview was transcribed and translated into English, if in Shona, and the body maps were photographed. Pseudonyms were used and any personal identifiers were removed from the transcripts before being entered into NVivo 10 (QSR International, Melbourne, Australia), a qualitative data storage and retrieval program. The transcripts were separately coded by a child psychologist based in Harare and me. The two separately coded transcripts were then compared and discrepancies resolved by discussion. Once the coding was consistent for both the transcripts, they were single-coded. Codes were then grouped in to categories and emerging themes were identified following the general principles of thematic analysis (Attride-Stirling, 2001). The photographs of each body map were also analysed together with the transcriptions. Common themes from the different interviews and body maps were then identified and were illustrated with quotes and images.

Data were labelled with an ID unique to that individual with a link log kept securely and separately from the interview transcriptions, audio data and body maps. Names, addresses and locator information were kept securely for follow up purposes and kept securely and separately from the research information in a lockable filing cabinet, accessed only by me.

3.3 Ethics

Permission to conduct this study was sought from Stellenbosch University and the Medical Research Council. Approval was also sought from Zimbabwe's Ministry of Health and Child

Care (MoHCC) and the Medical Research Council of Zimbabwe (MRCZ). Permission was obtained from Africaid to conduct the interviews at Zvandiri House, a training and support centre for adolescents with HIV in Harare.

3.3.1 Confidentiality and privacy

Confidentiality and privacy were ensured through a strict recruitment protocol in which the psychologist or psychiatrist provided adolescents meeting the inclusion criteria with information about the study. They were then informed by the psychiatrist that if they would like to find out more about participating in the study, that they may present themselves to the researcher in the same building. The researcher then met with the adolescent in a private, closed counselling room where the study was explained in full and consent / assent procedures carried out. No personal information has been disclosed to any other person, and participants' names and identifiable details have not been revealed in this thesis or in any other documentation regarding the study.

3.3.2 Consent and assent procedures

This study's principal participants were adolescents between the ages of 13 and 19 years old. As this research involved minors, strict procedures for obtaining informed consent from guardians and assent from minors was adhered to. Informed consent was obtained from parents/guardians for adolescents less than 18 years old to take part in this study. Assent was also sought from adolescents less than 18 years of age in addition to the consent obtained from the parent/guardian. Informed consent was obtained from participants 18 to 19 years of age. If consent was granted by the guardian but the potential participant was not willing to take part in this study then their decision was respected.

All potential study participants had the opportunity to meet with the researcher to learn about the study and to seek clarification as required. The consent process began with the

researcher reading through the informed consent form with each parent/guardian and participant individually, including the asking of clarifying questions. The participants were told that they were being asked to participate in a confidential research to explore their own experiences of depression and perceptions of care. The researcher informed them that participation would involve a one to two hour in-depth interview with the researcher during which the participant would be asked questions about his/her experiences and involved in a body mapping process. Body mapping was explained as a process during which the researcher would draw the outline of their body on a large paper and they would then use paints and coloured pens on the paper to help them explain answers to the questions being asked by the researcher.

In the event that the parent / guardian was not available for consenting procedures, a home visit was made with the adolescent's permission. The interviews were held at Zvandiri House in Harare, Zimbabwe. This training and support centre for adolescents with HIV was chosen as the venue as it is well known to the adolescents attending the Zvandiri programme and is considered a private, confidential and safe space by adolescents with HIV. Interviews were conducted on a Saturday when staff and other adolescents were not present in order to create a private, conducive environment for the interviews.

This study presented moderate risk to the participants as it explored sensitive issues with depressed adolescents. Otherwise, the study did not entail any other potential risks (physical, social, psychological, legal and ethical) to the participants.

Each participant received a stipend of \$5 for participating in the research, in line with the requirements of the Medical Research Council of Zimbabwe. Their transport costs to attend the interview were also reimbursed.

3.4 Gender considerations and human subject protections

This study involves both HIV positive male and female adolescents. Although the researcher aimed to recruit equal numbers of male and female adolescents to the study, convenience sampling was used and data collected until thematic saturation. 11 males and 10 females were recruited.

All research participants were referred for follow up management with a psychologist or psychiatrist. In the event that a study participant expressed suicidal ideation during the interview, plans were in place to stop the interview and for immediate referral to the participant's psychologist or psychiatrist and follow up support.

Considerations relating to children contained in the principles of Good Clinical Practice (GCP) were complied with. Both the research assistants and I completed ethics training and collected data in line with GCP principles prior to data collection.

Chapter 4: Results

In this chapter I describe the results from the in depth interviews and body mapping sessions conducted with 21 adolescents with HIV and depression. I present these in response to my three research questions:

1. What are the subjective experiences of depression among depressed adolescents living with HIV attending a community adolescent HIV programme in Harare, Zimbabwe?
2. What idioms of distress are used by depressed adolescents living with HIV attending a community adolescent HIV programme in Harare, Zimbabwe?
3. To what extent do depressed adolescents living with HIV attending a community adolescent HIV programme in Harare, Zimbabwe perceive that their experiences are being addressed by families, communities and service providers?

4.1 Sociodemographic characteristics of the study participants

A total of 21 participants were recruited to the study, 11 males (52%) and 10 females (48%). Of these, 19/21 (90%) were orphaned of whom 12 were double orphans (63%), 3 were maternal orphans (16%) and 4 were paternal orphans (21%). Only 3/21 (14%) participants lived with a biological parent. The majority of participants (18/21) (86%) were vertically infected with HIV while 3/21 (14%) were horizontally infected with HIV following sexual abuse. The majority were on a 1st line ART regimen (16/21) (76%) and 5/21 (24%) were on a second line ARV regimen. Notably, it was intended that 13 – 19 year olds would be enrolled in to the study, there were no HIV positive 13 and 14 year olds presenting with depression during the enrolment period.

All participants had received a diagnosis of depression by a psychologist or psychiatrist within the previous one to four weeks. Those who were diagnosed within the previous week were newly entering therapy whilst others had been engaged in therapy for up to three weeks’.

Table 1: Sociodemographic characteristics

No.	Name (participants’ chosen pseudonym)	Sex	Age	Orphan status	Caregiver	Mode of Transmission	ART regimen
1	Dambudzo	M	17	DO	Grandmother	Vertical	1 st
2	Hope	F	17	DO	Grandmother	Vertical	1 st
3	Mitchell	F	19	PO	Grandmother	Vertical	1 st
4	Pain	F	19	PA	Parents	Horizontal	1 st
5	Persevere	M	18	DO	Uncle	Vertical	1 st
6	Runyararo	M	18	DO	Grandmother	Vertical	1 st
7	Tariro	F	19	DO	Grandmother	Horizontal	1 st
8	Tarisai	F	18	DO	Uncle	Horizontal	1 st
9	Melissa	F	18	DO	Grandfather	Vertical	2 nd
10	Janet	F	19	MO	Stepmother and father	Vertical	1 st
11	Ephraim	M	19	DO	Grandmother	Vertical	1 st
12	John	M	18	DO	Grandmother	Vertical	2 nd
13	Russel	M	18	DO	Grandmother	Vertical	1 st
14	Rejoice	F	19	PA	Mother	Vertical	1 st
15	Kudzana	M	17	PO	Brother	Vertical	1 st
16	Juliet	F	19	MO	Father	Vertical	1 st
17	Prince	M	16	DO	Grandmother	Vertical	2 nd
18	Tambudzai	M	18	PO	Grandmother	Vertical	2 nd
19	Wangaa	M	17	PO	Grandparents, Uncle	Vertical	1 st
20	Paradzai	F	15	MO	Step mother	Vertical	1 st
21	Tafadzwa	M	18	DO	Lives on the streets	Vertical	2 nd

Key: DO – Double Orphan (both parents deceased); MO – Maternal Orphan (mother deceased); PO – Paternal orphan (father deceased); PA – Both parents alive; NK – Not Known

1st line: ARV drug combination including three of the following: AZT, 3TC, D4T, TDF, NFP, EFV

2nd line: ARV drug combination including three of the following: ATZ, LPV/ RTV, 3TC,

4.2 The subjective experiences of depression among adolescents living with HIV

When asked about their experiences of depression, participants primarily chose to narrate past and current events in their lives to which they attributed their depression. They all described lives characterised by negative and traumatic experiences. They conveyed these through both their verbal narratives and the evocative imagery which they chose to paint on their body maps to illustrate their experiences and emotions. Seven main themes emerged from the data which all related to their emotional experiences of depression: 1) Being different from others 2) Learning of their HIV status 3) Isolation and rejection 4) Loss and grief 5) Low self-worth 6) Lack of protection 7) The future. Sub-themes were also identified within each theme. These are now presented below and illustrated with quotes and images.

4.2.1 Being different from others

One of the most dominant themes to emerge in the data was adolescents' sense of being different from others and the effect that this has had on their daily lives. Five sub-themes were identified in their descriptions of this sense of being different: HIV status, physical differences, orphanhood, educational failures and poverty.

4.2.1.1 HIV Status

Participants commonly described feeling different from others due to their HIV status, particularly in relation to their parents, guardians or siblings who they live with and are HIV negative. They referred to the confusion and pain they felt as a result of being the only one

to be HIV infected, asking “*How did I get it?*” and “*Why me when others do not have it?*” They described an intense need for answers to these questions and attributed this sense of being different to their depression, as illustrated by one male participant who stated “*HIV...how did I get it? My father does not have it and it is said my mother did not have it.Up to now it still depresses me. My brother and my dad don't have it*” (Runyararo, 18 years).

Four participants posed rhetorical questions to God, such as “*Why did you choose me, meaning I am no longer a human being. I am just someone that is not the same as others*” (Tarisai, 18 years).

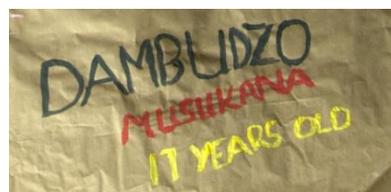
In addition to being different from family members, participants also described the way their HIV status made them different to their friends. They referred to the “*hurt*” and “*torment*” they feel as a result of not being able to do the things that their peers do, as illustrated by one female participant who stated that “*my friends at all times are the first cause of my depression. Why? Because what they are and what I am are totally different*” (Mitchell, 19 years). Others also referred to the way in which HIV has affected their daily functioning, social interactions and ability to have relationships, in contrast to their HIV negative peers. In particular, they attributed their poor school attendance to their HIV infection and stated that this separated them from their peers. Participants often described their distress when seeing their friends going to school whilst they remained at home.

Participants’ clearly articulated their sense of being different from their peers and their intense desire to identify with them when they talked about their antiretroviral medicines (ARVs). One male participant described his peers who do not take antiretroviral medicines as ‘*normal*’ (Persevere, 18 years) in contrast to himself. Others often described the fears they have that their friends will see their medicines and subsequently get to know their HIV status, as illustrated by a female participant who explained “*I don't want anyone to see me*

drinking tablets, because if I was seen drinking they would laugh at me or they would talk about me or the person would stop playing with me because I drink tablets” (Tarisai, 18 years).

4.2.2.2 Physical Differences

Other participants described the pain and hurt they have felt as a result of their physical differences in contrast to their peers. This was usually expressed by participants whose growth is stunted or where puberty has been delayed. One male participant stated that *“my body is hurt by the words said by people that I am sick, I am short” (Dambudzo, 17 years)*. Others used colours on their body map to illustrate this pain. Another male participant added that *“red represents the pain that I go through each day I go to school because of my body...it’s small so people always tease” (Persevere, 18 years)*.



The body mapping process was noted to be particularly helpful where participants wanted to narrate their distress over physical differences. For example, they were able to use colour and paint pictures on their body to illustrate different skin disfigurements before then describing the way these made them different from their peers. One male participant, (*Dambudzo, 17 years*) also noted that he did not need a large piece of paper like other participants because his body is severely stunted. He went on to paint the word ‘*musikana*’ (meaning ‘girl’ in Shona) in large letters across the bottom of his body map, before then narrating his experiences with peers who refer to him as a girl because of his short stature and lack of pubertal development.

4.2.2.3 Orphanhood

Orphanhood was another way in which participants described themselves as being different from their peers and attributed this to their depression. They narrated their experiences of being '*judged*' or '*looked down upon*' by peers because they live with guardians and elderly grandparents rather than their biological parents. One male participant stated "*my body will be depressed when people pass comments. Am I not a person if I'm being looked after by my grandparents?*" (Dambudzo, 17 years).

This sense of being different from others due to orphanhood was also illustrated by another male participant who, after painting red on his body map, explained "*the reddish at the bottom is how I feel sometimes when I am lonely, when I think sometimes of my late father. Because there is my uncle....he has a son. Sometimes when I look at them, they talk, they understand each other. I always wish I had a father* (Persevere, 18 years).

4.2.2.4 Educational Failures

Educational failure was frequently referred to by participants as a contributory factor in their depression, where failure to achieve at school resulted in their being different from their peers. One male participant explained that the cause for his depression is "*the inability to read and write. It is what affects me, because you can see a grade two child taking a book and being able to read but I am not able to such that it is something that pains me*" (Runyararo, 18 years).

4.2.2.5 Poverty

Participants also described their sense of being different from others because they do not have the possessions or the opportunities which their friends have and attributed this to poverty. They conveyed their fears and anxieties around a lack of money and the implications that this has on their current and future lives. One female participant explained "*if I cannot find just a little amount to go to school then I am not anything in this world so I was depressed*" (Mitchell, 19 years).

4.2.3 Learning their HIV status

When reflecting on their experiences of depression, many participants chose to narrate their experiences around the time when they initially learned of their own HIV status. They described feelings of 'sadness', 'stress' and 'great pain' in their lives at this time which then led to depression, as articulated by one female participant. *"After hearing (the) results ... when you are told that you have it (HIV). That is when you find all the stresses. That is when you start to think of bad ideas.... that's when depression comes"* (Tarisai, 18 years). Participants often painted symbols (e.g. red ribbon) or words (e.g. 'HIV') and used these to then narrate their experiences and emotions. In addition to these emotions, several participants described a loss of sense of self when they learned of their HIV status. For example, one female participant stated *"I was greatly pained..... I knew then that the old me I knew was dead and replaced by a new person residing inside of me* (Rejoice, 19 years).

4.2.4 Isolation and Rejection

Participants commonly described a sense of isolation and rejection in their lives. Three sub-themes emerged within this theme, reflecting their different experiences of isolation and rejection: 1) isolation and rejection by others 2) self-imposed isolation and rejection and 3) anticipated isolation and rejection.

4.2.4.1 Isolation and rejection by others

Isolation and rejection, together with judgement and criticism, was conveyed through participants' words and pictures of significant others in their lives who had isolated and / or rejected them. This was most often explained in the context of peers not wanting to play with them and their experiences of feeling set aside from their peer group. Participants commonly described being ridiculed, laughed at and talked about by peers as result of their HIV status or the fact that they take medicines. One female participant also referred to the concerns of her peers around HIV transmission when she explained *"they will not play with me because if they touch me they will be infected"* (Tarisai, 18 years).

One male participant used his own pseudonym to convey this sense of isolation and rejection when he named himself “*Dambudzo*”, a Shona name meaning “*Persecute*”. He went on to draw a picture of himself playing alone with no friends and of people making fun of him. A female participant chose to call herself “*Paradzai*”, meaning “*Destroyer*”. She explained that “*when I make little mistakes I am told that I am a destroyer by nature*” (*Paradzai, 15 years*).

In addition to isolation and rejection from peers, participants narrated distressing experiences at home with relatives where they had been isolated and / or rejected. They also often conveyed how they had been unable to share this with anyone else, as expressed by one male participant who stated,

“When I was sick some relatives would say that I was to be left to die just the same way my mother died. I was moved from relative to relative It hurt, but then I had no one to share with” (*Kudzanai, 17 years*).

Participants often described their ‘*pain*’ and ‘*hurt*’ as being worse when the isolation or rejection in their lives was imposed by the people they expected should support them, and commonly depicted this with paintings of relatives and peers. They conveyed their hurt and confusion over why friends and family members would treat them badly. One female participant stated “*it is worse when it comes from someone whom you think is there to support you but rather he is the first one to bring you down*” (*Mitchell, 19 years*). A female participant shared similar experiences and emotions when at home but attributed it specifically to her antiretroviral medication, stating, “*they hurt me when they say this one drinks pills, so there is no need to bother with him because she is not my child*” (*Tarisai, 18 years*).

4.2.4.2 Self-imposed Isolation

Some participants referred to the way in which they isolated themselves from others in order to conceal their HIV status. In particular, they gave examples where they had avoided interacting with peers or social activities in order to prevent their friends from seeing their antiretroviral medicines, resulting in accidental disclosure of their HIV status. They narrated their fears around the possibility of peers finding out their HIV status and the resultant self-imposed withdrawal from activities. One female participant explained the way she chose not to attend a school camp, stating “*I am so scared to keep the tablets in my bag (when I go on camp). I am hiding, I am protecting myself*” (Mitchell, 19). Another female also described this self-imposed isolation when she explained “*I find it difficult having friends because they will disclose my status and talk about me behind my back. They will start looking down upon me, and so that is why I prefer doing things alone*” (Melissa, 18 years).

4.2.4.3 Anticipated isolation and rejection

The fear of future rejection or isolation by family, friends and partners was referred to often. They described concerns and anxieties surrounding what would happen to them if they were to be rejected by these people. Some described the experience of staying with relatives, but being repeatedly reminded that the place they live is not their home and their caregivers are not their parents. They feared being rejected from the home, having been told “*this is not your home, you will leave anytime*” (Hope, 17 years). A few participants also feared rejection by partners if they disclose their HIV status. One male participant explained “*I wish I could just tell her [my status] and she would understand but the way if I tell her the other thought is like if I tell her what will she think about me?*” (Persevere, 18 years).

Anticipated rejection and ridicule was also described as impacting on adherence to their antiretroviral medicines. Participants often attributed their fear of others finding out about their HIV status as leading them to not taking their antiretroviral tablets on time. A female participant illustrated this by explaining “*you will not be drinking the tablets on time, because*

you will be saying if I drink the tablets and people see me they will laugh at me” (Tarisai, 18 years).

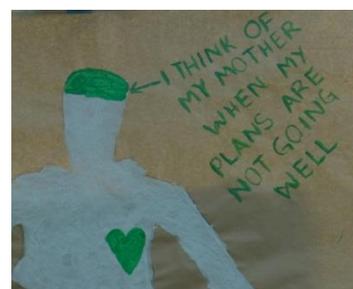
4.2.5 Loss and Grief

Loss and grief was a major theme, expressed both in participants’ narratives and paintings. Three sub themes emerged: 1) Actual loss and grief; 2) ambiguous loss and grief 3) anticipated loss and grief.

4.2.5.1 Actual loss and grief

Participants commonly described the death of a parent or parents as contributing to their depression. They expressed a yearning to have known their parents through their words, paintings, body language and emotions. This was particularly evident where participants had lost either one or both parents when they were too young to remember them. The need and desire for the love of a parent was expressed vividly in many of the paintings and their verbal narratives, as illustrated by a female participant when she stated:

“You need that love, but you won’t get it. I cry myself to sleep every day. My mother died when I was three. I never knew her, I don’t have a picture of her” (Janet, 19 years).



Grief for a parent was conveyed through the use of colour, paintings of their parents and words to convey their emotions. When describing why he had used the colour green, one male participant explained that *“the green part....this represents the depression part..... I think if my mother was around she would be beside me, talking and just doing things that mothers and children do. I still want to think of my mom, I just don’t want the thoughts of her*

going.... (but) when I think of my mum, I don't do good, I don't feel well mostly" (Russell, 18 years).

Grief was often exacerbated where participants were living in unsupportive households or where a loving, parental relationship was lacking. A female participant symbolised her step mother by drawing a snake then going on to explain *"I stay with my stepmother who is very cruel to me. She ill-treats me because she has her own child and so it is done on the basis that I am not her child. My mother passed away a long time ago....I wish she was around"* (Paradzai, 15 years).

One participant who had lost his mother as an adolescent described his conflicting emotions in relation to his loss, adding *"All I could do was cry and blame my mother because she had just disappeared on me.... how could my mother do this to me? (Russell, 18 years).*

4.2.5.2 Ambiguous loss and grief

Participants often conveyed their considerable distress, confusion and pain as a result of the uncertainty regarding their parent's whereabouts. Three participants stated that they had grown up not knowing whether their father and / or mother are alive or not and used pictures and their verbal narratives to convey their need for the truth. They described their reliance on relatives for information which could help them to locate a lost parent but that this information was not always forthcoming. One male participant attributed this ambiguous loss and grief to the *"darkness"* in his life, explaining,

"I lived a life where I did not know where my father was, where my mother had gone to. I grew up with my maternal grandmother. That's why I am saying it was all darkness (Runyararo, 18 years).

Another female participant attributed this uncertainty to the depression in her life, adding that *“if I know my father, and if I know if he is alive or not, I think that is what would make me happy for now (Hope, 17 years).*

4.2.5.3 Anticipated grief and loss

Anticipated future loss was also common, particularly where the primary caregiver was an elderly relative and there are no other relatives to care for them in the event of their caregivers' death. Those who lived with grandparents painted their caregivers as elderly, frail and unwell and expressed their dependence on their caregivers and concerns regarding their own future.



Participants who were searching for the whereabouts of their parent(s) also feared the loss of their elderly relatives as they were considered to have access to information which would help them to find them. One female participant who did not know her father explained that her grandmother is sick and *“What if she dies? What will happen? Yet she is the one with information about who my mother dated and stuff like that” (Hope, 17 years).* In addition to her verbal narrative, she conveyed her longing to know her father's whereabouts through painting herself, named *“Hope”*, holding hands with her father.

4.2.6 Low Self worth

Low self-worth was expressed by participants through their narratives. They conveyed a yearning to matter or to be important to the people closest to them in their lives, particularly their relatives and peers. They described the way relatives lacked care or concern for them compared with their HIV negative siblings or other children in the household. Others narrated the way they were moved from household to household, without being cared for or loved. One male participant explained *“when I was sick some relatives would say that I was to be left to die just the same way my mother died. I was moved from relative to relative*



(Kudzanai, 17 years). Another participant also conveyed her low self-worth in the context of relatives when describing her lack of relationship with her older brother: *...(my brother) is HIV negative so when I compare him with me I just realise that I may not be that loveable...because he is learned, he has a good job and all that". But I don't have anything* (Mitchell, 19 years).

One male participant conveyed his sense of low self-worth when he painted a picture to symbolise depression. He painted a 'pawn' in a chess set, explaining that *"a pawn is worthless among other pieces"* (Wangaa, 17 years). He then went on to describe the way a pawn is alone at the front on a chess board and is attacked before all the other pieces, using the chess piece as a metaphor for his own life.

Participants' low self-worth was also evident in the way they blamed themselves for their families' burdens. A few participants suggested that their families' lives would have been easier without them, particularly as they felt unable to contribute financially to the household. *"I regret being born. I blame myself for my mother falling pregnant and having to conceive me"* (Mitchell, 19 years).

4.2.7 A lack of protection

Participants described events in their lives where they had not been protected by the people closest to them, and the pain they felt as a result of those people not only not protecting them, but being the ones who inflicted abuse. A sense of betrayal and disillusionment was evident in their narratives, particularly by those whom had been sexually abused, both by the perpetrator and by family members who did not then seek justice. The colour black was often used to explain *"the way the people in my life have ill-treated me"* (Pain, 19 years). One female participant painted her entire body black and explained *"my mother died.....my father I have but he doesn't care about me. He was sexually abusing me* (Janet, 19

years). This girl's case is being co-managed by the study site's psychologist and the Department of Social Services.

Others also used colour to illustrate this pain and betrayal and to link their life experiences with the bodily experience, particularly in the case of sexual abuse. When explaining the use of the colour black, another female participant explained that the black parts of her painting refer to the events that stress her, stating

"I will be wishing (they) would come off me, but you find them all there. ...Like the things of mischief and naughtiness (the rape) I was talking about, you will be wishing if they would leave me. The black I have drawn there reflects the people who want to hurt me. Those who want to rape and sleep with me (Tarisai, 18 years).

This girl is also being co-managed by the study site's psychologist and Department of Social Services.

4.2.8 The Future

Participants described or illustrated their future in two different ways. Most participants depicted high expectations for a successful, brighter future, where their definition of 'success' was clearly conveyed through their drawings of



getting married, having children, academic achievement at school and gaining employment. The need for independence from unsupportive caregivers was significant for some participants and was linked to the desire to be employed and economically stable. They also conveyed that marital status and children of their own, along with completing their education and becoming employed, would improve their sense of self-worth. They longed to be valued by others, as illustrated by one girl when she drew a picture of a graduation cap to symbolise her desire to graduate, explaining *"I should be a graduate and I should be a worthy person among other people"* (Runyararo, 18 years).

Others also described their desire to be important to someone in the future, to matter and to be valued. This was often expressed in relation to their being needed by their own children in the future. *"I wish that I could be able to be someone in life and I wish to be able to there for my son, my daughter in the future"* (Persevere, 18 years). Others described their desire to help vulnerable children in similar situations to their own and gave examples of social work, law and counselling.

Although some described high expectations for the future and a yearning to be important and needed by others, these expectations were often accompanied by an uncertainty regarding whether they could actually achieve this, giving examples of ill health and a lack of finances, academic qualifications or lack of support. One male participant narrated his aspirations to be a pilot but explained that his uncle had told him that this would not be possible due to the health regulations (and his HIV status). He stated *"this makes me feel depressed cause it's what I want to be in life.....so sometimes the disease that I have makes me feel sad"* (Persevere, 18 years).

There were also participants who described a loss of hope for the future and had difficulty envisaging what their future would hold. They referred to the same aspirations for a family of their own to love and support them, an education and employment. However, they could not visualise how this could be possible. One male participant stated *"for now there is nothing (in my future). It's just hazy and a bit complicated to understand where it's headed to. At times it's just sorrowful and just so sad"* (John, 18 years). This sadness for the future was reiterated by a female participant who explained *'it doesn't bring happy thoughts to me so I don't think about my future'* (Mitchell, 19 years). Yet another participant referred to his fear of the future when he painted a hen as a symbol for 'depression'. He described himself as a 'hen' *"because anytime it can be killed. So just like me I am like a hen. I don't know when I will die but I just know that I will die because of the situation that I am in"* (Prince, 16 years).

4.3 Idioms of distress used by adolescents living with HIV

4.3.1 Thinking too much

Participants' idioms of distress were conveyed through both their verbal narratives and the words and images which they chose to paint on their body maps. The most commonly used terms to describe depression were '*thinking too much*' or being '*lost in thought*' as result of the events in their lives. Participants often chose to use a colour they identified with depression such as black or red and painted parts of the body with which they associated depression. The brain and heart were the parts of the body which they most commonly identified. One female participant used the colour purple to link the different parts of her body affected by depression. She began by painting her head and her heart purple, explaining that is where she associates with depression. However, she then went on to paint her legs the same colour, explaining that when she feels depression in her heart and head, this leads her to want to walk to the dam to drown herself.

4.3.2 Stress

The next most commonly used term was '**stress**'. Again, stress was represented by a certain colour which they chose and located this on certain parts of the body. Participants tended to use black or red and painted this on the head. Stress was often used in connection with '*thinking a lot*'. One female participant explained that stress arises from deep thinking and in turn results in suicidal ideation, stating:

"I think depression is when a person is under stress and it's this stress which in turn leads them to doing the unexpected such as committing suicide because they would have given deeper thought of what is affecting them in their life and this troubles them" (Pain, 19 years).

4.3.3 Challenges with daily functioning

Some participants referred to the struggles they face in daily functioning where *'it's more like everything I do I have to work hard. There is no like easy time. Even when I am sleeping it's not easy (Persevere, 18 years)*. Another male participant explained that *"depression, I think is something that doesn't want you to achieve something that you want as it keeps on keeping you down.... (Russell, 18 years)*.

4.3.4 Pain

Many participants referred to depression as the *'pain'* they experience in their lives, in relation to many of the themes reported above, including 1) being different from others, 2) HIV status 3) isolation and rejection 4) loss and grief and 5) lack of protection 5) uncertainty for the future. The pain they described was often attributed to a combination of these themes. This is illustrated by one male participant who used black paint to convey the pain he felt



having never known his father, before going on to describe the pain he feels as a result of being different from others and his lack of hope. He stated:

"Pain is when sometimes I feel sick cause sometimes like each year there is not a year I was normal. I go through every day with the suffering of knowing who I am and knowing that I cannot change anything" (Persevere, 18 years).

The somatic symptoms which are typically associated with depression were rarely identified, and even then only when probed for. Difficulty sleeping and poor appetite were generally denied. The somatic symptoms that were described in response to probing included stomach pain or headaches, with the few participants who did identify somatic distress explaining they had used specific colours of red and black to identify that pain. However, these experiences were not identified by participants as being associated with depression or other illness.

Participants did describe generalised pain where “*everything is very hurtful*”. One female participant identified the pain in her hands with the trauma of sexual abuse in her life, explaining,

“My left hand, I also painted black because I felt a lot of pain (there). I have held bad things and what I have felt with my hands that are bad that deeply depresses me” (Pain, 19 years).

Those that talked about pain also narrated the way they have hidden the pain. A female participant explained “*I am just a person who by when people see me smiling...it’s a fake smile. I don’t smile but I hide all the pain that I feel inside and smile all the time (Janet, 19 years).*”

4.3.5 Darkness

Darkness was referred to widely when participants were describing their depression. It was illustrated by the use of colour with black being the most commonly used. They chose to paint specific places on the body with which they identified this darkness. One male participant explained “*my heart is dark*” (*Dambudzo, 17 years*) whilst others painted their heads or whole body black to reflect their experiences and emotions, as demonstrated by a female participant when she stated,

“The whole of my head is full of darkness. Let us say my thoughts and things I have seen or things I have said they are all bad. What I have faced is full of darkness that is why I painted my head black” (Pain, 19 years).

Yet another participant referred to ‘darkness’ when he explained that he had painted his eyes black because “*black shows that there is no light that I am seeing or brightness ahead of me*” (*Tambudzai, 18 years*).

4.3.6 Hopelessness

A sense of hopeless or lack of hope for the future was often described. One male participant explained *“I don’t see a future for myself at times. I feel it’s better to die, there is no reason to live”* (Tambudzai, 18 years). Hopelessness was most often linked to their need to be someone of worth and to matter to others. For example, hopelessness was often in relation to the desire for an education, as expressed by one female participant who wanted to go to school but was told there was no money for her for school fees, yet her siblings go to school. She explained:

“It’s like I don’t have life, it’s just me in my own world. I have no hope for the future that I will be someone. Right now I have dropped out of school Sometimes I feel I should just die” (Janet, 19 years).

4.3.7 Suicidal Ideation

Suicidal ideation was also described by several participants. Four participants named or painted the methods they have considered in the past, including poisoning, hanging and drowning. One female participant noted, *I was disappointed to know I was HIV positive and I contemplated being dead was better* (Rejoice, 19 years). Another weighed in, *“Depression has made me feel like killing myself (in the past). It has made me feel like not possible in life, it has made me feel like giving up and do drugs, alcohol and those kinds of things* (Russell, 18 years). Yet another female participant stated,

“On my neck I painted a rope because there are times when I feel like killing myself using a rope, just hanging myself. Then on my head I drew small circles that are representing tablets. Sometimes I feel like committing suicide so that’s why I used them” (Pain, 19 years).

Slow suicide was also referred to by five participants who described a desire to intentionally default from antiretroviral treatment as a means of ending their life, as articulated here by

one female participant. *“Sometimes I feel like giving up on life by not taking my (antiretroviral) medication so that people stop talking about my (HIV) status” (Melissa, 18 years).*

In summary, a combination of idioms of distress were identified and expressed through a combination of colour, pictures and words. This is demonstrated by one female participant's description of her body map:

“Green is for when I will be stressed and pained. Purple represents when I will be crying because of thinking and keeping it to myself because I will not be sure how people will take my problems. And blue (on her head)..... that is where the thoughts of suicide are from” (Rejoice, 19 years).

4.4 Adolescents' perceptions of care from families, communities and service providers

When analysing the data for adolescents' perceptions of the care they receive, four main sources of care were identified including the care or support that had been received as well as care that was wished for. These four sources were 1) families 2) peers and support groups 3) clinic staff and 4) Zvandiri House. Church was referred to as a source of support by two participants, but was not a strong or recurring theme. The importance of care was referred to by all participants who articulated the way care from significant others can help them to cope with the difficult experiences and emotions they had narrated. However, it was also implicit in their narratives that care could also help to prevent these difficult experiences and emotions. One female participant articulated her need for care and reliance on others for support by painting a stone in her heart which she coloured brown. She explained that she needed someone to *“take the stone from that place where it is. If there is no one who wants to use that stone it will remain there” (Hope, 17 years).*

4.4.1 Families

When describing the care they desired, participants most commonly referred to a longing for care from parents, guardians and other family members. They desired love and emotional support as well as financial and material support. Yet the few participants that did describe positive experiences of family support usually referred to the material support they have received such as food, clothes and shelter. Some participants did recognise that their relatives worked hard to provide this care. Participants with ageing grandparents shared their concerns around their own future welfare. One male participant who was living on the streets at the time of the study but was about to be reunited with his grandmother described the way he is motivated by her:

“the fact that she works hard to feed us, and (provide) clothes ... gives me a reason to move on, and sometimes it depresses me that she is no longer able to do what she used to do when she was still very active to take care of us (Tafadzwa, 18 years).

Yet few of the participants described feeling loved and cared for emotionally. Instead, they described conflicting emotions where relatives “took good care” of them yet they then went on to narrate feelings of isolation and rejection or a sense of being different from others at home. For example, one female participant explained how her grandfather took care of her because he provided for her material needs. However, later in the interview she shared her distress that “he “constantly tells me that I am a sick person” (Melissa, 18 years).

This desire for parental care was often exacerbated by grief and loss for parents who had died. Participants described a desperate need for parental care and if that was not possible, they wanted this to be provided by an alternative relative. One female participant explained that as her mother was dead, she yearned for her cousin (whom she calls sister) to fill that gap in her life by visiting her at home. “That is what I wish for as a child. I wish if my mother

was there. So I wish if my sister would take that place to help... it is good if she would just visit and I will see that she cares (Hope, 17 years).

One participant also referred to the helpful role that his aunt played in helping him to accept his HIV status and to adhere to his antiretroviral medication. However, reference to care around positive living and adherence was notably lacking in all other interviews.

4.4.2 Peers

When describing the care they desired or have already received, all participants narrated the importance of peers in their lives in helping them to move forward, particularly HIV positive peers. The majority of participants referred to the care and support they had received from other young people living with HIV in the Zvandiri programme. They illustrated this by painting pictures of their friends and shared the way peers have helped them to accept their HIV status and to reduce their stress, isolation and lack of hope for the future. They conveyed the way their lives had improved as a result of being connected with people with similar experiences and who understood one another. In contrast, one male participant who was not yet linked to HIV positive peers, explained *“I feel like I have a lot of people around me but to understand me? They do not understand me. That is how I feel” (Persevere, 18 years).*

Many of them described transformational processes, in which they conveyed distress and sadness in the past which was then alleviated after being linked to HIV positive peers. One male participant was able to articulate this through his painting and verbal narrative. *“I have drawn myself in the past when I was alone but as time progressed I got support from my peers then I saw that I have a bright future (Dambudzo, 17 years).*

Support groups for HIV positive young people at Zvandiri were also important to participants as they were seen to provide an opportunity to interact with their peers. In the support groups, they described no longer feeling isolated, rejected or different from their peers, as explained by this female participant:

“(In the support group) I received love that I was not getting from my relatives. I now have a friend from my support group which I am glad because at my school there was stigmatization” (Rejoice, 19 years).

4.4.3 Service Providers

4.4.3.1 Clinics

All participants were registered in an HIV clinic and required to attend their regular clinic appointment on a 1 to 3 monthly basis, depending on their particular clinic. Despite the significant role of the clinics in the management of their HIV and provision of antiretroviral treatment, there was a notable lack of reference to the clinics by participants as a source of care. A few participants did explain the importance of the information and counselling received from their clinics, as demonstrated by one female participant when she explained *“What helped me not to be depressed was the fact that I went to the doctors to ask them what had happened, that’s when I started accepting it” (Tariro, 19 years)*. Only one participant referred to the antiretroviral medicines she receives as being part of the care received.

Another female participant described the role of the clinics in referring her to support groups, explaining *“that gave me hope to living...they introduced me to support groups, where I would mingle with other HIV positive children like me (Kudzanai, 17 years)*. However, the majority of participants did not refer to the role of clinic-based care in their lives.

4.4.3.2 Zvandiri House

Participants frequently referred to Africaid's Zvandiri House training and support centre as a key source of care in their lives. This was described as a place where they have found love and support. One female participant stated "*they love me at Africaid*". Participants explained that the counselling and support which they were receiving was helping to improve their hope for the future, encouraging them to progress with their education and restoring their self-worth. They narrated that the connection with others with similar experiences was helping them to see that they are not alone in their own experiences and that they have peers who accept them for who they are. Zvandiri House was often painted on to their maps and described as a place where young people are valued, loved and supported and provides a sense of constancy. These various facets of care were articulated by one male participant when he explained:

"Zvandiri House has always been there for us. Even the counsellors telling us to accept who we are and helping us to talk about the things that we feel, and how we can find solutions to help us get better and to help us to the level we want to get. I will draw the aunts and uncles and the House as well. I feel that if they had not been there in my life things could have been very complicated than they are. They were difficult for me, I would still be that unhappy child.. they are those people in my life to guide me and support me and to encourage me in my life, showing that I am needed, that I am great, important to the society" (John, 18 years).

Other participants described Zvandiri House as a place where they were listened to and understood and where they did not feel alone. One female participant explained she had used the colour pink at the top of her painting "*because I know I am going to get support, I know I am not carrying this alone, so my road is easier to walk on*" (Mitchell, 19 years).

4.5 The Process

At the end of each interview, participants were asked how they felt about having participated in the body mapping process and interview. All participants expressed feeling positively about the process, stating that they had found it helpful and that it had helped them to share experiences and emotions which they had not previously shared. One male participant explained “*I was glad because I was able to open up drawing and writing what I was keeping in my heart (Paradzai, 15 years)*. Several participants narrated the way they had kept silent about their emotions and had ‘*lied*’ to their relatives and clinics and even themselves about what was affecting them, as expressed by another female participant. “*I felt that for once I have been really honest with myself. So it has off loaded some of the things I was hiding (Mitchell, 19 years)*).

Although the reflection on these life events was evidently painful for all participants, there was also evidence of a therapeutic benefit whereby participants explained the benefits of being able to step back and reflect on their life through engaging in this process. It enabled them to re-story their own narratives by recognising “*the things that make me happy and the things that make me sad*” (John, 18 years). In this way, the body mapping process was transformative for individual participants. This transformation was also expressed by one female participant when she stated, “*at first I was feeling anger in my heart, I was depressed, I was stressed. Afterwards I then felt relieved because I have let everything out that has affected me (Pain, 19 years)*).

Participants also recognised that this approach would help others to understand them better as it had enabled them to articulate thoughts and feelings which they had been unable to express to counsellors before. They shared a sense of relief that others may now understand their needs, as expressed by a female participant:

“I felt that at least I was able to say things I am not able to normally talk about. I was able to draw things I am not normally able to say. Even if someone sees my drawing, they will know what I was trying to say... I felt that at last I emptied out and now there is someone who now knows my situation or that Hope needs this and that” (Hope, 17 years).

4.6 Conclusion

The 21 interviews generated a rich set of verbal and visual data which were combined to provide answers to the three research questions, as summarised below:

4.6.1 What idioms of distress are used by HIV positive adolescents with depression?

In this study, it was possible to elucidate participants' own idioms of distress which included 'darkness', 'pain', 'stress' and 'thinking too much' or 'too deeply' and 'hopelessness'. Some participants did refer to somatic symptoms of stomach ache and headaches, however this was only after probing. Suicidal ideation was commonly referred to, including 'slow suicide' by five participants through intentional defaulting from antiretroviral treatment.

4.6.2 What are the subjective experiences of HIV positive adolescents with depression?

Participants in this study generally described a *relational model* of depression, attributing their experiences of depression to the expressed thoughts, behaviours and attitudes of the most significant people in their lives. More specifically, relatives and peers were central to their experiences of depression throughout each of the six identified themes: 1) Being different from others 2) Learning of their HIV status 3) Isolation and rejection 4) Loss and Grief 5) Low self-worth 6) Lack of protection 6) The future.

The majority of respondents had been orphaned and demonstrated signs of profound, unresolved grief. They were living with other relatives and whilst a few described elements of support caregivers, the majority narrated traumatic relationships with their primary caregiver. In addition, participants' interactions with peers, or lack of peer support, were particularly distressing.

4.6.3 What are the perceptions of care of HIV positive adolescents with depression?

Four main sources of care were identified by participants: 1) Family 2) Peers 3) Clinic 4) Zvandiri. They conveyed their own definition of care to include love and emotional support together with financial and material support. Material support was most commonly described at home whereas love and emotional support was found from peers and Zvandiri. There was a notable lack of reference to the clinical care they received.

In summary, this small participatory study has generated data to inform the three research questions. In the next chapter, these data will now be discussed further in the context of the current literature and the implications for programming, policy and future research.

Chapter 5: Discussion

In this chapter, I discuss the study results in relation to each of the three research questions and in the context of the current literature I propose a theoretical framework for depression in adolescents with HIV before then discussing the implications of the study results on the health of adolescents with HIV and the implications for health service delivery. I also present the limitations of this research study.

This study sought to explore adolescents' subjective experiences and perceptions of care of HIV positive adolescents with depression. According to the theory of social constructionism, the way people experience themselves and their situation is "constructed" through culturally mediated social interactions (Shapiro & Ross, 2002). People tell dominant stories where certain aspects and themes have come to represent their experience and these become a powerful factor in reinforcing and embedding the person's perception of her dilemmas and conflicts, and of her view of herself. In this study, the body mapping process enabled me to explore adolescents' individual constructs of depression, as they narrated or depicted the dominant themes in their own lives. In particular, I was able to explore their own idioms of distress, their experiences of depression and their perceptions of the care they receive. I will now discuss these in turn.

5.1 Idioms of distress

In clinical practice, major depressive disorder in adolescence would be diagnosed when an adolescent met a pre-determined set of criteria, such as those set out in the Diagnostic Standardised Manual (DSM) (American Psychiatric Association, 2013) which largely focuses on the presence or absence of somatic or vegetative symptoms. The DSM-V criteria do recognise that the spectrum of depressive symptomatology may differ in adolescents compared with adults, including irritability rather than low mood in this age group. However, the results from this small study of HIV positive adolescents with depression in urban

Zimbabwe suggest even greater differences in the way adolescents conceptualise depression and depressive symptoms compared with the DSM-V criteria. Of note, participants rarely identified somatic or vegetative symptoms in their narratives of depression and when probed, the majority denied having experienced such symptoms including change in appetite, sleep disturbance and lack of energy. Instead, their idioms of distress included *'thinking too much'*, *'pain'*, *'stress'*, *'darkness'*, *'hopelessness'* and *'suicidal ideation'*. *'Thinking too much'* was the most commonly used idiom by participants and is in keeping with other research in Zimbabwe which found *'kufungisisa'* (thinking too much) to be a Shona idiom for non-psychotic illness among adults (Patel, Simunyu, & Gwanzura, 1995). This is also in line with the Ugandan study cited in the literature review in which HIV positive adults with depression commonly referred to *'thinking too much'* (Okello et al., 2012). Although pain may be considered to be a somatic symptom, participants generally referred to emotional pain rather than physical aches and pains.

These idioms of distress present an important, new insight in to the way HIV positive adolescents experience and perceive depression which to my knowledge, has not been identified or documented in the literature to date. In this study, participants' constructs of depression was based around concepts of *'pain'*, *'darkness'* and *'thinking too much'*, rather than somatic or vegetative symptoms. Therefore, if diagnostic tools focus on the presence or absence of somatic symptoms without including items to measure adolescents' own idioms of distress such as those identified in this study, then these measures may be poor indicators of depression in this group. This concern is described in the literature where a lack of measurement equivalence across diverse cultural groups can lead to missed diagnosis, underestimation and impacts on the validity of measures across different groups (Vandenberg, 2000). A more sensitive measurement tool would therefore be useful for this population of young people, in order to promote the identification of depression in HIV positive adolescents and the subsequent provision of appropriate therapeutic interventions. The need for culturally validated diagnostic tools which take in to account local idioms of

distress has been documented both in the adult population (Bass, Ryder, Lammers, Mukaba, & Bolton, 2008; Patel et al., 1995; Tesfaye, Hanlon, Wondimagegn, & Alem, 2010) and adolescent population (Rivera, Bernal, & Rosselló, 2005).

The study results also highlight another challenge in the diagnosis of depression in young people with HIV. It is documented in the literature that comorbidities complicate the diagnosis of depression (Malee et al., 2011; Patel, Flisher, Hetrick, & McGorry, 2007). In this study, 18/21 participants had been living with HIV since birth (median 17.9 years). As long term survivors of HIV, the somatic and vegetative symptoms typically associated with depression may well have been common experiences in the lives of these participants. For example, a systematic review of the psychiatric side effects of Efavirenz identified high rates of neuropsychiatric side effects including vivid dreams, insomnia and mood changes in approximately 50% of patients who initiate Efavirenz (Kenedi & Goforth, 2011). As global and national HIV treatment guidelines recommend Efavirenz for use in 1st line antiretroviral regimens (WHO, 2013b), the majority of participants in this study were taking Efavirenz. Although participants did not refer to vivid dreams or insomnia, it is not known to what extent Efavirenz contributed to depression in this group of young people. The role of Efavirenz in mood changes among adolescents on ART requires further research.

Another significance of the study results is that the use of a visual, participatory technique enabled participants to identify, articulate and share their idioms of distress which they had previously not identified or been able to share. Yet all participants have been attending clinics with experienced counsellors on a monthly basis for many years. This suggests that the more traditional counselling styles to which they are accustomed may be inadequate if they are to be assisted to identify and share their distress. If more participatory, creative approaches are available for young people, they may be helped to communicate their experiences, emotions and symptoms so that cases of depression are not missed.

Furthermore, the insight gained from this study around the manifestations of depression as narrated by adolescents themselves may be used to improve health care workers' skills in understanding, recognising and responding to depression in this group of young people. The standard package of HIV care in Zimbabwe does not include the screening, assessment or management of depression. Service delivery tends to focus on the management of Opportunistic infections, provision of ARVs and adherence counselling. The study findings regarding the manifestations of depression, as perceived by adolescents themselves, can be used to strengthen the training of health care workers so that the counselling they provide is sensitive to the potential for depression. This study provides an insight into the way in which depression manifests in adolescents and the care required, as perceived by young people themselves.

Finally in this discussion on the idioms of distress used by HIV positive adolescents with depression, it is important to acknowledge the issue of non-adherence to antiretroviral medicines. Although this was not directly stated as an idiom of distress, non-adherence was referred to throughout all the interviews at different stages and in connection with different experience and emotions. In particular, they alluded to non-adherence as a form of slow suicide, where intentional non-adherence is one strategy which could be used to end their lives. I could find no studies which investigate non-adherence to antiretroviral medicines as a potential form of suicide. However, bearing in mind there are known to be multiple, diverse causes for poor adherence in this age group, this study raises important questions regarding what role depression and suicidal ideation has to play in adolescents' poor adherence to ART.

5.2 Subjective experiences of depression and perceptions of care

When asked about their experiences of depression, participants identified seven dominant themes: *being different from others; learning of their HIV status; isolation and rejection; loss*

and grief; low self-worth and lack of protection; the future. Yet throughout each theme, relatives and peers were central to their experiences of depression. In this way, participants described a *relational model* of depression with participants' generally attributing their experiences of depression to the expressed thoughts, behaviours and attitudes of the most significant people in their lives. Similarly, when describing their perceptions of the care they have received or need, their relatives and peers were central to their narratives. The role of family relationships and peers in adolescents' experiences of depression and their perceptions of care will now be discussed.

5.2.1 The role of family relationships

Theories of developmental psychology recognise the critical role of stable, supportive families in promoting normal childhood development (Bowlby, Ainsworth, & Bretherton, 1992; Erikson, 1989). Yet the results of this study suggest that stability and support from parents were critically lacking in participants' lives, with 90% being double orphans and only 14% living with a biological parent. Participants were coping with unresolved grief, or complicated grief (Prigerson, 1995) from losses that included not only the death of one or both parents, but siblings and grandparents, in addition to non-death losses, such as changes in primary caregivers and households. The results confirm that grief and loss are prominent themes in their narratives of depression.

The role of grief and loss in their narratives of depression is supported by the literature which confirms that a significant number of children who experience the death of a parent demonstrate lower self-esteem and higher rates of psychological problems than non-bereaved children (Haine, Ayers, Sandler, Wolchik, & Weyer, 2003; Luecken, 2008). Furthermore, multiple losses can negatively affect the development of a sense of self-worth, interfere with a person's ability to trust or depend on others, and can lead to an avoidance of close interpersonal relationships (Field, Gao, & Paderna, 2005). There is also evidence that disruptions in our primary attachments due to death and other losses experienced when

young can play a subsequent role in difficulties forming stable attachments later in life (Zech & Arnold 2011).

The results from this study and the literature suggest that there is a critical need for therapeutic grief interventions for children and adolescents living with HIV. These interventions should account for their multiple losses, their evolving cognitive and emotional capacities and understanding of death. Yet grief and loss has been largely neglected in this group of young people in Sub-Saharan Africa, despite the magnitude of losses in the lives of children and adolescents with HIV in the region. A study of adolescents' experiences of parental AIDS-related deaths conducted in Zimbabwe (Wood, Chase, & Aggleton, 2006) found that adolescents strongly desired direct communication about their parents' illnesses and deaths. However, adult caregivers felt ill equipped to address these issues, leaving the youth to manage these difficult experiences on their own. Of note, the study investigators found that existing bereavement intervention models, which tend to focus exclusively on the children, are inadequate and should also focus on their caregivers.

The need to involve caregivers in grief interventions is supported by the findings of my research. Importantly, participants did not attribute their depression to their grief and losses alone, but also to the consequences of those losses. The majority of participants who had lost one or both biological parents placed unsupportive caregivers or householders at the centre of their narratives. They yearned to be loved, accepted, valued and supported by their immediate relatives and the absence of this further compounded their sense of grief and loss for their biological parents. This is supported by research in Zimbabwe which found that adolescents felt cared for and supported in the Zvandiri programme yet life at home with extended family relatives was more difficult due to unsupportive relationships (Mavhu et al., 2013). Programmatic data confirms the same where information sharing and counselling for caregivers of HIV positive adolescents contribute to more supportive home environments for children and adolescents with HIV (Jackson, Willis, Dziwa, Apollo, 2015).

This study therefore provides evidence to support family-based interventions which address grief and loss but also the importance of supportive, caring households for adolescents with HIV. These interventions need to be developed so that they are culturally relevant, rather than drawing on Western models.

The way in which participants attributed their experiences of depression to their family relationships is in-keeping with other research studies which have found a strong causal relationship between parental relationships and adolescent depression (Mellins & Malee, 2013). This study did not set out to analyse the characteristics of individual caregiver relationships and their relationship with adolescent depression although this would be important to investigate further in subsequent research. The literature does describe protective factors that promote mental health in young people in the general population such as stronger caregiver-child relationships, increased caregiver support, caregiver limit-setting and parent-child communication and involvement. However, to my knowledge, this has not been studied in adolescents living with HIV and their families.

5.2.2 The role of peer relationships

The results from this study indicate the profound significance of peer relationships in the lives of adolescents with HIV and depression. Participants commonly attributed their negative experiences to the behaviour of their peers but also to their desire to identify with their peers. Likewise, they identified peers as being central to the care and support that they need.

The importance of peer relationships among adolescents with HIV and depression is perhaps not surprising. Adolescence is a unique stage of life characterised by rapid growth and development and characterised by increasing autonomy and independence. Significantly, it is a period associated with an intense desire to associate and identify with

peers (World Health Organisation, 2013). Like all adolescents, it is therefore developmentally appropriate that peer relationships are critically important for adolescents with HIV. However, as demonstrated clearly in the results of this study, adolescents with HIV recurrent clinical, social and developmental challenges identify them as being different from their peers.

For example, adolescents narrated their desire to be physically like their peers but recounted numerous examples where this was not the case, including stunted growth, delayed puberty and skin disfiguration. These physical manifestations of HIV are increasingly reported in the literature (Ferrand et al., 2009; Lowe et al., 2010; Lowenthal, Bakeera-Kitaka, et al., 2014b) but there is a clear lack of attention to the impact on their mental health. In this study, it was evident that these differences have had a dramatic impact on participants' confidence, self-esteem and sense of identity. It is likely that this would result in concerns around emerging sexuality and desire for relationships although this issue was not articulated in their narratives. Other physical differences, such as skin disfiguration or stunted growth, were clearly identified as contributing to stigmatising behaviour by peers, again setting them aside from their peers and affecting their confidence and self-esteem. Participants also described being different due to poor academic achievement in school and narrated a deep yearning to succeed, like their peers. Although cognitive impairment and the potential for educational challenges at school, to my knowledge, there has been little if any exploration of the impact that this 'academic failure' has had on adolescents' mental health.

Participants' demonstrated that in their own constructed realities, they are worthless, of no value and have no future, when compared with their peers. Participants' yearned to be accepted and valued by their peers and to have opportunities to socialise with them, but to also identify with them physically, socially and developmentally. They also commonly referred to the way in which their peers do not need to take medication. Similarly, in the same way that peers were identified as contributing to their negative experiences,

participants clearly identified them as being central to the support that they require. Participants who had accessed peer support through the Zvandiri programme, narrated the way in which this support had played a significant role in improving their sense of self-worth and confidence, reducing their sense of isolation and rejection.

Despite the clear role of peers in the normal development of adolescents and the potential importance of peers in supporting young people as described here by participants, studies to investigate the role of peer-led interventions are minimal. Programmatic and research experience from the Zvandiri programme in Zimbabwe confirms that engagement with HIV positive peers has had a transformative effect on psychological well-being, linkage and retention in HIV care services and adherence (Jackson, et al. 2015; Willis et al. 2014; Willis 2016) . A few other examples of peer-led interventions exist but these are located in the USA and South Africa (Bhana et al., 2014). Despite this lack of data from randomised control trials, the World Health Organisation has now recognised the potentially significant role of peer-led interventions for adolescents with HIV and has adopted this as a recommendation within its 2015 guidelines (WHO 2015). However, studies that specifically investigate the role of HIV positive young people in supporting their peers diagnosed with depression are lacking.

5.3 A theoretical framework for depression in adolescents with HIV

In this study, adolescents attributed their experiences of depression to their interactions, or lack of interaction, with the most significant people in their lives, namely their family members and peers. This phenomenon is confirmed by Bronfenbrenner's ecological systems theory (Bronfenbrenner, 1986). In this study of adolescent's own experience and perceptions of care, the data does not imply any role of characteristics at the exosystem, macrosystem and chronosystem level but that adolescents' interactions at microsystem level are central to their experiences of depression and the care they desire.

In Bronfenbrenner's theory, at the micro level, the person interacts with people and objects in their immediate and intimate world, including parents, siblings, friends, spouse, children and other significant others. In the context of this study, parents were commonly deceased, resulting in extended family members adopting the role of parent and playing a significant role in adolescents' microsystems. Significantly, adolescents' described these relationships as traumatic, unsupportive and lacking in emotional support. Equally, adolescents found their peer relationships to be distressing and yearned to identify with their peers and to be accepted by them. Across the study, the recurring theme was that participants wanted above all to be loved, valued and accepted by their family members and peers, placing an emphasis on the role of the microsystem in their experiences of depression.

Whilst it is indeed likely that the development of HIV positive adolescents with depression is influenced by characteristics at all system levels, adolescents did not allude to any role of characteristics at other levels. I propose that this needs further study in order to examine the full extent and interrelation of influences at these varying levels in the adolescents' lives.

The ecological model provides a holistic approach to understanding depression in adolescents with HIV. In this study, depression had not occurred in isolation, but was instead the result of interactions with their environment over time with an emphasis on family and peer relationships. As discussed in the literature review, there is increasing awareness of psychosocial stressors as determinants of adherence and health outcomes in adolescents with HIV. However, there has been minimal exploration of factors influencing depression in this group of young people. This understanding of an ecological model for depression presents new insights in to their experiences and can be used to inform preventive and management interventions for young people growing up with HIV.

5.4 Implications for service delivery and policy

The literature describes multifactorial causes for mental health disorders in young people (Patel, Flisher, Hetrick, & McGorry, 2007; Thapar et al., 2012a). However, this study set out to explore adolescents' own experience and perceptions of depression with the aim that this will help to inform prevention and management interventions for this group of young people. In this study, adolescents' constructed a relational model of depression. This is in keeping with the literature which suggests that adolescents with exposure to chronic, severe stressors that affect relationships with relatives, peers and social networks are at greatest risk of depression (Thapar et al., 2012a).

Antiretroviral therapy seeks to improve the survival and quality of life for people living with HIV (WHO, 2013b). Yet despite the tremendous survival gains and quality of life improvements achieved for people living with HIV worldwide, the needs of adolescents with HIV have been largely neglected in policy development, funding allocations, national planning and service delivery. Virological failure rates and increasing mortality in this age group are a grave concern. At the same time, there is increasing evidence to suggest that these same adolescents are at risk of mental illness, including depression, and that depression is associated with poor adherence to ARVs. There is need for evidence-based interventions which address the complex, evolving needs of young people with HIV.

Despite the growing number of studies that show HIV-infected adolescents are at increased risk of mental health problems including depression, current models of adolescent HIV service delivery in Zimbabwe do not integrate mental health services. This lack of attention to the importance of mental health services for young people with HIV leads to challenges in ensuring early, accurate diagnosis and treatment, resulting in the mental health needs and

HIV treatment and care being unmet. This is not only essential for their own HIV outcomes but also for their development, and survival in to adulthood.

Based on the lived experiences of adolescents with HIV in this study, it is proposed that HIV services should integrate family and peer based interventions. This should therefore include services to support grief and bereavement, stigma and discrimination, parenting and communication, treatment literacy and adherence support. Support groups should be an essential component of the package, together with peer- based interventions for adherence support. The interventions should actively engage young people living with HIV to ensure that they are meaningfully engaged in the planning of services which meet their needs but also to demystify fears and misconceptions held by caregivers. The delivery of these interventions should involve community stakeholders, faith based organisations and traditional leaders to endorse these messages.

There is also need for training of health care workers in the mental health needs of adolescents with HIV and for mental health to be integrated within the comprehensive package of care for young people with HIV. In a country like Zimbabwe where there is one child psychiatrist and a small number of child psychologists across the country, it is essential that mental health interventions be adapted for health workers or lay workers so that this can be effectively rolled out and integrated within the national HIV programme. There is then a need for clear referral pathways for those diagnosed with severe mental health challenges and in need of more specialised services. This approach has been effectively implemented in Zimbabwe by the Friendship Bench which engages lay counsellors as therapeutic counsellors for adults with depression (Chibanda et al., 2015).

As part of the effort to optimise the package of care available for adolescents with major depressive disorder, there is a need for further research into the effectiveness of pharmacologic interventions in this population, including studies in to the concurrent use of

antidepressants and antiretroviral medicines in this population. Acceptability studies are also essential in this population where adherence is already known to be extremely challenging and an additional drug regimen may be unlikely to be adhered to.

The results of this study suggest that depressed adolescents face difficulties with adherence. It is therefore imperative that causal factors for depression are both recognised and addressed so that depression in this population may be minimised / prevented, both for the adolescents own mental health and as part of a comprehensive approach to promoting adherence to ARVs. Although there has been a global call for mental health research in adolescents with HIV yet there has been a lack of studies to date.

5.5 The feasibility of body mapping as a research methodology

Although I did not set out to investigate the use of body mapping as a research methodology *per se*, I propose that these results do provide valuable, preliminary data to suggest that this is a feasible, effective and acceptable participatory research methodology for engaging adolescents in qualitative research. In keeping with the principles of participatory research (Rodríguez & Brown, 2009), participants were not objects of the research but engaged as informed subjects within a body mapping session. In contrast to a formal interview in which the researcher sets out to obtain the information required based on preconceived questions), participants were guided through a creative, visual process of discovery and exploration of their own emotions and experiences. They were then able to share these in a variety of verbal and non-verbal ways. This is highly significant when conducting qualitative research with adolescents with developing, varied cognitive capacities as their skills and abilities to identify and articulate complex understandings may still be developing (Drew, Duncan, & Sawyer, 2010).

Body mapping enabled participants consider the questions being asked in a safe, confidential, informal manner whilst sitting on the floor with the researcher. They were then able to use the life-sized painting of themselves to externalise their personal experiences and emotions and to communicate sensitive, traumatic issues in a creative way. These were expressed verbally or visually, but participants usually painted first, processing their experiences, thoughts and emotions on a non-verbal level before then narrating it verbally. Colours, pictures, symbols and words were used freely to convey their experiences and emotions, enabling the researcher to gain an insight in to their experiences of depression, idioms of distress and perceptions of care.

This technique provided a group of young people with HIV and depression to be heard, in their own unique, creative ways. All participants confirmed that the process of being guided through an interview based around a body mapping process assisted them to share and articulate experiences and emotions which they had not shared with anyone others. Furthermore, some adolescents explained that they were narrating issues which they themselves had not recognised before. Body mapping enabled participants to step back and reflect on issues through visual artistic expression, strengthening their own understanding of factors contributing to their depression, manifestations of depression and perceptions of the care they have, or have not received. This is in keeping with other research where the combination of visual arts and story-telling has been found to promote self-awareness, understanding and expression as well as being therapeutic in its own right (Willis et al., 2014).

Participants were able to locate where and how depression manifested itself by positioning words and images in specific locations on the body. Colour proved to be an extremely useful tool. Although this study did not aim to analyse the use of different colours per se, colour was a notably helpful tool for adolescents who wish to convey negative versus positive emotions and experiences. For example, black and red were commonly used to convey pain

and distress. It enabled those with varying literacy and language levels to express themselves freely in whichever way they felt most comfortable. Whilst these were evidently painful reflections, all adolescents were able to complete the interview and body maps and were evidently proud of what they had produced at the end of the interview.

In addition to further use with HIV positive adolescents with depression, this body mapping technique has important potential as a research methodology with other marginalised groups of young people. It also has the potential to break down communication barriers associated with an in-depth interview, in which adolescents may feel unable to articulate themselves or share sensitive, personal issues with a researcher.

5.6 Limitations

The sample size for this study was small. Although data were collected to thematic saturation, it is not possible to make generalizations about the larger population of adolescents living with HIV and depression. However, these data from 21 young people in urban Zimbabwe do provide important evidence towards an improved understanding of the needs and experiences of HIV positive adolescents with depression and their perceptions of the care they have received. Furthermore, the use of body mapping as a participatory research methodology in this small sample provides important feasibility data to support the use of this research methodology in larger studies, both with HIV positive young people with depression and other marginalised groups of young people.

Although efforts were made to ensure homogeneity among participants recruited to the study, the participants were recruited at different time points since their diagnosis of major depressive disorder by a psychiatrist or psychologist linked to the study. Some had been diagnosed that week and were newly entering therapy whilst others had been diagnosed within the previous month and therapy had already commenced with a psychologist or

psychiatrist. The different time periods between diagnosis and study recruitment were largely due to the participants' varying availabilities due to school and family commitments. It is therefore acknowledged that whilst some participants' experiences were current, others were reflecting on prior experiences. Similarly, participants had varying exposure to care. Both factors present a risk of recall bias (Schmier & Halpern, 2004) as a result of potential differences in the accuracy of recollections and varying levels of exposure to depression and care. The study could have been improved by the use of a standard measure of depression at the point of recruitment for each participant. However, the sample size allowed for a range of experiences and the body mapping methodology enabled participants to reflect on and share their experiences of depression over the previous month, idioms of distress and their perceptions of care.

Finally, it was observed that adolescents' psychological status would fluctuate according to the events in their daily lives. For example, participants diagnosed with major depressive disorder and suicidal ideation in the previous week then presented for the interview with improved mood and symptoms. However, the body mapping process enabled them to reflect on current, recent and past experiences rather than a single point in time. This generated rich, multi-layered narratives through which they conveyed their emotions and experiences at different time points.

Chapter 6: Conclusions and Recommendations

This research study aimed to explore the subjective experiences and perceptions of care among HIV positive, depressed adolescents (13-19 years old) on antiretroviral therapy and attending a community programme for adolescents with HIV in Harare, Zimbabwe. Although this is a small study with a population of 21 HIV positive adolescents in Harare, Zimbabwe, the study has addressed a gap in the literature around HIV positive adolescents' own narratives of depression, their idioms of distress and their own perceptions of the care which they need. The study has provided a platform through which adolescents' experiences and voices may be heard so that policy makers and service providers can better understand and plan for their complex needs. It is anticipated that the findings from this study will now be shared widely so that they may be used to inform services and policies which are responsive to those needs. Based on the findings from this study, I now make four recommendations for the way forward:

1. Evaluation and integration of family and peer-based interventions for the prevention and treatment of depression in adolescents with HIV

To date, there has been minimal effort to adapt and evaluate adolescent mental health interventions as culturally-appropriate mental health interventions for adolescents with HIV. Despite the multiple aetiologies described in the literature (Malee et al. 2011; Patel et al. 2007), adolescents in this study described an ecological systems model of depression, where causal and protective factors for depression related to significant people in their lives, particularly relatives and peers. There is now need for the development of culturally-specific, family and peer based interventions which address the causal and protective factors raised in this study. In a country like Zimbabwe where there is a dearth of mental health trained professionals, community based, family and peer-based interventions which are grounded in psychological therapies provide an important, task-shifting approach for supporting adolescents with HIV. This has the potential for improving morbidity and mortality rates in

this group through improving both their mental health and HIV outcomes. This will have subsequent public health benefits and resulting cost savings for governments where second and third line drugs are prohibitively expensive in addition to the monitoring and management of ARV-related toxicities. There is also the potential for health benefits and savings from the prevention of transmission to partners and children. The potential role of depression in contributing to poor adherence to ARVs should be urgently investigated due to the consequent impact on mortality and morbidity in adolescents with HIV.

2) Validation of depression scales for adolescents with HIV in developing countries

Further research is now needed to evaluate the reliability and validity of diagnostic tools for depression in adolescents with HIV. Within this process, there needs to be a more extensive review of adolescents' idioms of distress so that these may be factored in to the development of validated tools with reliable, culturally appropriate measures for depression in this group of young people.

3) Research in to the use of body mapping as a participatory research methodology for adolescents with HIV and depression, and other groups of marginalised young people

This study has also generated important feasibility data for the use of body mapping as a participatory research methodology when engaging adolescents in research. There is now need to investigate this methodology further so that this potentially important approach can be used more widely, both as a therapeutic tool and data collection tool. The literature demonstrates that adolescents with HIV are at risk of depression. Bearing in mind the scale of the adolescent HIV epidemic in Sub Saharan Africa, including Zimbabwe, there is the potential for an overwhelming number of young people with HIV and depression. Yet there is a dearth of research in to their subjective experiences and perceptions of care. Bearing in mind the escalating interest in the field of adolescent HIV together with the lack of research studies in to their mental health needs, it is critical that feasible, appropriate, acceptable and

ethically sound research methodologies are evaluated and available for further research with this population. Following the success of body mapping as a participatory research methodology in this study, it is now important that further research is conducted to evaluate the effectiveness and validity of body mapping and indeed other arts-based therapeutic approaches as research methodologies for young people.

4) Training of health workers and lay counsellors in mental health for adolescents with HIV

Training and mentorship for health care workers are currently being scaled up with the aim of strengthening health care workers knowledge, skills and understanding of the multi factorial barriers to treatment and care, including adherence in this age group (MoHCC, 2015) . However, this training does not address mental health nor equip counsellors with an understanding or skills to identify or respond to mental health issues in this group. There is a critical need for the development of training curricula and therapeutic counselling tools which health workers may use to support adolescents attending HIV services. This includes the training of adolescents and young people with HIV as lay counsellors as a task sharing approach which is argued to be acceptable and relevant for adolescents with HIV (Kidia et al., 2015; WHO, 2013).

Finally, although the global community is celebrating the successes of HIV treatment, adolescents with HIV continue to face increasing mortality rates. It is now time for urgent action if we are to really understand their lived experiences and the impact that this has on their treatment, care and mental well-being, so that young people with HIV may also attain and maintain the same therapeutic gains as adults with HIV. I sincerely hope that this research contributes to this improved understanding and leads to further work in this field.

Annex 1: Information Sheet and Informed Parental Consent Form and Assent Form

INFORMATION SHEET AND INFORMED PARENTAL CONSENT FORM

AND ASSENT FORM

(For participants 13 years to 17 years)

Title of the Research Study: Subjective experiences and perceptions of care among depressed adolescents living with HIV attending a community adolescent HIV programme.

Principal Investigator: Nicola Willis

Phone Numbers: 04 335805; 0731 253205

Address: Zvandiri House, 12 Stone Ridge Way, Avondale, Zimbabwe

Your child is being invited to take part in a research project. Please take some time to read the information presented here, which explains the purpose, process, risks and benefits of this research study. Please ask the study staff any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how your child could be involved.

What is the purpose of this study?

You are being asked if your child may participate in a research study involving HIV positive adolescents whom have been diagnosed with depression. The purpose of the study is to explore the experiences and perceptions of care of depressed adolescents living with HIV, aged 13-19 years old. 20 – 30 adolescents with HIV whom have been diagnosed with depression will be selected to participate in this study, from adolescents attending the Zvandiri community adolescent HIV programme in Harare, Zimbabwe. The results of this study will help health workers to have a better understanding of the experiences of depressed adolescents living with HIV and to provide care which addresses their needs.

Why is my child being invited to participate in this study?

Your child was selected as a possible participant in this study because he/she is living with HIV, is 13-19 years old, is attending Africaid's Zvandiri programme and is currently receiving care for depression from a psychiatrist.

What will be involved by participating in this study?

If you consent for your child to participate in this study and he/she also assents to participate, he/she will be invited to attend a two hour interview with the researcher. This interview will be held at Africaid's Zvandiri House in Avondale, Harare. During the interview, the researcher will ask your child open questions about his/her experiences of living with depression and perceptions of the care he/she receives. During this interview, your child will be invited to produce a body map. This involves drawing and painting as a way of helping your child to express his/her experiences. With your consent, the interview will be audiotaped and photographs will be taken of your child's body map.

Will your child be paid to take part in this study and are there any costs involved?

Your child will be given \$10 for participating in this study. He/she will also be reimbursed for transport costs to and from the interview. He/she will also be given juice and a snack after the interview is completed. He/she will not incur any costs through participating in this study.

Will my child benefit from taking part in this study?

Your child will not benefit directly from taking part in this study but the results will help health care professionals to better understand the experiences of adolescents with HIV and depression. This will help us to improve care and support for depressed adolescents living with HIV, including your child.

Are there any risks to your child by participating in this research?

There is a minimal risk to your child as the researcher will be asking your child to share his/her experiences of living with HIV and depression. The researcher is a skilled counsellor and in the event that your child becomes distressed, he/she will be counselled and referred to his/her psychiatrist if necessary.

If I do not want my child to participate in this study, what choice do I have?

Participation in this study is entirely voluntary. If you do not want your child to participate that is entirely your choice and will not affect his/her future care in any way.

Can I withdraw my child from the study if I have already given my consent?

Yes, you may choose to withdraw your child from this research study at any time without penalty or loss of benefits. If you decide to leave the study, please tell the research nurse or clinic staff why you wish to leave. This will help us to do a better job.

Your child may be removed from the study without your consent for the following reasons:

- If he/she does not attend the interview and body mapping session;
- The study is cancelled by the funding agency, or the Ethical committee;
- Other medical or administrative reasons.

Who will have access to my child's taped interview and body map?

Only limited study research staff will have access to your child's files, specifically the Principal Investigator (Nicola Willis), her Supervisor (Professor Ashraf Kagee) and a research assistant from Africaid. All personal information collected will be treated as confidential and access to it will be strictly controlled and limited to the investigators. In addition, the ethics research committee members may need to inspect the research records.

All identifying information will be anonymised at the earliest possible time point. Your child's taped interview, body map and photographs of the body map will be assigned numbers for identification purposes when used in a publication or thesis. If you indicate your willingness to allow your child to participate in this study by signing this document, we plan to disclose only general details from the interview and body map that will not be linked directly to your child as a person.

In any literature published as a result of this study, your child's name will be completely anonymous in name and situation to protect your child's identity in such a way that his/her responses will not later be traceable back to your child. Any information that is obtained in connection with this study that can be identified with your child will remain confidential and will be disclosed only with your permission.

What will happen in the unlikely event of some form injury occurring as a direct result of your child's participation in this research study?

In the event of injury resulting from your child's participation in this study, treatment shall be offered by the study. You should understand that the costs of such treatment will be the study's responsibility. In the event of injury, please contact Nicola Willis (0731 253205).

What do I do if I have further questions?

Before you sign this form, please ask any questions on any aspect of this study that is unclear to you. You may take as much time as necessary to think it over. You can contact Ms Nicola Willis on telephone 0731 253025 if you have any further queries or encounter any problems.

What will happen if the details of the study change?

You will be told any new relevant information that arises during the course of the study and if the research protocol is changed in any way.

Authorization

You are making a decision whether or not to allow your child to participate in this study. Your signature indicates that you have read and understood the information provided above, have had all your questions answered, and have decided to allow your child to participate in this study. Your child will also be asked to sign assent below if he/she is willing to participate in the study. You will be given a copy of this consent form to keep.

If you have any questions concerning this study or consent form beyond those answered by the investigator, including questions about the research, your child's rights as a research participant or research-related injuries; or if you feel that you have been treated unfairly and would like to talk to someone other than a member of the research team, please feel free to contact the Medical Research Council of Zimbabwe on telephone (04) 791792 or (04) 791193.

This study is being funded by Maruva Trust, UK who has no conflict of interests.

This study has been approved by the Medical Research Council of Zimbabwe and the Human Research Ethics Committee at Stellenbosch University. It will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, Zimbabwean guidelines for Good Clinical Practice, South African guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

A. Declaration by participant's parent / caregiver

By signing below, I (parent/caregiver) agree for my

child..... to take part in a research study entitled “Subjective experiences and perceptions of care among depressed adolescents living with HIV attending a community adolescent HIV programme in Harare, Zimbabwe.

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to consent for my child to take part.
- I may choose to withdraw my child from the study at any time and will not be penalised or prejudiced in any way.
- My child may be asked to leave the study before it has finished, if the study researcher feels it is in his/her best interests, or if he/she does not attend the interview as agreed to.

Signed at (*place*) on (*date*) 2014

.....

Signature of participant

Signature of witness

B. Declaration by investigator

I (*name*) declare that:

- I have explained the information in this document to
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above.

Signed at (*place*) on (*date*) 2014.

.....

Signature of investigator

Signature of witness

C. Audio recording

Name of Parent/Guardian (*please print*)

Date

Signature of Parent/Guardian or legally authorized representative

Time

Relationship to the Participant

F. Statement of Assent

We are doing a research study to explore the experiences of adolescents living with HIV who have been diagnosed with depression. We are asking you to help with this study because we would like to have a better understanding of what it means to you to be depressed, how it affects you and what type of support you need.

If you agree to be in this research study, you will be invited to meet with the researcher, Nicola Willis, at Africaid's Zvandiri House for a one-one-on interview. This interview will take up to two hours and you will be asked to share your experiences of depression and the type of support you feel would be helpful. During the interview, you will be invited to take part in a body mapping session. During this session, you will be given a large piece of paper and asked to lie down while the researcher draws the outline of your body. As the researcher asks you questions about your experiences, you will be invited to colour, write and draw on your body map to show how you are feeling and how events have affected you. You do not have to be a good artist to take part in this. It is intended to be an interesting way to explore how you are thinking and feeling. At the end of the interview, you will have produced your own body map.

You can ask questions about this research study at any time. If you decide at any time not to finish the study, you can ask us to stop.

The questions we will ask are only about what you think and what you have experienced. There are no right or wrong answers because this is not a test.

If you sign this paper, it means that you have read this and that you want to be in the research study. If you do not want to be in the study, do not sign this paper. Being in the study is up to you, and no one will be upset if you do not sign this paper or if you change your mind later.

My participation in this research study is voluntary. I have read and understood the information, asked any questions which I may have and I have agreed to participate. I will be given a copy of this form to keep.

Name of Research Participant (*please print*)

Signature of Research Participant

Name of Witness (*please print*)

Signature

Date

Annex 2: Information Sheet and Informed Consent Form

INFORMATION SHEET AND INFORMED CONSENT FORM

(For participants 18 to 19 years)

Title of the Research Study: Subjective experiences and perceptions of care among depressed adolescents living with HIV attending a community adolescent HIV programme.

Principal Investigator: Nicola Willis

Phone Numbers: 04 335805; 0731 253205

Address: Zvandiri House, 12 Stone Ridge Way, Avondale, Zimbabwe

You are being invited to take part in a research project. Please take some time to read the information presented here, which explains the purpose, process, risks and benefits of this research study. Please ask the study staff any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved.

What is the purpose of this study?

You are being asked if you would like to participate in a research study involving HIV positive adolescents whom have been diagnosed with depression. The purpose of the study is to explore the experiences and perceptions of care of depressed adolescents living with HIV, aged 13-19 years old. 20 – 30 adolescents with HIV whom have been diagnosed with depression will be selected to participate in this study, from adolescents attending the Zvandiri community adolescent HIV programme in Harare, Zimbabwe. The results of this study will help health workers to have a better understanding of the experiences of depressed adolescents living with HIV and to provide care which addresses their needs.

Why am I being invited to participate in this study?

You have been selected as a possible participant in this study because you are living with HIV, are 13-19 years old, are attending Africaid's Zvandiri programme and are currently receiving care for depression from a psychiatrist.

What will be involved by participating in this study?

If you consent to participating in this study, you will be invited to attend a two hour interview with the researcher. This interview will be held at Africaid's Zvandiri House in Avondale, Harare. During the interview, the researcher will ask you open questions about your experiences of living with depression and perceptions of the care you receive. During this interview, you will be invited to produce a body map. This involves drawing and painting as a way of helping you to express your experiences. You do not have to be a good artist to take part in this. It is intended to be an interesting way to explore how you are thinking and feeling. At the end of the interview, you will have produced your own body map. With your consent, the interview will be audiotaped and photographs will be taken of your body map.

Will you be paid to take part in this study and are there any costs involved?

You will be given \$10 for participating in this study. You will also be reimbursed for transport costs to and from the interview. You will also be given juice and a snack after the interview is completed. You will not incur any costs through participating in this study.

Will I benefit from taking part in this study?

You will not benefit directly from taking part in this study but the results will help health care professionals to better understand the experiences of adolescents with HIV and depression. This will help us to improve care and support for depressed adolescents living with HIV, including yourself.

Are there any risks to me by participating in this research?

There is a minimal risk to you as the researcher will be asking you child to share your experiences of living with HIV and depression which you may find distressing. The researcher is a skilled counsellor and in the event that you become distressed, you will be counselled and referred to your psychiatrist if necessary.

If I do not want to participate in this study, what choice do I have?

Participation in this study is entirely voluntary. If you do not want to participate that is entirely your choice and will not affect your future care in any way.

Can I withdraw from the study if I have already given my consent?

Yes, you may choose to withdraw from this research study at any time without penalty or loss of benefits. If you decide to leave the study, please tell the research staff why you wish to leave. This will help us to do a better job.

You may be removed from the study without your consent for the following reasons:

- If you do not attend the interview and body mapping session;
- The study is cancelled by the funding agency, or the Ethical committee;
- Other medical or administrative reasons.

Who will have access to my taped interview and body map?

Only limited study research staff will have access to your file, specifically the Principal Investigator (Nicola Willis), her Supervisor (Professor Ashraf Kagee) and a research assistant from Africaid. All personal information collected will be treated as confidential and access to it will be strictly controlled and limited to the investigators. In addition, the ethics research committee members may need to inspect the research records.

All identifying information will be anonymised at the earliest possible time point. Your taped interview, body map and photographs of the body map will be assigned numbers for identification purposes when used in a publication or thesis. If you indicate your willingness to participate in this study by signing this document, we plan to disclose only general details from the interview and body map that will not be linked directly to you as a person.

In any literature published as a result of this study, your name will be completely anonymous in name and situation to protect your identity in such a way that your responses will not later be traceable back to you. Any information that is obtained in connection with this study that can be identified with you will remain confidential and will be disclosed only with your permission.

What will happen in the unlikely event of some form injury occurring as a direct result of your participation in this research study?

In the event of injury resulting from your participation in this study, treatment shall be offered by the study. You should understand that the costs of such treatment will be the study's responsibility. In the event of injury, please contact Nicola Willis (0731 253205).

What do I do if I have further questions?

Before you sign this form, please ask any questions on any aspect of this study that is unclear to you. You may take as much time as necessary to think it over. You can contact Ms Nicola Willis on telephone 0731 253025 if you have any further queries or encounter any problems.

What will happen if the details of the study change?

You will be told any new relevant information that arises during the course of the study and if the research protocol is changed in any way.

Authorization

You are making a decision whether or not to participate in this study. Your signature indicates that you have read and understood the information provided above, have had all your questions answered, and have decided to participate in this study. You will be given a copy of this consent form to keep.

If you have any questions concerning this study or consent form beyond those answered by the investigator, including questions about the research, your rights as a research participant or research-related injuries; or if you feel that you have been treated unfairly and would like to talk to someone other than a member of the research team, please feel free to contact the Medical Research Council of Zimbabwe on telephone (04) 791792 or (04) 791193.

This study is being funded by Maruva Trust, UK who has no conflict of interests.

This study has been approved by the Medical Research Council of Zimbabwe and the Human Research Ethics Committee at Stellenbosch University. It will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, Zimbabwean guidelines for Good Clinical Practice, South African guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

A. Declaration by participant

By signing below, I(name) agree to take part in a research study entitled “Subjective experiences and perceptions of care among depressed adolescents living with HIV attending a community adolescent HIV programme in Harare, Zimbabwe.

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to consent for my child to take part.
- I may choose to withdraw from the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study researcher feels it is in my best interests, or if I do not attend the interview as agreed to.

Signed at (*place*) on (*date*) 2014

.....

Signature of participant

Signature of witness

B. Declaration by investigator

I (*name*) declare that:

- I have explained the information in this document to
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above.

Signed at (*place*) on (*date*) 2014.

.....

Signature of investigator

Signature of witness

C. Audio recording

If you agree, your interview with the researcher will be audio recorded. This is to make it easier to communicate during the interview and so that the interview can be transcribed later, rather than during the interview. Once the interview is transcribed, the audio, which will be recorded on a digital electronic recording device, will be erased. Prior to that, the recording will be kept in a locked cabinet which only the research staff will have access to.

Statement of consent to your interview being audiotaped

I understand that audio recordings will be taken during this study

- I agree to my interview **being audio recorded**

Yes
No

Name of Participant (*please print*)

Date

Signature of Participant

Time

E. Body map photography

If you agree, your body map will be photographed. This makes it easier to communicate during the interview and so that the body map can be analysed later, rather than during the interview. Once the

body maps have been photographed and analysed, the body maps will be returned to you if you would like it.

Statement of consent to your body map being photographed:

I understand that photographs will be taken during this study

I agree to my body map **being photographed**

Yes

No

Name of Participant (*please print*)

Date

Signature of Participant

Time

Annex 3: In-depth interview and body mapping guide

Research Study: Subjective experiences and perceptions of care among depressed adolescents living with HIV attending a community adolescent HIV programme.

IN-DEPTH INTERVIEW AND BODY MAPPING GUIDE

Step 1: Getting Started

Welcome the participant to the interview and body mapping session. Focus on ensuring the participant feels safe and comfortable.

Review the participant's consent and assent forms, asking the participant to confirm the signatures on the forms.

Remind the participant that this process is completely voluntary and if he/she wishes to stop at any time, then he/she may do so without any implications on his/her future care.

Remind the participant that you are going to have an interview which will focus mainly around the development of a body map. Ask the participant if he/she has any questions before you get started.

Step 2: Body Mapping Guide

1. Start by giving the participant a large piece of paper and laying it down on the floor. Explain to the participant that you will now trace the outline of his/her body. Ask the participant to lie down on the paper and with a black marker pen, trace around the participant's body. When the participant stands up, explain that this represents his/her body and that he/she will now be exploring his experiences living with depression by adding colour, pictures, words and symbols to the body map. Emphasize that this is not a test of his/her artistic skills and ability.
2. Start by asking the participant to choose a colour which he/she feels represents him and paint his body using that colour. Ask the participant to explain why he/she chose that colour.
3. Now ask the participant to write the following on the edge of his/her map: age, gender, who he/she lives with, how long he/she has known his/her HIV status and ART history. Explain that he/she can use colours, drawings, words and symbols.
4. Remind the participant that the purpose of this study is to explore the participant's experiences of depression and perceptions of care. Ask the participant to think about the word 'depression'. Ask him/her to think of a symbol which represents 'depression' for him/her and to draw this on the body map. Explain that he/she can choose where he/she thinks is the most appropriate place to put this. Ask the participant to then explain why he/she chose the symbol, its meaning and positioning on the body.

5. Now ask the participant to reflect on how depression has affected him/her? If necessary, use the probes “how have you been feeling over the past two weeks?” what have you been thinking about over the past two weeks?” Additional probes may be asked about appetite, sleep, energy, interest and pleasure, concentration and optimism. However these probes should be limited where possible to minimize demand characteristics. Ask the participant to explain what he has drawn or written.
6. Now ask the participant to reflect on what he/she thinks may have contributed to this depression? What may have caused it? Explain to the participant that he/she can choose where to place these drawings or words. It may be on the inside of the body or on the outside. Ask the participant to explain the words and drawings and their positioning on the body map.
7. Now ask him/her to describe how he/she thinks and feels about his/her future? Ask him/her to use words, symbols and colours on the map to symbolise this and to explain what he/she has written or drawn and the positioning on the map.
8. Now ask the participant to think about whether he/she has been getting any support? Has this helped with the thoughts, feelings and behaviour he/she has been describing? Ask him/her to use words, symbols and colours to show what support he/her has been getting and how it has helped? Ask him/her to explain this and the type of support, who was providing it, where?
9. Now ask him/her to use words, pictures and colours to show what else would make him/her feel better? Ask him/her to explain what he/she has written or drawn and the positioning on the body map.
10. Ask the participant whether there is anything he/she would like to add to his/her body map that he may have forgotten or that he/she feels has been missed.
11. Ask the participant to look at his completed body map and ask how he/she feels when he/she looks at his/her body map. Then ask how he/she felt during the process of making the body map.
12. Ask the participant if he/she would like a photograph of their body map to keep. If the participant would like a photograph, photograph the body map and inform that he/she will be given the photograph after two days when it has been printed. Remind the participant that the body map will be kept confidentially in a locked cupboard and that only the researcher (NW), research assistant and supervisor (AK) will have access to the body maps. However, as explained in the consent and assent form, words and pictures from the body map may be used in the research report but these will be anonymous with no identifying markers.

Thank the participant for his/her time and participation in the research.

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