A DESCRIPTION OF THE MENTAL HEALTH OUTCOMES OF HIV POSITIVE ADOLESCENTS ACCESSING CARE IN JOHANNESBURG

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DECLARATION

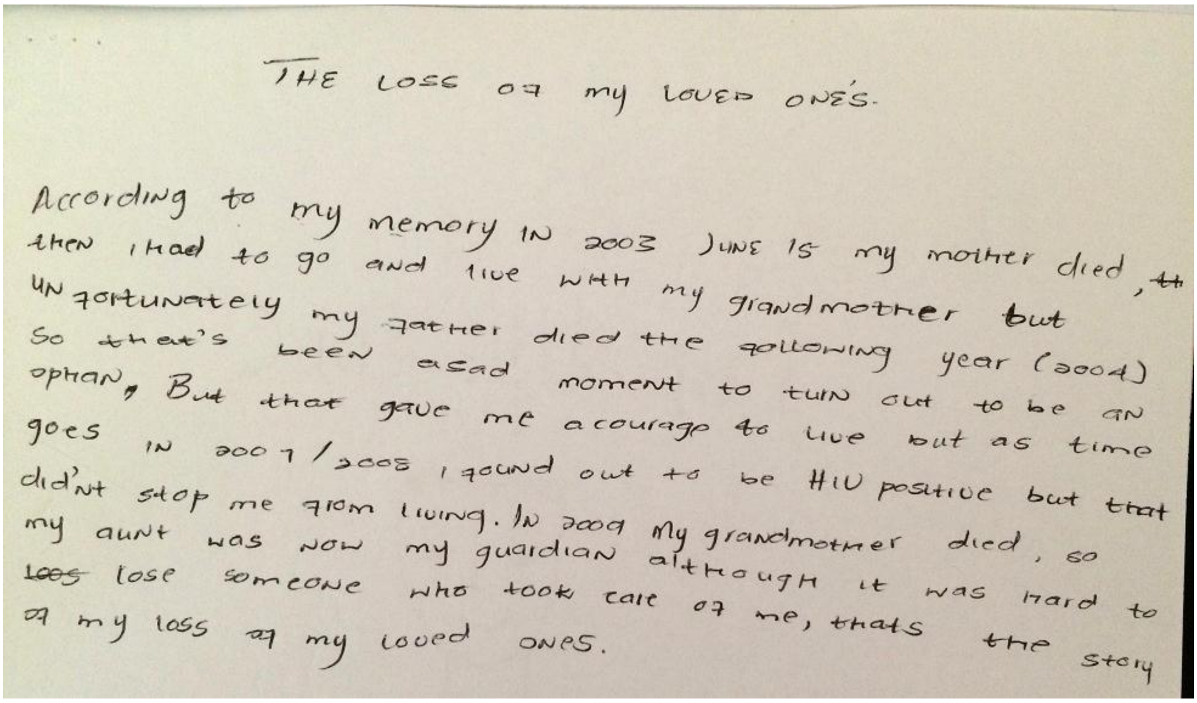
I, NATALY WOOLLETT do solemnly declare, in accordance with Rule G27, that this thesis is a construction of my own work. Where there has been contribution from other people, this has been duly acknowledged. It is being submitted for the degree of Doctor of Philosophy in Clinical Medicine at the University of the Witwatersrand, Johannesburg, South Africa. In addition, this thesis and all of its contents has not been used as a submission for any other degree or submitted at any other university.

NWoollett

Nataly Woollett
Johannesburg,
September, 2017

DEDICATION

This thesis is dedicated to all the HIV positive adolescents who come into care and typically have been for many years. I am humbled by your journeys and experiences. I also dedicate this work to the lay counsellors who serve these young people. I am inspired by your tenacity, kindness and commitment.



THE LOSS of my LOVED ONE'S.

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~~loos~~ lose someone who took care of me, thats the story
of my loss of my loved ones.

Figure 1. 'The loss of my loved one's' (Female, 16 years old at time of interview in 2014)

"According to my memory in 2003 June is [when] my mother died, then I had to go and live with grandmother but unfortunately my father died the following year (2004). So that's been a sad moment to turn out to be an orphan. But that gave me a courage to live but as time goes in 2007/2008 I found out to be HIV positive but that didn't stop me from living. In 2009 my grandmother died, so my aunt was now my guardian. Although it was hard to lose someone who took care of me, that's the story of my loss of my loved ones."

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ABSTRACT

Background: Adolescents living with HIV are an emerging group in the global HIV/AIDS epidemic. Mental health in this population impacts HIV care, treatment, consequential morbidity and secondary transmission. Perinatally infected HIV positive adolescents (PIA) have high prevalence of mental health disorders; loss and bereavement are particularly pervasive in their lives, however little is known about the mental health of PIA retained in care in South Africa. How PIA beliefs concerning their HIV infection are affected by the cumulative effect of bereavement (particularly of parents), the failure to disclose to them the cause of death and the manner in which they learn their own HIV positive status, is a subject understudied. Similarly, there is a paucity of research on effective ways to manage such bereavement. Resilience, or positive adaptation to challenging situations, may be particularly important for PIA, who are exposed to significant stigma, risks and stressors. However, there is limited research regarding adolescents in South Africa, partly because section 71 of the National Health Act (NHA) requires parental or guardian's consent. This presents a significant barrier to research on HIV infected adolescents aged under 18 years.

The aim of this research is to describe the mental health of HIV positive adolescents (13-19 years) accessing care and treatment in Johannesburg and generate evidence to inform mental health policy for this population in South Africa. The study describes the mental health outcomes of this population with a focus on how bereavement and disclosure impacts on mental health, as well as how resilience is manifest in this group.

Methods: Prior to commencement of the research, an order was obtained from the High Court in Johannesburg as upper guardian of minor children for the statutory parental or guardian’s consent. For the thesis, data from three studies are presented in five published papers. These studies were conducted using a combination of qualitative and quantitative techniques resulting in a mixed methods study design. For the quantitative study, HIV positive adolescents aged 13-19 years (n=343) accessing five pediatric antiretroviral clinics in Johannesburg were assessed using standardized measures for depression (Children’s Depression Inventory), anxiety (Children’s Manifext Anxiety Scale), post traumatic stress disorder (PTSD) (Child PTSD Checklist) and suicidality (MINI International Psychiatric Interview). In addition to mental health, the survey captured information regarding HIV, sexual reproductive health and coping. Descriptive and bivariate analyses were conducted on all variables using Statistica v13.

Two qualitative studies were conducted. The first purposively selected 25 participants from the larger study. The aim was to identify elements of resilience through in-depth interviews in this group of PIA. The second identified the most and least symptomatic participants (n=26) from the larger cohort on scores for mental health (depression, anxiety, post traumatic stress disorder, suicidality). Drawings and written accounts of the loss of a significant attachment figure of participants were assessed and compared by professionals (art therapists, psychologists, social workers and counsellors) in three focus group discussions. The goal of this study was to understand the influence of bereavement on mental health and the use of drawing and writing in expressing the experience of loss. Data were analysed in NVIVO 10 using a thematic approach to coding.

The final paper details the process of obtaining ethical approval for research with adolescents in public health facilities through a case study (this PhD).

Results: Of the enrolled 343 participants, 27% were symptomatic for depression, anxiety or PTSD; 24% reported suicidality. Results indicated high rates of comorbidity amongst depression, anxiety and PTSD. Females scored significantly higher for depression ($p<.001$), anxiety ($p<.01$), and PTSD ($p<.001$) than males. Those reporting suicidality also reported significantly higher on all three mental health scales suggesting that suicidal individuals are more likely to present with higher levels of depression ($p<.001$), anxiety ($p<.001$) and PTSD ($p<.001$). Almost 90% did not feel that they belonged in the family with which they lived. Peer violence was significantly correlated to all mental health problems, also hunger, being inappropriately touched, being hit and being female. High exposure to violence was evident and not feeling safe at home or in community increased risk for all mental health disorders. Knowing one’s HIV status, however, was protective as was having dreams for the future.

The qualitative studies highlighted that despite marked stressors in the lives of these adolescents, a high degree of resilience was described. Characteristics of resilience in this group included a pertinent set of beliefs, including a belief in fate and recognition of personal strength as a consequence of managing adversity. Character traits such as a pragmatic acceptance about one's life, actively taking responsibility, and a robust self-esteem were evident. Social behaviours included the ability to pursue and access adults and healthcare to meet developmental needs, having a desire to support and help others and challenging HIV related stigma. These characteristics were underscored by the capacity for self-reflection.

The studies also revealed that PIA have limited understanding of how they became infected, vertical transmission and potential benefits of PMTCT to their future reproductive needs, despite disclosure. Most participants were experiencing complicated grieving which was impacting negatively on their mental health, ability to accept their HIV status and adhere to treatment.

The drawings and written accounts of the qualitative study accentuated contextual deprivation, including high exposure to multiple and consistent losses of significant attachment figures. They also pointed to emotional deprivation and impoverishment, including unresolved complicated grieving. Views from participants emphasized missed opportunities, including failure to address the mental health concerns of this population at risk.

The case study suggested that without court intervention, most of the participants, being orphans without guardians, could not have participated in the research because the statutory consent was otherwise impossible. This case study argues for exceptions to the parental consent requirement, by reason of the exclusion of Orphaned and Vulnerable Children and Youth (OVCY) from research. Inconsistent and confusing legal policy that inadvertently silences voices that most need to be heard, as well as law that is inconsistent with principles of justice, inclusiveness and autonomy, are put forward to argue for a change to the National Health Act.

Conclusion: HIV positive adolescents accessing care demonstrate high levels of mental health problems that are largely unrecognized and could potentially be addressed within health systems. Recognition of mental health challenges in PIA is crucial to effective HIV care and treatment and providers need to be sufficiently sensitized to this reality.

PIA need improved communication regarding vertical transmission and PMTCT to properly understand their HIV status and engage effectively in management. Honest communication about how relatives died and disclosure of HIV status is necessary to reduced stigma, complicated grieving and improve mental health.

The impact of unprocessed loss early in life has long-term negative consequences for PIA. Innovative methods are required to address unmet mental health needs of this patient population. The use of non-verbal methods (drawing and writing) by healthcare professionals could be especially valuable to both patient and provider, particularly in the case of managing bereavement.

PIA, who face high levels of hardship and change, nevertheless exhibit strong resiliency beliefs, traits, and behaviours. Healthcare environments have the potential to be utilized as powerful resources in fostering resilience in PIA, if characteristics of adolescent resilience are integrated into prevention and intervention programming.

Finally, a balance is required between protecting adolescents from exploitation and permitting access to benefits of research. Mandating parental consent for all research does not necessarily give effect to policy. For the vast majority of South African HIV infected adolescents parental consent is not possible. Adolescents are understudied and poorly understood and although these laws are there to protect this vulnerable group, it also makes them and their problems less visible. In order to scale up interventions, careful consideration needs to be placed on how the laws can help researchers benefit adolescents. Section 71 of the National Health Act ought to be amended to facilitate valuable and necessary research concerning HIV infected orphan children and adolescents.

Keywords: perinatal HIV infection, HIV positive adolescents, vulnerable youth, mental health, healthcare system, disclosure, violence, orphan, bereavement, complicated grief, drawing, resilience, research, National Health Act

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ACRONYMS

AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral Therapy
CAB	Community Advisory Board
CD4	Cluster of Differentiation 4
CHC	Community Health Centre
EMTCT	Elimination of Mother to Child Transmission
GBV	Gender Based Violence
HAART	Highly Active Antiretroviral Therapy
HCT	HIV Counselling and Testing
HIV	Human Immunodeficiency Virus
HREC	Higher Research Ethics Committee
IPV	Intimate Partner Violence
LMIC	Low and Middle Income Country
OVCY	Orphans and Vulnerable Children and Youth
PIA	Perinatally Infected Adolescents
PLWHA	People Living With HIV/AIDS
PMTCT	Prevention of Mother to Child Transmission
PTSD	Post Traumatic Stress Disorder
SANAC	South African National AIDS Council
SSA	Sub Saharan Africa
UNAIDS	Joint United Nations Programme on HIV and AIDS
UNFPA	United Nations Population Fund
UNICEF	United Nations International Children’s Emergency Fund
WHO	World Health Organization

CHAPTER 1

Introduction – setting the scene

Introduction

This chapter provides an overview on the context of HIV in adolescents both globally and locally. It describes the mental health of children and adolescents infected with HIV and the South African health system response to this. The challenge of undertaking research with minors in South Africa is presented. A conceptual framework that guides the work is explained, as well as the motivation for undertaking this research. Chapter two offers a literature review that expands and broadens the picture of mental health in adolescents as well as in perinatally infected HIV positive adolescents.

Context of HIV in adolescents

Child is defined in this thesis as ‘a person under the age of 18 years’ (Children’s Act 38 of 2005, Section 1; Constitution of the Republic of South Arica Act 108 of 1996, Section 28(3)). Meaning all people under the age of 18 years are permitted the protection guaranteed by section 28 of the Bill of Rights and the provisions of the Children’s Act. There are many definitions of adolescence but for the purposes of clarity, this thesis will use age of majority (>18yrs in South Africa; Children’s Act 38 of 2005, Section 17) as a marker for the end of adolescence and 13yrs (typically the onset of puberty) as the marker for the beginning of adolescence).

Today, 1.8 billion adolescents stand at the challenging crossroads between childhood and adulthood (UNFPA, 2014). Nine out of ten of these young people live in the developing world and face especially profound challenges, from obtaining an education to simply staying alive. Adolescents are vacillating in a developmental stage characterized by increased flux; they are moving towards autonomy but still require protection and oversight. At no other time except infancy do human beings undergo so much development in such a short period. During adolescence, children gain 50% of their adult body weight, become capable of reproducing, and experience an astounding transformation in their brains (UNICEF, 2011; Blakemore, 2012). All these changes occur in the context of rapidly expanding social spheres. During adolescence, an individual acquires the physical, cognitive, social and economic resources that are the foundation for later life health and wellbeing (Patton et al, 2016). These same resources define trajectories into the next generation. Thus, investments in adolescent health and wellbeing bring benefits in the present, for decades to come and for the next generation (Patton et al, 2016). Although there have been tremendous strides made in children's health outcomes, the paucity of attention and resources devoted to adolescents is threatening to limit the impact of these efforts on the lives of adolescents transitioning to adulthood.

Adolescents living with HIV are an emerging group in the global HIV/AIDS epidemic. Almost 2.1 million adolescents in LMICs were living with HIV in 2012, and of the approximately 3.2 million children under the age of 15 years infected with HIV globally, 90% are living in sub-Saharan Africa (SSA) (WHO, 2013; UNAIDS, 2014). Indeed, almost one-sixth of all new HIV infections occur in adolescents aged 15-19 years (UNICEF, 2013) making this age group the most vulnerable incident infection population in South Africa (Shisana et al, 2014). Prevalence amoungst women is still nearly double that of men and intergenerational sex for young girls 15-19yrs has escalated significantly over time (Shisana, 2014). Due to dramatic improvements in access to antiretroviral therapy (ART), children born with perinatal HIV infection are growing into adolescence in increasing numbers, especially in LMICs (Ferrand et al, 2009; Idele et al, 2014). Large proportions of children with slowly progressing disease (sometimes defined as having no progression of disease in the first ten years of life or CD4 cell percentages at or above 25% at 10 years (Ofori-Mante et al, 2007), or as median survival of 12 to 13 years (Ferrand et al, 2009), infected before PMTCT interventions became widely available, are presenting for the first time in adolescence, having lived with untreated HIV for a decade or more (Bernays et al, 2014; Marston et al, 2011). Based on 2013 population estimates, Zanoni et al (2016) estimate that 124 070 adolescents and young adults aged 15-24 years in South Africa are receiving ART. However, coverage of ART is notably reduced in adolescents and children than in adults (WHO, 2013) and the proportion of adolescents with virological suppression at 12 months ranges from 27% to 89% (Ferrand et al, 2015). South African studies with direct comparison between adolescents and adults indicate lower retention and viral suppression amoung youth (Zanoni et al, 2016).

Low ART treatment rates amoung adolescents are thus currently inversely related to the high number of new HIV infections in this age group. Previously, youth who were newly infected were less likely to qualify for ART based on National HIV Treatment Guidelines (CD4 below 500 cells/mm^3) due to asymptomatic disease and higher CD4 counts (NDoH, 2015). Recently, the WHO recommended universal treatment for HIV-infected individuals, including adolescents and young adults (WHO, 2013) and at the time of this writing, National Department of Health has endorsed these recommendations (September, 2016). The cohort of sexually active, HIV-infected and viremic youth could have a large impact on HIV transmission rates in South Africa and warrants consideration for public health investment.

Around the world, adolescents are the only age group in which AIDS-related deaths are not dissipating (UNICEF, 2013); AIDS-related illnesses have been reported to be the leading cause of death among adolescents in Africa (Dahourou et al, 2017). In 2013, in South Africa alone, there were more than 9,500 deaths amoung HIV-infected adolescents (UNAIDS, 2013). Biomedical responses are vital but not sufficient and they remain impeded by weak procurement and supply management systems, human resources shortages and the high cost of particular treatment regimens and diagnostics (Cluver et al, 2015). Psychosocial and community based responses are equally important, and although evidence of impact of these interventions is being more recognized, there is still more evidence required to determine how effective they are and could be (Cluver et al, 2015; Cluver et al, 2016; Hensels et al, 2016; Sherr et al 2014; Sherr et al, 2009). Moreover, South Africans between 13-19 years comprise roughly 30% of the population (STATS SA, 2010, 2014). Thus, adolescents are considered a key population contextually for HIV prevention, care and treatment (UNAIDS, 2011) as their engagement is critical to a successful and meaningful HIV response.

The thoroughly defined burden of survival to older childhood with untreated, vertically acquired HIV infection, the young age of sexual debut (up to a quarter of 15-19 year olds in SSA report sex before age 15 years) and the high HIV incidence rates in SSA further emphasise the need for efficient and adequate strategies for HIV counselling and testing in older children and adolescents in the region, but also for suitable care and treatment (Govindasamy et al, 2015). Strategies to improve HIV diagnosis and early ART initiation in adolescents could drastically improve the continuum of care for youth in South Africa (Zanoni et al, 2016).

Vertical transmission rates have decreased to less than 3% nationally in South Africa (Goga et al, 2012), however, the prevention of mother to child HIV transmission (PMTCT) programmes were only rolled out in the public health sector around 2004 (Meyers et al, 2007) impacting on the current population of HIV positive children and adolescents (Zanoni et al, 2016). In 2012 it was estimated that there were approximately 369,000 0-14 year olds and 720,000 15-24 year olds living with HIV (Shisana et al, 2014). It is unclear how many perinatally infected HIV positive adolescents (PIA) are on treatment and engaged in care as there is currently no precise test to determine perinatal infection, especially in resource poor settings where accurate clinical records are a challenge to obtain, and disclosure of HIV status often occurs late, if at all, so symptoms and time of first hospitalization are used as guides (Ferrand et al, 2009).

Adolescence is a time of profound physical, cognitive and psychological development but PIA have a host of additional issues to manage. HIV is a disease that affects systems at the household level. After inheriting the virus from a parent, PIA are typically orphaned and have changing or absent guardianship, which often leads to being isolated through neglect or separation from other family members (Bernays et al, 2014). Emotional bonds to those taking care of them can be tenuous. It is also typical for children/adolescents to be reared without fathers contributing to their upbringing either socially or financially (Coovadia et al, 2009). This tendency has accentuated the difficulty of childhood poverty (Coovadia et al, 2009).

For many PIA, their childhoods have been characterized by frequent illness, hospitalizations, multiple losses, and poor school attendance (Mavhu et al, 2013). They are more likely to have lower educational achievements and consequently less chance of gaining economic independence, as little financial support for school fees exacerbates the risks of interrupted school attendance and the existing learning disadvantages that they might face through HIV-related cognitive impairment (Bernays et al., 2014; Sherr et al, 2014). Identity formation, accepting their HIV status and the influence of stigma can be overwhelming (Mutumba et al, 2015). Issues of disclosure both to those infected and then later to friends and partners are daunting (Vaz et al, 2010; Pinzon-Iregui et al, 2013); and many encounter challenges with mental health (Gadow et al, 2012; Mavhu et al, 2013; Mellins & Malee, 2013; Bernays et al, 2014; Lowenthal et al, 2014), often as a consequence of being orphaned (Cluver et al, 2012). Bereavement is a particularly difficult undertaking amidst these circumstances and compounds mental health risk (Cluver et al, 2012; Willis et al, 2014). Adolescents have to negotiate the complex demands of treatment, social pressures, and vulnerable health within the context of bereavement and disrupted care, without having necessarily developed the skills to manage these circumstances. Compounded by a cycle of poverty, these interconnecting factors shape the ability of these adolescents to manage their health and prepare for adult life.

Adolescents in many urban, poor settings also typically live in environments typified by high levels of migrancy, urban poverty, violence, and lack of family structure (Mmari et al, 2014). In South Africa there are increased amounts of emotional, physical, and sexual abuse and neglect of children and adolescents that have a significant impact on their mental and physical health (Meinck et al, 2016; Coovadia et al, 2009). All these factors exacerbate the burden of being infected.

Protecting children from abuse and poverty and strengthening the financial and social roles of fathers in children and adolescent's lives are essential aspects of a social policy agenda that aims to improve health (Coovadia et al, 2009). While social grants have reduced absolute poverty, 45% of the population remains living on about \$2 per day (the upper limit for the definition of poverty) (Mayosi et al, 2014). Implementation of a sizeable social grant system, which has vastly expanded since 1997, has improved the health of children through the reduction of poverty (Mayosi et al, 2012). Government-provided cash transfers, have been shown to improve mental health, education and sexual health amoung adolescents (Robertson et al, 2013). Governments in countries with high prevalence of HIV are starting to realise that universal cash transfers, as well as universal school provision, are fundamental HIV prevention approaches and good policy (Remme et al, 2014). However, cash alone is an essential component, but not a magic bullet (Cluver & Sherr, 2016). To navigate this risky developmental stage, adolescents also need attention, supervision, and care (Cluver & Sherr, 2016). In addition, research indicates that in South Africa, adolescent HIV risk behaviours are not driven exclusively by behavioural choice; rather their incidence is associated with structural and resulting psychosocial deprivation, that can be assuaged by unconditional cash/cash-in-kind and psychosocial care. Thus, incentive-based cash interventions that are founded on the basis that adolescent sexual risk is fundamentally a conscious behavioural choice may fail those who are at the utmost structural risk of HIV infection (Cluver et al, 2016). The challenge now is to understand the mechanisms and to explore pathways to widen the scope of the effects of social protection (Cluver & Sherr, 2016).

As ART continues to be scaled up in LMICs and improve morbidity and mortality outcomes associated with HIV infection, prevention of new HIV infections amoung adolescents is critical (Davies & Pinto, 2015). Increased efforts are required to understand the *global* health needs of this population (including mental health needs) to mitigate and prevent secondary transmission, and manage consequent adult burden of disease as they transition from adolescence. In addition, although a focus on risk for this population serves an important function in getting appropriate attention paid to the realities of growing up with HIV in this context, it is also critical that such an emphasis does not dominate the plurality of experiences of HIV infected and affected children and adolescents and the ability of some to deal successfully with significant adversity (Skovdal, 2012). The concept of resilience is not well understood in this population although it is quite evident in some patients and needs to be explored more thoroughly to serve an important function in strengthening protective factors that may improve the health of patients and the healthcare system.

Prevalence of mental health issues in South Africa

Mental disorders typically have their onset in late childhood and adolescence; and as many persist into adulthood, adolescent mental disorders make a greater contribution to adult disease than ever before (Patton et al, 2016). HIV is a further reason why adolescents and young adults, particularly in southern and eastern SSA, have seen fewer benefits from the epidemiological transition (Patton et al, 2016). Studies in high and low income countries indicate that just under half of all people living with HIV/AIDS (PLWHA) have a diagnosable mental disorder and in some instances a threefold higher rate of mental disorder (Freeman et al., 2007; Myer, 2009; Lazarus et al., 2009; Thom 2012, 2009). The reasons for this are complex but include pre-morbid mental conditions, the effects of the virus on the central nervous system, the psychological impacts of living with HIV/AIDS, side-effects of medication and results of social stigma and discrimination (Freeman et al., 2007). Mental health disorders have been shown to occur with increased frequency amoung HIV positive children and adolescents (Williams et al, 2007; Gadow et al, 2012; Lowenthal et al, 2014).

While the virus itself or an opportunistic infection, such as one causing meningitis or encephalitis, may lead to neurodevelopmental impairments that affect mental and psychomotor development, it appears that the social context of HIV (such as familial disruption, poverty, stigmatization, orphanhood and so on) may play a greater role in the higher prevalence of mental health problems in this population (Domek, 2009). As a consequence of the combined neuropathological effects of HIV and the environmental context, the most common psychiatric disorders found amoungst HIV positive adolescents globally are depression, severe anxiety and post-traumatic stress disorder (PTSD) (Williams et al., 2007; Thom 2012; Lowenthal et al., 2014; Gadow et al, 2012). There is evidence to support that these same mental health issues are pervasive for HIV infected adolescents in South Africa (Cluver et al, 2007; Cluver et al, 2008; Cluver et al, 2009; Thom, 2009; Petersen et al, 2014).

While there are high rates of acute hospitalization in adolescents as a result of chronic conditions (Ferrand et al, 2010); the emotional effects of coping with HIV infection can be severe, and the frequency of psychiatric admissions amoung HIV-infected adolescents is significantly higher compared with that in the general paediatric population in high-income countries (Gaughan, 2004). These mental health needs typically receive very little attention both in South Africa and generally in LMICs (Patel, 2007; Thom, 2009). Most adolescents and young adults with mental health problems do not receive treatment from health professionals (Patton et al, 2016). Poor mental health is highly associated with other health and development issues in youth, particularly lower educational achievements and neurocognitive delay, substance abuse, violence, and poor reproductive and sexual health (Domek 2006; Domek, 2009; Sherr et al, 2009; Sherr et al, 2014; Meinck et al, 2016). Key challenges to addressing mental health needs include the shortage of mental health professionals, the fairly low capacity and motivation of non-specialist health workers to provide quality mental health services to young people, and the stigma associated with mental disorder (Patel, 2007). Reaching adolescents during this developmental period thus serves a preventive function regarding long standing adult disease burden; but more importantly, it can help this age group navigate a predictably difficult period in terms of developmental risk and mental health.

Health system responses to HIV and mental health problems in South Africa (historical and recent)

The history of South Africa has had a marked effect on the health of the population and the current health policy and services (Coovadia et al, 2009). The introduction of highly active antiretroviral therapy (HAART) in 1996 in the international community qualitatively changed the HIV treatment landscape. Although it took a little longer for HAART to arrive in South Africa, the national antiretroviral treatment programme in South Africa commenced in 2004 (years of denial, blaming, moralizing and inaction finally came to an end in the watershed year of 2003, when the South African Government approved a national programme to make ART drugs publicly available to all HIV infected people who qualified for treatment). South Africa currently has the world's largest programme of ART, with approximately 1·8 million people estimated to be taking antiretrovirals by April, 2011 (Mayosi et al, 2012). In 2011, about half of individuals in need of ART in South Africa were receiving treatment, which is an increase attributed to the consistently revised and updated guidelines for treatment initiation. Incidentally, South Africa has recently undertaken WHO recommendations for universal test and treat as of 1st September 2016 (National Department of Health, 2016). However, extending treatment to the individuals who need ART but are not receiving it is a challenge to the capability of the health service (Mayosi et al, 2012). This is especially the case in children and adolescents where the prevalence of undiagnosed infection is significantly higher compared to adults and, amoung those diagnosed HIV positive and eligible for treatment, coverage of ART is minimal at 34% (Govindasamy et al, 2015).

The South African health sector in has been affected by a legacy of maldistribution of staff and poor skills of many health personnel, from 1994, that has compromised its ability to deliver key programmes, particularly for HIV, tuberculosis, child health, mental health, and maternal health (Coovadia et al, 2009). The national public health sector, staffed by around 30% of the country's doctors, remains the exclusive provider of health care for more than 40 million people who are uninsured and who constitute around 84% of the national population (Mayosi et al, 2014). There is a shortage of nursing staff in the country and South Africa needs at least three times its current health workforce to provide satisfactory care for patients with HIV/AIDS (Mayosi et al, 2014). The HIV/AIDS and associated tuberculosis epidemics have seen the rapid expansion of a range of community carers (lay counsellors, tuberculosis directly observed treatment, short course (DOTS) supporters and home based carers) to attend to the service delivery gaps (Sharp et al, 2015).

The prevalence of mental disorder in South Africa is relatively high as reported in the 2003 South African Stress and Health (SASH) study (Herman et al, 2009). The SASH study reported a 12-month prevalence of 16.5% and a lifetime prevalence of 30.3% for depression and anxiety disorder in the adult South African population (Stein et al, 2009). Yet, only one in four people with common mental health disorders (depression, anxiety, PTSD), have access to treatment of any kind (Seedat, 2009). Mental disorders result in lower life expectancy and increased risk of comorbid physical illnesses, and often result in limited access to appropriate general healthcare services (Schneider et al, 2016). From an economic standpoint, it costs South Africa more not to treat mental disorder than to treat it (Lund et al, 2013); investment in mental health is a smart development strategy currently underutilized in South Africa (Becker & Kleinman, 2013).

Recently, governments have been encouraged to take action and promote research and policy to inform national health plans with a focus on mental health care (Ventevogel, 2014). Promisingly, South Africa has committed to a National Strategic Plan 2013-2020 for mental health, however it remains to be seen how this policy can be implemented at local level (Stein, 2014). Some of the most significant barriers are insufficient resourcing, poor knowledge of mental disorders and lack of confidence (Schneider et al, 2016; Mall et al, 2012). Psychologists and psychiatrists are in short supply with 0.28 psychiatrists and 0.32 psychologists per 100,000 population working in the public health sector (Lund et al, 2010). Given the global focus on the integration of mental health into existing health platforms to address the lack of human resources, task-shifting or task-sharing has been proposed as a strategy to manage this shortfall (Kakuma et al, 2011; Patel et al, 2011; Becker & Kleinman, 2013).

Lay HIV counsellors, historically funded by the USAID to provide HIV counselling and testing (HCT) are based in most primary health care clinics in South Africa (Petersen et al, 2014). There is growing evidence that lay counsellors are able to provide skillful and effective task-sharing interventions (Petersen et al, 2014; Brooke-Sumner et al, 2015; Padmanathan & De Silva, 2016; Murray et al 2013; Mendenhall et al, 2014); but require robust training, consistent supervision and support structures to ensure high-quality services and retention of human resources (Schneider et al, 2016). Mental disorders can be detected through appropriate screening by trained non-professionals, but more evidence is required on optimal detection methods, including when and for whom screening might be appropriate (Kagee et al, 2012). This should be provided together with a well-functioning referral mechanism to ensure those who require more specialized services are able to access them. System strengthening is vital to ensure continuity of care across primary, secondary, and tertiary care and access to medication and psychosocial care (Schneider et al, 2016; Zanoni et al, 2016). HIV could be seen as a chronic illness and gateway to mental health care when healthcare professionals are sensitized to the issues and how they present in patients, especially children and adolescents.

Issues of ethics of research with adolescents

An imminent need to research mental health in HIV positive adolescents is apparent. Unfortunately, in South Africa, while being well intentioned, recent legal requirements often preclude adolescents from research that may benefit them. The framework governing research in South Africa, prior to March 1st 2012, permitted adolescents to consent independently to take part in research (Zuch et al, 2012). National Department of Health ethical guidelines observed that consent for children/adolescents to participate in health research be obtained from the parents or legal guardian; *but*, where there was minimal risk and no community objection was expected, older children could consent to research unassisted (Department of Health, 2004; Strode & Slack, 2011).

With regards to independent consent, the provision of Section 71 of the National Health Act No 61, 2003, which was amended and passed in 2012, contrastingly does not make the same distinctions between children and adolescents. The Act is the first attempt of the South African government to protect research participants under law (Strode et al, 2005); however, Section 71 of the Act now mandates ***active written consent*** from a parent or legal guardian for all research undertaken with participants under the age of 18. The Act says: –“where research or experimentation is to be conducted on a minor for a therapeutic purpose, the research or experimentation may only be conducted–(a) if it is in the best interests of the minor; (b) in such manner and on such conditions as may be prescribed; (c) with the consent of the parent or guardian of the child; and (d) if the minor is capable of understanding, with the consent of the minor.” For non-therapeutic research and experimentation, it may only be conducted–“(i) in such manner and on such conditions as may be prescribed; (ii) with the consent of the Minister (of Health); (iii) with the consent of the parent or guardian of the minor; and (iv) if the minor is capable of understanding, the consent of the minor” (National Health Act, 2003). Thus, even though caregivers had historically been the proxy for consent, they no longer are able to give consent for a child’s involvement in research under the new provisions of the act.

This becomes particularly difficult in the case of children and adolescents who do not have legal guardians (and there are many in the context of HIV/AIDS in South Africa); or children/adolescents who do not live with or have access to their legal guardians. Only 32% of South African children live with both of their biological parents and 19% have lost one or both parents (SAHRC & UNICEF, 2011). Typically when a biological parent dies, the children/adolescents are taken into care by extended family members or friends and these caregivers rarely go to the courts to obtain legal guardianship (i.e. legally adopt the minor). Hence these minors are without legal guardians in terms of the law. At this point, the high court becomes their legal guardian, so in keeping with the conditions of the National Health Act, researchers need to approach the high court for consent of minors to participate in research.

There has been a great deal of debate over allowing youth to consent in health research (Strode & Slack, 2011; Zuch et al, 2012; Jaspan et al, 2006; Fisher et al, 2004). These debates are likely to continue, especially in places like South Africa, where HIV research is still abundant and where the burden of disease has moved from generalized population studies, to vulnerable groups, like adolescents, who currently carry the greatest burden of disease. Including adolescents in research is thus prudent and arguably unethical if not conducted. Obviously it is difficult to conduct research with this group if research does not include their participation.

Provision 71 of the National Health Act is in contradiction with parts of the Children’s Act (2005), another progressive piece of legislation relied upon to govern the rights of minors. For example, the Children’s Act enables children to consent to a variety of health interventions before the age of 18 (e.g. independent consent can be given by someone as young as 12yrs for HIV counselling and testing; the age of consent for sexual activity is 16yrs and a female of any age can get a termination of pregnancy without parental consent (Children's Act, 2005)) whilst the NHA bars any independent consent to research before adulthood (Strode et al, 2010). Thus an adolescent can come into a clinic and consent to an HIV test and its potential consequential emotional outcome and that same adolescent cannot enroll in mental health research that would give him/her access to mental health referrals and support. As a result of this disjuncture between access to necessary medical interventions and participation in research and evaluation, young people's agency is undermined, which potentially leads to poor returns on mental health strategies as well as rising rates of burdens of disease in this population.

UNICEF (2011) does highlight that in many countries, especially developing countries, regardless of national laws, children (defined as any person <18yrs) take on 'adult' responsibilities such as labour, marriage and childbearing. In fact, in most guidelines that discuss HIV care and treatment, there is a conflict between the wish to protect and the recognition that all adolescents, particularly older adolescents (15–19), should be able to take increasing responsibility for their lives including health care decisions (WHO, 2013).

Research with children who do not have parents or legal guardians will no longer be achievable due to the present restriction of the authority to provide proxy consent according to the NHA. Moreover, such children may not volunteer for health research as they do not have an adult with the legal capacity to provide proxy consent. This will also have far-reaching implications for research particularly with child-headed households, orphaned and vulnerable children and youth (OVCYs) and undocumented migrant children. OVCYs are increasingly acknowledged as a unique population in terms of HIV risk and transmission (Cluver et al, 2011). OVCYs and child-headed households are an exceptional and contemporary issue placing many South African institutions (including government) under immense pressure. Innovation and responsiveness are key determinants to counter these challenges.

Vulnerable groups need to be protected from exploitation, including from self-seeking researchers, however, these same groups need information and access to benefits that come from research. The tension that exists between protecting adolescents from exploitative research and excessive regulation that may impede on their human rights and autonomy as individuals cripples research being undertaken to improve access to care and treatment and reform national policy (Zuch et al, 2012). A rights-based approach is necessary in managing these tensions; “health and human rights are complementary approaches to the central problem of advancing human well-being” (Mann in Kirby, 2004). Vulnerable groups are the last to benefit from research, if at all, and they are the group that needs it the most. Excluding adolescents from studies is likely to delay access to treatment and prevention interventions (Pettifor et al, 2013).

Inadequate and inconsistent legal frameworks can powerfully affect the health, rights, and potential of adolescents and young adults (Patton et al, 2016). The proposed new provision of section 71 of the National Health Act do not sufficiently take into account the particular social context adolescents live in in South Africa, or their emerging autonomy; there needs to be a better balance between adolescent’s admittance to research and their safety as research subjects (Zuch et al, 2012).

Recently the National Department of Health has updated their guidelines for Ethics in Health Research (2015). These guidelines were not in effect at the time this study was given ethical clearance. The guidelines give RECs greater possibilities of accepting waivers and in terms of independent consent, the document highlights the following:

“An ethical justification for independent consent by minors may be made in the following manner:

- By prior engagement with participating community role players, the PI can request (and justify explicitly) REC approval of a waiver of the parental (or substitute) permission requirement. Engagement could include outreach to relevant role players such as canvassing the opinion of a representative body of parents e.g. via schools.
- Factual evidence of such engagement must form part of the PI’s justification in the protocol. Factual evidence may be in the form of a letter from a relevant role player (like a community leader, school principal or a CAB) that confirms the view that independent consent is acceptable to the parents.
- If the REC accepts the ethical justification and the factual evidence of parental support for independent choice by their minor children, then the REC may grant a waiver of the requirement of written parental permission and must document the

process carefully" (pg. 33). Various ethics committees will implement these guidelines as they see fit, but it still does contradict the law, leading to further difficulty in managing research with adolescent populations.

Conceptual framework (Bronfenbrenner's ecological model)

Approaches to understanding human development rely heavily on Bronfenbrenner's ecological model of 1979. In his original theory, Bronfenbrenner postulated that in order to understand human development, the entire ecological system in which growth occurs needs to be taken into account. This system is composed of five socially organized subsystems that support and guide human development. Each system depends on the contextual nature of the person's life and offers an ever-growing diversity of options and sources of growth. Furthermore, within and between each system are bi-directional influences. These bi-directional influences imply that relationships have impact in two directions, both away from the individual and towards the individual. As we potentially have access to these subsystems we are able to have more social knowledge, an increased set of possibilities for learning problem solving, and access to new dimensions of self-exploration (Bronfenbrenner, 1979).

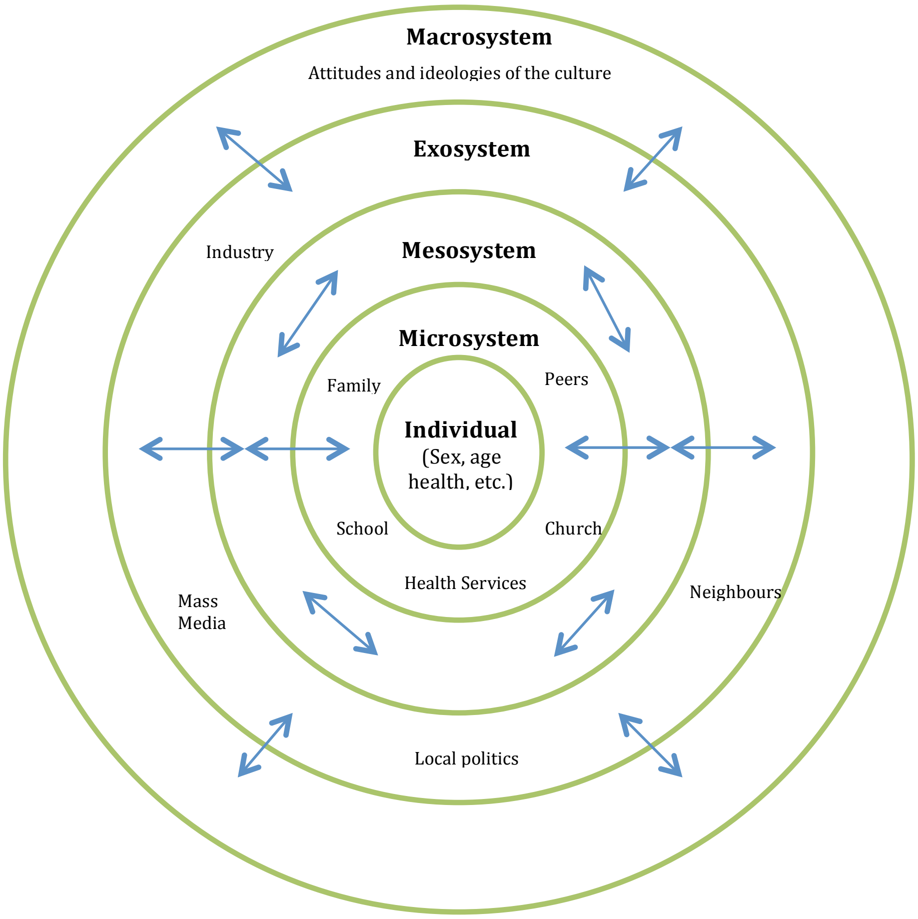


Figure 2. Bronfenbrenner's Ecological Model

Bronfenbrenner's model of human development starts with an initial mapping of the settings where most social interactions occur, those settings where we interact with others on a face-to-face basis. From this micro-level analysis it is possible to explore how we are influencing those around us and how we are concurrently being influenced. But if the mapping of human development ended at this point, the scope of shaping on our development would be incomplete. Other questions would endure: how does the relationship between and amoung our experiences in different settings where we interact with other people impact our development? What is the impact on our development when significant events and interactions occur in environments that we do not occupy but someone in our circle of family or friends does? Most importantly, in what ways does an increasingly complex and interconnected cultural, political and economic world reach into our lives in ways that effect our development? Bronfenbrenner answered these questions by creating a model that exposes how our development is inseparable from our environment throughout our lives. After explaining the multiple interconnected and interlocked rings of influence surrounding us as developing individuals, Bronfenbrenner helps decode the complex ways these rings of influence advance and restrain our development. Ecological models of development require that we genuinely consider the impact of the social world on the development of the individual (Bronfenbrenner, 1979).

Initially, individuals are born with a host of biological characteristics and traits ranging from their sex to their health and personality type – this is the individual level of Bronfenbrenner's model. From there we advance to the microsystem and this includes our family, friends, and environments where we interact most with others, including school, the health system we utilize and so on. Most people regularly move through various settings that constitute their microsystem (e.g. from home to school, to recreational environments with peers, to clinics to receive treatment and so on). Bronfenbrenner's mesosystem captures the idea that individuals develop by interacting and relating to others within multiple settings in their microsystem (e.g. familial, academic, recreational and health settings). As people must learn to simultaneously manage experiences in more than one setting, a synergy is created across settings that affect the developing person. This is the mesosystem which captures the developmental importance produced by the connections across settings (Bronfenbrenner, 1979). The concept of resilience can be highlighted here.

Resilience is both a function of characteristics of the individual child and the relationships that support the child, as well as the quality of that child's environment, which provides the resources necessary for positive development, despite adverse circumstances (Ungar et al, 2007).

The mesosystem has important considerations on adolescent development. An adolescent typically experiences the behavioural expectations of more than one important adult in their lives; for an HIV positive adolescent this might be their primary caregiver and their treating doctor, nurse or lay counsellor, and in more than one setting, e.g. home and the clinic. Caregivers and doctors/nurses/counsellors must interact with each other so that their independent interactions with the adolescent communicate identical expectations about disease management at home that can impact health, adherence, nutrition and sexual risk taking behaviour, and so on. Likewise, what occurs in the health setting (e.g. lack of agency, medication stock-outs, poor service delivery) influences an adolescents' behaviour at home. Another pertinent example is that of the complex social environment that influences all aspects of HIV disclosure. Major domains within which disclosure takes place include caregiver/child; family, neighbours, friends ('close community'); and church, school and media ('wider community) (Vreeman et al, 2015). Negative beliefs about HIV may be defining characteristics of the social context for if, when, and how disclosure takes place.

The exosystem also assumes a linkage between two or more settings. But unlike the mesosystem, the developing individual does not partake directly in one of those settings. Initially, it might seem both obvious and developmentally inconsequential that the people who populate our lives have experiences in settings that do not include us. However, our experiences are interrelated and the systems influence each other. If a caregiver loses their job, the adolescent in their care may experience an increase in poverty that has a significant impact on their development. Similarly, an adolescent's interactions at school may indirectly influence interactions in the home setting. A poor report card, interactions with peers, stigma experienced at school are all interactions that are outside of the caregivers experience but have a major influence on the home environment. The impact of the exosystem on our development can be overwhelmingly powerful and examples occur across the lifespan. If an adolescent loses their primary caregiver, they have to move somewhere else, their microsystem tends to change and home life is highly impacted. If they are unable to receive their ARVs at a clinic as a result of stockouts, they miss out on schooling by having to return to clinics and experience increased stress that impacts everyone living at home. The context and processes of human lives are powerfully shaped in the exosystem through the decision-making authority of legislative bodies at the local, state and national levels (Bronfenbrenner, 1979). Although the developing adolescent is not likely interacting with the Minister of Health, that ministry's decision to create fixed dose combinations for HIV positive youth impact the adolescent in a myriad potential ways, from increased adherence to medication, to improved health outcomes, to improved schooling and increasingly safer sexual behaviour and so on.

The macrosystem is Bronfenbrenner's overall term for cultural patterns in society. This component of the model reflects the understanding that any explanation of human development must locate knowledge about people in the pervasive cultural context in which they find themselves. Like the exosystem, the macrosystem is external to the individual and highly influential on development. This system tends to be most imperceptible when the focus is on one individual (Bronfenbrenner, 1979). For example, in a society structured through a complex linking of capitalism, privilege and patriarchy, individuals can be expected to be over- or underprivileged based on race, class, gender and other divisions indicative of a society characterized by a set of hierarchies. Thus, any unequal power relation that exists in the macrosystem can be expected to imitate the human experience on the micro-, meso- and exosystems. South Africa is characterized by extreme inequality, with a high gini-coefficient (0.6 in 1995 to 0.7 in 2009) to confirm this (Mayosi et al, 2014).

A final system, the chrono-system, that threads through the entire system, takes into account history and the time that shapes one's development. For HIV positive adolescents living in South Africa, this might involve the generation they are currently borne into with its consequent political systems and social inventions, and the era of AIDS denialism in South Africa in the early part of this century that is their inheritance.

Bronfenbrenner's model is a useful one in explaining the systemic links between contexts and how this impacts individuals. Adolescents who are HIV positive face multiple risks that can be compounded or protected against depending on the impacts of these various systems of influence and how they navigate them.

Aims of PhD

The aim of this research is to describe the mental health of HIV positive adolescents (13-19 years) accessing care and treatment in Johannesburg and generate evidence to inform mental health policy for this population in South Africa.

Research objectives

The objectives of this PhD thesis are to generate knowledge regarding:

1. The description of mental health outcomes in HIV positive adolescents aged 13-19yrs accessing healthcare in Johannesburg.
2. The impact of bereavement on HIV positive adolescents aged 13-19 years accessing healthcare in Johannesburg.
3. Describe resilience in HIV positive adolescents aged 13-19 years accessing healthcare in Johannesburg.

Organization of thesis

Chapter 1 has highlighted that the mental health of perinatally infected HIV positive adolescents is largely unknown and unaddressed in the healthcare system at present. Research is necessary to describe the mental health of this particularly vulnerable population, although recent changes to the National Health Act do impede this kind of research being undertaken. A conceptual framework has been presented to highlight the systems that impact mental health and will be described in this thesis.

Chapter 2 presents a review of the literature on mental health of HIV infected people in LMICs as well as evidence of mental health problems in children and adolescents with HIV. A focus on the mental health of perinatally infected HIV positive adolescents is presented as well as other salient issues that impact significantly on mental health in this population.

Chapter 3 described the methodologies of five publications that resulted from three studies: a quantitative study (cross sectional observational study) and two qualitative studies (in depth interviews with sample from the larger study). The first publication (chapter 4) is an additional paper that provides insight into the ethics of conducting mental health research with HIV positive adolescents in the public health sector in Johannesburg.

For the findings of this thesis, five published papers are presented as chapters.

Chapter 4 details the ethical and legal issues concerning undertaking this research with the current restrictions on independent consent enforced by the National Health Act. Issues of consideration, particularly with regards to orphaned and vulnerable children and youth are presented along with a case study of this PhD. Recommendations to increase ethical integrity of conducting mental health research with adolescents are provided.

Chapter 5 identifies risks for mental health problems in a sample of 343 adolescents accessing care and treatment in Johannesburg. The findings indicate that this population, who are retained in care, have significant common mental health problems that are largely unrecognized and untreated. Almost a third of the sample (27%) had depression, anxiety or PTSD and 24% showed signs of suicidality. Mental health difficulties are driven by social challenges that are described further in this paper.

Chapter 6 highlights that many perinatally infected HIV positive adolescents have had poor disclosure experiences and this, together with multiple bereavements, impacts their understanding of their HIV disease in negative ways. The majority of this population did not understand vertical transmission and nor PMTCT and its potential benefits to their own reproductive futures.

Chapter 7 described resilience in this population of health seeking adolescents. Despite significant stressors and adversity being described by the adolescents, a high level of resilience was described. Characteristics of resilience were apparent in beliefs, traits and active behaviours. Recommendations for the healthcare systems are provided to increase resilience in adolescent patients.

Chapter 8 shows that bereavement has a crucial impact on the mental health of perinatally infected HIV positive adolescents. Loss led to many experiences of emotional and contextual deprivation, which compounded complicated grieving that was largely unrecognized in the patients. Innovative methods are required to address unmet mental health needs of this patient population and the use of non-verbal methods, such as drawing and writing, are described in this paper.

In **chapter 9**, the findings of the thesis are represented in relation to the aims and objectives. Implications for mental health services are discussed and future research directions are proposed.

CHAPTER 2

Literature review – what do we know?

Mental health issues in adolescents and HIV positive adolescents (globally and in South Africa)

Mental health needs of children and adolescents globally do not get the attention and resources required, but are severely underserved in LMICs (Cortina et al, 2012; Becker & Kleinman, 2013; Gore et al, 2011; Kieling et al, 2011; Patel et al, 2007). A large proportion of disease burden and mortality in young people in all societies are accounted for by mental disorders, but this is especially so for youth in LMICs as a result of scarce resources and strong associations with social determinants of health, such as poverty, food insecurity, violence, poor access to education and healthcare etc. (Patel et al, 2007). The adjusted prevalence of mental disorders in adolescence in South Africa has been estimated to be between 15-17% (Patel et al, 2007; Kleintjes et al, 2006). A recent study of mental health problems in Cape Town of 1034 14-15yr old learners revealed high prevalence of depression (41%), anxiety (16%) and PTSD (21%) (Das-Munshi et al, 2016).

Worldwide, HIV/AIDS and depression are the leading causes of disease burden for young people (those aged 10–24 years)(UNICEF, 2011). Major depression is highly prevalent amoung HIV positive patients, ranging between 18% and 81% depending on the population studied and the methodology of the study (Arseniou et al, 2013). In addition, depression amoungst AIDS-orphaned children is considerably higher than amoung other orphaned children (Kumar et al, 2014). HIV positive patients with depressive symptoms are 55% less likely to be adherent than HIV patients without depressive symptoms (Nakimuli-Mpungu et al, 2012). Non-adherence is similarly associated with other disorders such as anxiety and PTSD and particularly in youth with perinatal infection (Kacanek et al, 2015; Campos et al, 2010; LeGrand et al, 2015). There is some research to suggest that if mental health problems are treated, there are improvements in adherence to antiretroviral therapy (Sin & DiMatteo, 2014).

South African suicide rates range from 11.5 per 100 000 to 25 per 100 000 of the population, varying on sampling procedures and research methods; and on average

9.5% of non-natural deaths in young people are due to suicide (Schlebusch, 2012). Cluver et al (2015) have shown that suicide rates tend to rise amoung South African adolescents, as their exposure to adverse childhood events (e.g. parental death by AIDS or homicide, exposure to community violence, and abuse) accumulate. It is unclear what the attribution of orphan status and HIV diagnosis are to outcomes of suicidality, but these are arguably additional adverse childhood events that further the risk of suicidality.

There is evidence to suggest that violence exposure is also related to suicidal behaviour (Sorsdahl et al, 2011). Unfortunately, although violence is an important determinant for adverse mental health (Seedat et al, 2009), it is rarely screened for in young people. Violence and injuries are the second leading cause of death and lost disability-adjusted life years in South Africa (after HIV/AIDS) (Seedat et al, 2009). The overall injury death rate of 157·8 per 100 000 population is nearly twice the global average (Seedat et al., 2009). Violence or the fear of violence can pose formidable barriers to HIV prevention, care, and treatment, limiting individuals' ability to learn their status and adopt and maintain protective measures ranging from negotiating safer sex to remaining in school (Gardsbane et al., 2010; WHO & UNAIDS 2010).

Prevalence of mental health issues in perinatally infected adolescents (globally and in South Africa)

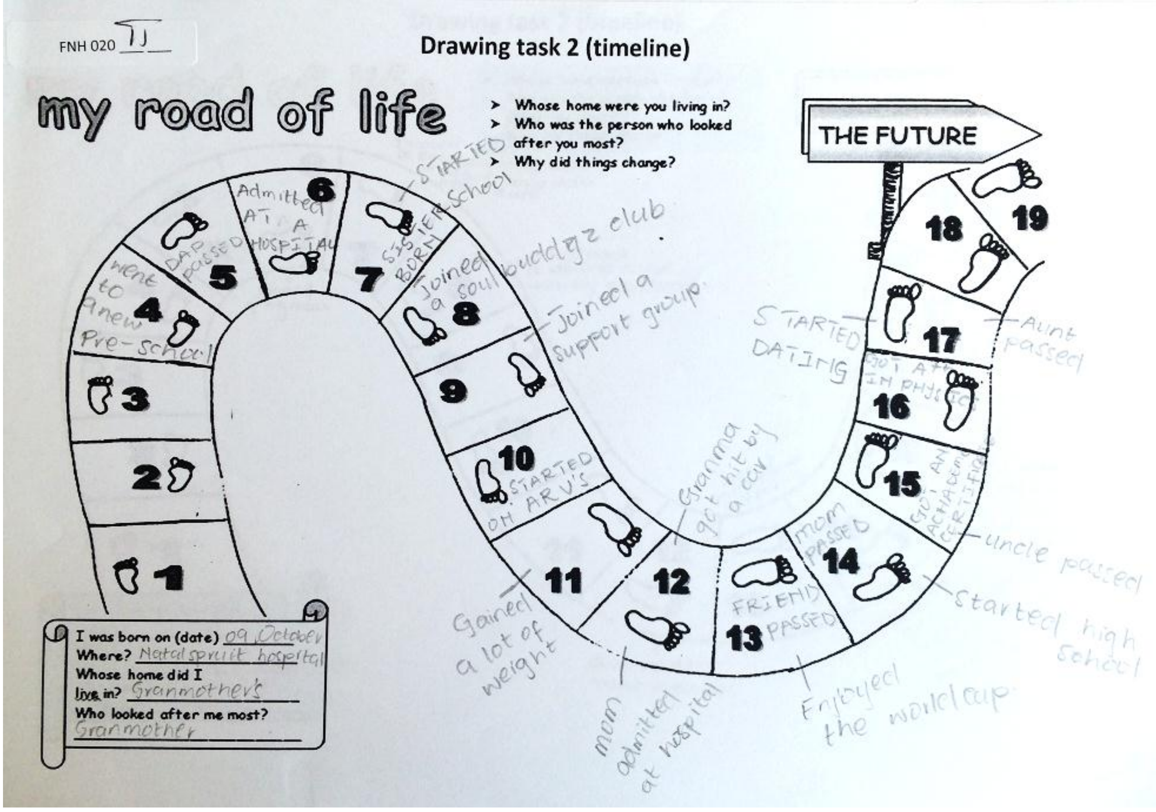
The HIV pandemic has increasingly brought attention to the unmet mental health needs of children and adolescents (Breuer et al, 2011), highlighting the necessity to integrate HIV and mental health care as positive mental health is critical in the management of HIV disease (Mellins & Malee, 2013; Lowenthal et al, 2014; Sherr et al, 2014; Stein et al, 2014).

Research indicates that perinatally infected HIV positive adolescents tend to have high levels of common mental health problems (Lowenthal, 2014; Mellins & Malee, 2013) and that this has a direct negative influence on adherence to ART (Kim et al 2014; Hudelson & Cluver, 2015; Nel & Kagee, 2011), retention in care (Lowenthal, 2014; Agwu & Fairlie, 2013), and high risk sexual behaviours (Mellins et al, 2011; Gadow et al, 2012). These factors lead to risk for secondary transmission. There have been consistent calls to improve prevention and research efforts regarding adolescent mental health and HIV (Ordonez & Collins, 2015; Mofenson & Cotton, 2013) in an attempt to further policy recommendations and strengthen the evidence base of mental health needs of young people in South Africa. There is a paucity of research on the mental health of perinatally infected HIV positive adolescents accessing care and treatment within the healthcare system.

Other salient issues perinatally infected adolescents are facing that affect their mental health:

Orphanhood

Approximately 15 million children in SSA have lost one or both parents to HIV/AIDS, including 2.5 million in South Africa (UNICEF, 2013). These orphans often experience patent and enduring stressors including poverty, stigma, educational disruption, and community violence (Collishaw et al, 2015). They are also at considerable risk regarding mental health problems compared to other children living in similarly impoverished communities (Betancourt et al, 2013; Sharp et al, 2015). The orphanhood epidemic has developed alongside the HIV epidemic. Thus, more than 50% of AIDS orphans are adolescents (Lowenthal et al, 2014). In South Africa, the overall level of orphanhood in 2012 amoung those 0–18 years of age and younger was 16.9% (maternal, 4.4%; paternal, 9.3%; double, 3.2%) (Shisana et al, 2014).



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Drawing task 2 (timeline)

my road of life

- Whose home were you living in?
- Who was the person who looked after you most?
- Why did things change?

I was born on (date) 09 October
Where? Natalspruit hospital
Whose home did I live in? Granmother's
Who looked after me most? Granmother

Figure 3. Road of Life Map detailing multiple losses (Female, 17 years old at time of interview in 2014)

'Father died at age 5yrs, grandmother died at age 12yrs, friend died at age 13yrs, mother died at age 14yrs, uncle died at age 15yrs, aunt died at age 17yrs'

Many adverse outcomes of being orphaned have been reported, including loss of effective guidance and supervision, inconsistent care, psychological distress and poor mental health, loss of educational opportunities, impoverishment, increased sexual vulnerability, and high rates of risk taking (Lowenthal, 2014). Studies from African countries have found that compared with non-orphans, children and young people who have lost at least one parent to AIDS have more unmet basic living needs, and more psychological problems including negative mood and pessimism (Makame et al., 2002; Richter, 2003; Atwine et al., 2005; Remien et al., 2007; Cluver 2009; Petersen et al., 2010). They are often exploited by new caregivers and have to survive with limited resources (Remien et al., 2007). In addition, being orphaned as a result of HIV/AIDS has more severe consequences than being orphaned as a result of non-AIDS related death (Cluver et al., 2011). Cluver and colleagues (2011) report that children and adolescents orphaned by AIDS were 117% more likely to be suffering from PTSD than children and adolescents whose parents were alive, and also 67% more likely than children and adolescents orphaned by other causes, including homicide, suicide and cancer. AIDS orphaned children and adolescents were more likely to be engaged in economic activities and go to bed hungry on a daily basis (Delva et al., 2009). There was higher prevalence of HIV infection amoung orphans compared with non-orphans and orphans of non-AIDS causes, higher rates of sexual behaviour amoung orphans, earlier sexual debut, increased risk of intergenerational sex, increased poverty, significant mental health problems (including PTSD, depression and anxiety), care giving stressors and increased family violence (Cluver et al., 2008, 2011, 2012; Mellins & Malee, 2013; Li et al, 2008; Sharp et al, 2015).

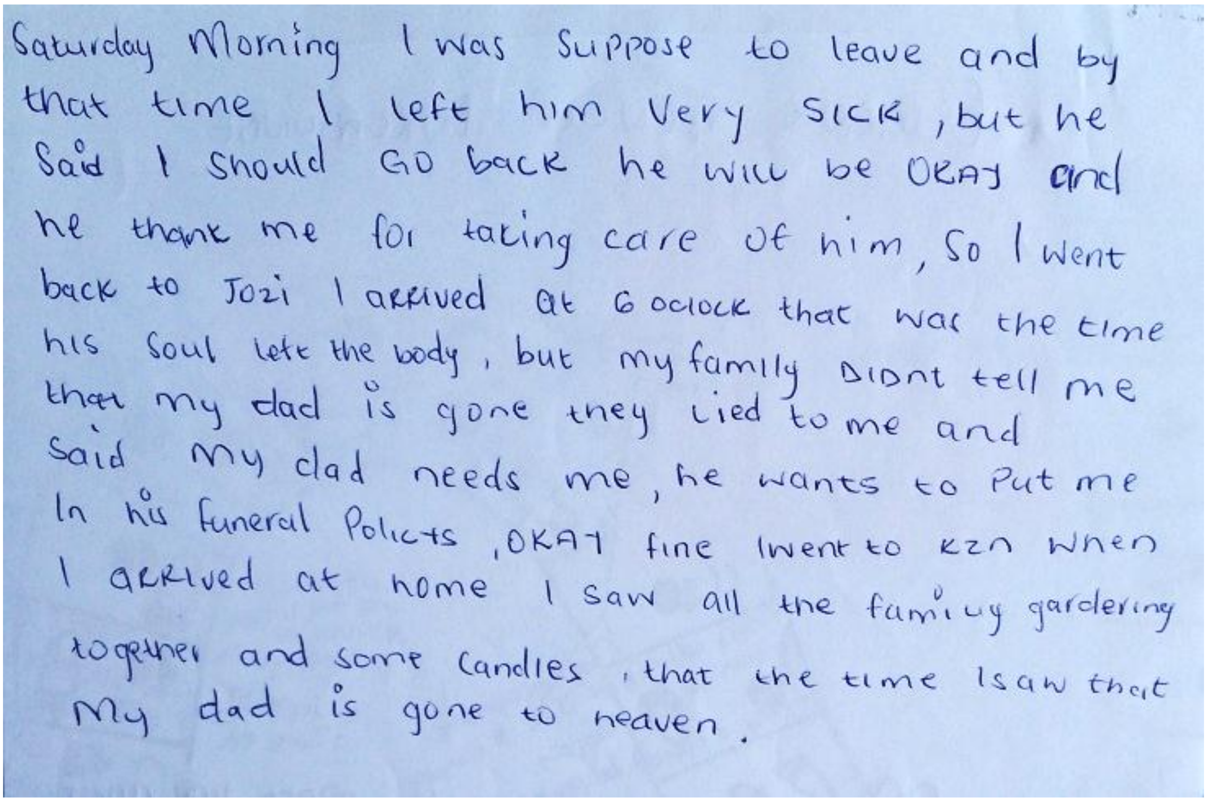
Bereavement

One of the key risks for poor mental health, especially amoung orphans, is bereavement (Cluver et al, 2012; Willis et al, 2014). When the death of a loved one takes place (even when the death is expected), individuals may experience an extensive range of emotions, commonly referred to as "bereavement and grief." Bereavement is defined as the state of having suffered a loss, grief as the normal reaction one experiences in that state (Li et al 2008). Bereavement is an upsetting but natural and possibly universal experience. Grief is recognised as an incorporation of diverse psychological (behavioural, affective, social, cognitive) and physical (somatic, physiological) manifestations, the explicit expression of which varies both between and within cultures (Webb, 2003).

Research indicates that most bereaved children and adolescents will show resilience in adjusting to loss (Skovdal & Daniel, 2012); however, certain factors may influence their ability to grieve (Currier et al, 2007). How children grasp and understand the reality and intricacy of death depends on many factors, including the child's level of cognitive development, the nature of his/her relationship with the person who died, the specific manner of the death (for example, sudden death that was not adequately prepared for such as car accident, or death that is stigmatised such as HIV related death or suicide), resilience, quality of subsequent care and social support (Webb, 2003; Wood et al, 2006). After a major death, a child's immediate social environment either facilitates or inhibits his/her ability to engage in adaptive grief progressions and achieve vital developmental tasks (Li et al, 2008; Kaplow et al, 2012).

Cross-cultural research on natural grieving processes suggests that most humans need to acknowledge their grief and be able to express it directly to resolve their loss (Li et al, 2008). Similar to the process of physical recovery after injury, there is evidence to suggest that the grieving process consists of a sequence of tasks that must be worked through before fully adjusting to the loss (Li et al, 2008) and include: accepting the reality and completely experiencing the emotional distress of the loss; acclimating to one's environment and sense of self without the loved one; finding sense in the loved one's death; and becoming involved with other adults who can offer ongoing comfort, security and nurturance (Mannarino & Cohen, 2011). Research indicates that if these tasks are not successfully completed, individuals will suffer complicated grief which includes "(1) a sense of disbelief regarding the death; (2) anger and bitterness over the death; (3) recurrent pangs of painful emotions with intense yearning and longing for the deceased; and (4) preoccupation with thoughts of the loved one, often including distressing intrusive thoughts related to the death" (Shear et al, 2005, pg. 98). Those who suffer complicated grief are 'stuck' in their grieving and experience difficulty integrating the event in their lives.

This can become formidable in contexts, such as South Africa, where there is a culture of silence around death and grieving when it comes to children and adolescents (Wood et al, 2006). In many instances, children and adolescents are not told their parent has died, or are informed of events with euphemisms such as the parent has 'gone away'. It is also typical for adults to whisper in the child's ear while they are sleeping regarding death of a family member and these events are discouraged to be discussed again thereafter (van der Heijden & Swartz, 2010; Daniel et al, 2007). Oftentimes, although intended to be protective, children and adolescents are excluded from cultural rituals, such as funerals, that would aid in their grieving and legitimise their role in participating in community practices (Daniel et al, 2007). AIDS-related bereavement is probably especially complicated and challenging to accommodate, largely as a result of HIV related stigma and its latent denial (Wood et al, 2006). The denial inherent in this silence and its formulation over time and through development leads to poor understanding of perinatally infected children and adolescent's own HIV disease and reinforces stigma around HIV with costs to mental health functioning (Daniel et al, 2007).



Saturday Morning I was Suppose to leave and by
that time I left him Very SICK ,but he
Said I Should GO back he will be OKAY and
he thank me for taking care of him, So I went
back to Jozi I arrived at 6 oclock that was the time
his Soul left the body , but my family DIDNT tell me
that my dad is gone they lied to me and
Said My dad needs me, he wants to Put me
In his funeral Policts ,OKAY fine Iwent to KZN When
I arrived at home I saw all the family gardering
together and some candles , that the time Isaw that
My dad is gone to heaven .

Figure 4. Written account of death of father (Female, 18 years old at time of interview in 2014)

'Saturday morning I was suppose[d] to leave and by that time I left him [father] very sick. But he said I should go back, he will be okay and he thank[ed] me for taking care of him. So I went back to Jozi [Johannesburg]. I arrived at six o'clock. That was the time his soul left the body. But my family didn't tell me that my dad is gone. They lied to me and said my dad needs me. He wants to put me in his funeral policy. 'Okay fine', I went to KZN [KwaZulu Natal]. When I arrived at home I saw all the family gathering together and some candles. That [was] the time [that] I saw that my dad is gone to heaven.'

Weighty and multiple losses, often unrecognised and unmourned can lead to complications in the ability to grieve. Doka (1989) defined the concept of 'disenfranchised grief' as the grief that one experiences when incurring a loss that is not or cannot be explicitly acknowledged, openly mourned or socially supported (Crenshaw, 2005). The child/adolescent not only does not receive recognition, support or facilitation of their grief, but there is also no social sanction for feeling a loss to begin with. These losses are devalued, trivialised or simply unrecognised (Crenshaw, 2005).

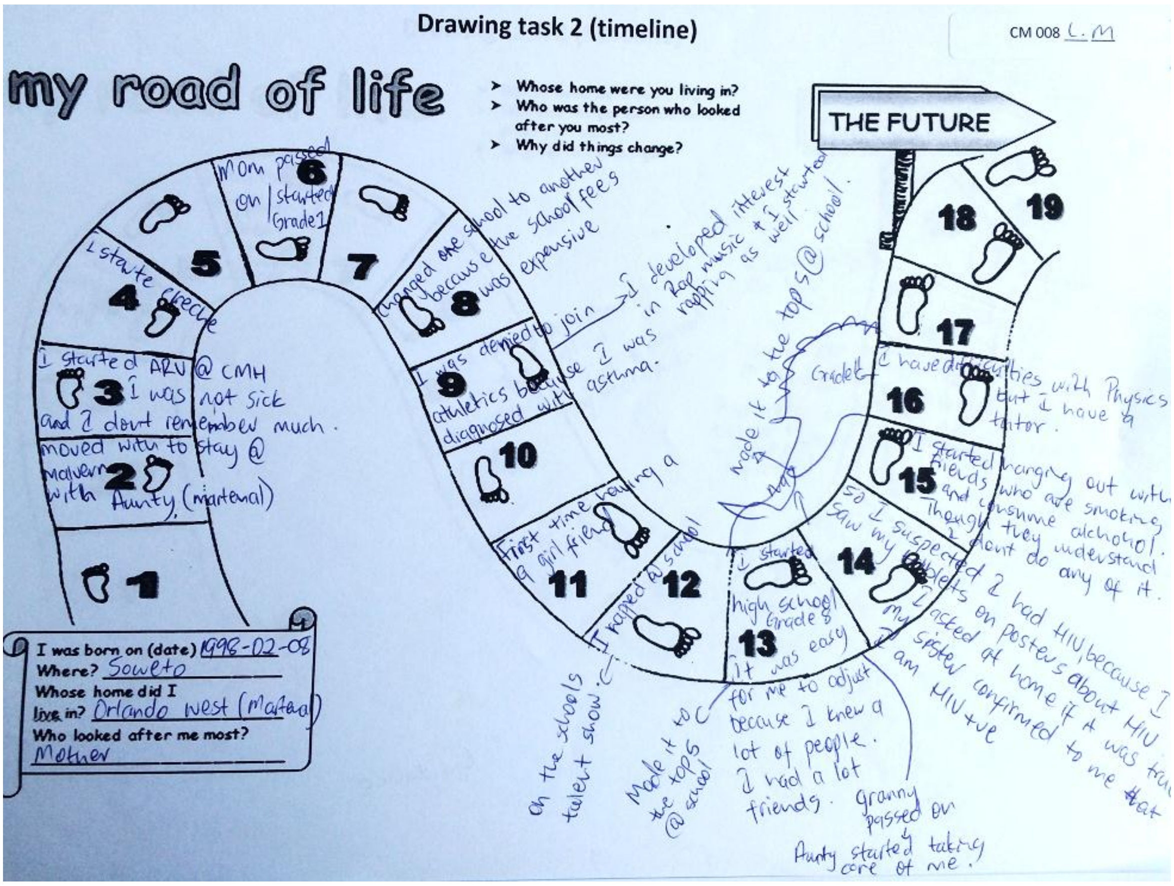
Children and adolescents, like adults, can't evade the reality of death in their lives. All people at all ages experience death, and children and adolescents, who are typically poorly prepared for its occurrence, often need assistance in dealing with their apprehensions, worries and feelings (Webb, 2003). Contextually, it appears that adults are poorly equipped to identify and manage children's and adolescent's grief well (Wood et al, 2006). Talking about, remembering, and maintaining a relationship with the person who died are thought to be helpful recourses for the bereaved and consistent with normal bereavement (Brown & Goodman, 2005).

Unfortunately, many perinatally infected children and adolescents have not been afforded the opportunity to grieve significant losses or express their feelings about those they have lost years after their losses (Willis et al, 2014; Wood et al, 2006). PIA have to navigate the complex demands of treatment, social pressures, and vulnerable health within the setting of bereavement and disrupted care, without having certainly developed the skills to handle these circumstances and without community support to enable swifter recovery (Bernays et al, 2014). It is imperative not to underestimate the probable psychological effects of the awareness of their own HIV status on their wellbeing, which is reinforced through taking daily treatment and witnessing HIV-related deaths within the household – a daily reminder of their own infection and a potential trigger for mental health challenges (Bernays et al, 2014). In addition, it is also probable that at the time of diagnosis for these adolescents, they were likely considered terminal (Small et al, 2014) and consequently, their own mortality may have been focal growing up. Little is known about how bereavement impacts on HIV positive adolescents' worldview, their beliefs regarding their own HIV infection, and access to HIV prevention options in the public health sector.

Disclosure

Disclosure of one's HIV status, both to others and how the status has been disclosed to oneself, is affected by these life events and most studies reveal that the majority of HIV-infected children and adolescents in resource-limited settings are unaware of their HIV status (Vreeman et al, 2013; Pinzon-Iregui et al, 2013) despite the positive consequences of HIV disclosure including: improved identity formation; adherence to treatment; and retention in HIV care (Santamaria et al, 2011; Kidia et al, 2014; Cluver et al, 2015). Consequently, the WHO (2011) recommends full disclosure to HIV positive children and adolescents. It should be highlighted that even though disclosure is recommended, it is still a controversial and difficult subject for individuals, families and providers in part due to the tremendous stigma that still exists. Many factors need to be considered for disclosure by providers including, assessment of child/adolescent's abilities (their level of understanding and ability to cope with diagnosis), consideration of caregiver abilities (ability to cope with stress of disclosure, levels of support available, ability to discuss stigmatized family secrets), rehearse and prepare the actual disclosure, identify sources of support (both children/adolescents and caregivers are likely to have a more positive experience if they can rely on support within their networks both inside and outside the clinic environment), and encourage ongoing open communication (Weiner et al, 2007).

If disclosure doesn't occur spontaneously between family members, it is reportedly undertaken via two alternate routes: hospitalization for serious illness with subsequent HIV testing and consequent disclosure, or, for those on treatment for years, a deliberate request from the child/adolescent to understand their diagnosis as a result of regular clinic visits and the ongoing need for treatment adherence (Dorrell & Katz, 2014; Ferrand et al, 2010).



- Whose home were you living in?
- Who was the person who looked after you most?
- Why did things change?

I was born on (date) 1998-02-08
Where? Soweto
Whose home did I live in? Orlando West (Maternal)
Who looked after me most? Mother

moved with to stay @ Malvern with Aunty (maternal)

I started ARV @ CMH I was not sick and I don't remember much.

I starte creche

Mom passed on | started Grade1

changed one school to another because the school fees was expensive

I was denied to join athletics because I was diagnosed with asthma.

→ I developed interest in Rap music & I started rapping as well

First time having a girl friend

I rapped @ school → on the schools talent show.

Made it to the top 5 @ school

I started high school Grade 8 It was easy for me to adjust because I knew a lot of people. I had a lot friends.

granny passed on → Aunty started taking care of me.

So I suspected I had HIV, because I saw my tablets on posters about HIV. I asked at home if it was true my sister confirmed to me that I am HIV +ve

I started hanging out with friends who are smoking and consume alchohol. Though they I don't do any of it. understand

Grade 10

made it to the top 5 @ school.

I have difficulties with Physics but I have a tutor.

Figure 5. Road of Life Map detailing disclosure (Male, 16 years old at time of interview in 2014)

'So I suspected I had HIV because I saw my tablets on a poster about HIV. I asked at home if it was true. My sister confirmed to me that I am HIV positive [at 14 years of age]'

Early and full disclosure (i.e. disclosure is not a discrete occasion but rather a progression over time where accurate information regarding HIV acquisition is communicated) is powerfully related to improved adherence amoungst ART-initiated adolescents; for those perinatally infected this is true for those disclosed to before age 12 years (Cluver et al, 2015; Vas et al 2010). Research indicates that adolescents who have been informed of their HIV status and understand their diagnosis are significantly less anxious than those who have not been told and those that know their status for longer report higher intentions to self-disclose to potential sex partners (Santamaria et al, 2011). However, literature also indicates that disclosure to romantic and sexual partners is especially challenging as a result of possible rejection and HIV related stigma and that most young people choose not to disclose their status (Fair & Albright, 2012; Hogwood et al, 2012). Disclosure may be an indispensable tool in amending adolescent adherence and decreasing mortality and onwards transmission.

Evidence suggests that paediatric disclosure can be undertaken effectively in a low-resource context and in an array of government health facilities (Kidia et al, 2014). Healthcare workers and caregivers are open to the incremental character of disclosure, and that adolescents may need numerous opportunities to understand the meaning of their status. Indeed, communicating comprehensive understanding of complex concepts needs both repetition and reinforcement (Kidia et al, 2014). This is particularly important especially for perinatally infected adolescent if accompanied by HIV-related cognitive delays (Sherr et al, 2014). Disclosure may also require sensitivity to the caregivers' stages of disclosure of their own HIV-status if they are still alive, or if they are deceased and explanations for death were not made clear (John-Stewart et al, 2013).

Adherence

Approximations of ART adherence suggest that adolescents are susceptible to suboptimal adherence and have trouble reducing viral load (Hudelson & Cluver, 2015; Kim et al, 2014; Zanoni et al, 2016). Features of the HAART regimens make adherence particularly problematic as these therapies require multiple drugs, sometimes up to six taken at different times of the day, some with food and some without. These medications are frequently taken in addition to numerous other drugs treating related ailments. Many of the HAART medications have disagreeable side effects, such as diarrhea, nausea, vomiting and peripheral neuropathy (Fogarty et al., 2002). Although treatment guidelines have changed significantly in South Africa with fixed dose combinations now being available in public health facilities, only newly diagnosed adolescents are eligible to receive these (National Treatment Guidelines, 2015). Unfortunately, most PIAs are not able to benefit from this progress.

Maintaining sustained high levels of adherence to ART is the basis of effective treatment, preventing the development of drug resistance and disease progression, and limiting risk of onward transmission once sexual debut occurs. Virological failure may also arise as a result of suboptimal drug dosing. Accurate weight-based dosing is a challenge to achieve during growth spurts that occurs in adolescence, and frequent dose changes are called for, which may be difficult in under-staffed healthcare facilities in low-resource settings, and can be confusing for the patient (Ferrand et al, 2016). In addition, as adolescents age and become more treatment experienced, needing complex regimens because of poor adherence and subsequent resistance, simplified regimens become less feasible, compounding the problem (Agwu & Fairlie, 2013).

Other characteristics of HIV treatment also make adherence more challenging – treatment is of a life-long duration, given to patients who are often asymptomatic, the high pill burden is a reminder of the stigmatized disease, and with a treatment payoff of delayed disease progression sometime in the future. Children and adolescents face the prospect of having to take ART with optimum adherence for 20 years longer on average than do adults, but fewer treatment regimens are available to them and consequently often encounter drug fatigue (Bernays et al., 2014).

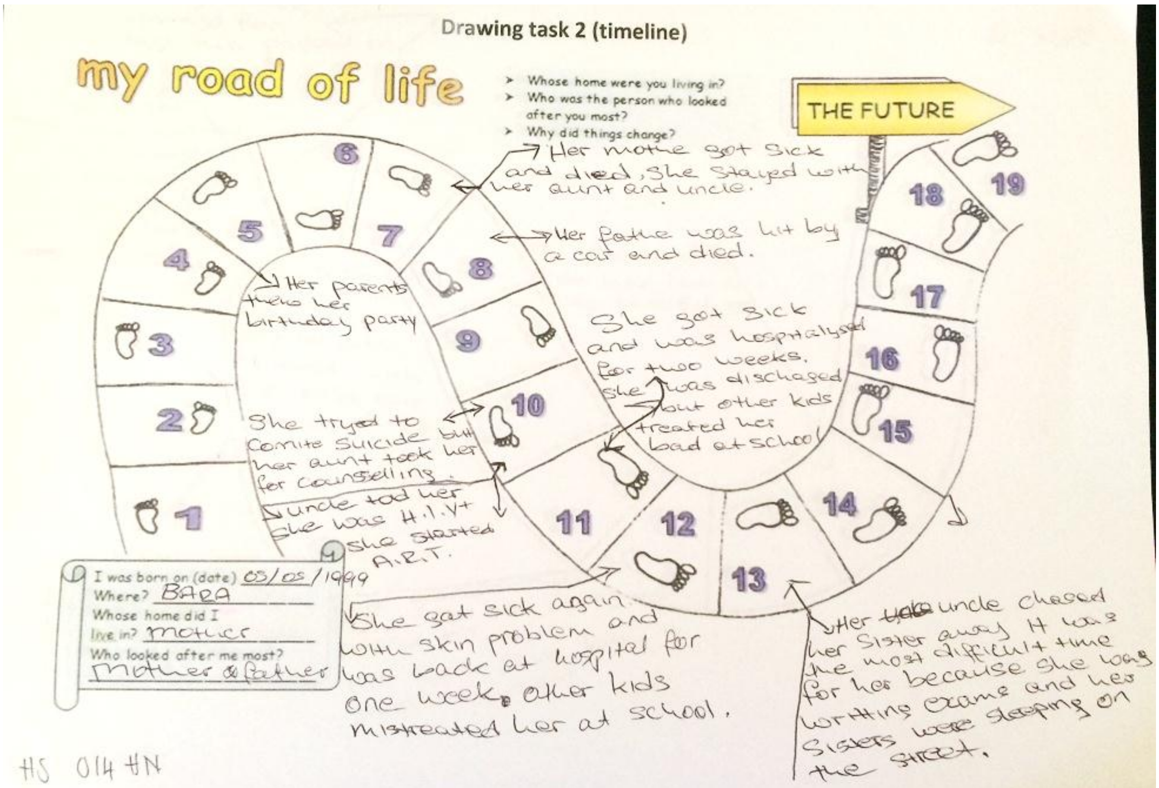
Correlates of poor treatment adherence in adolescence include being orphaned, lack of knowledge, mental health problems, changes of guardianship, attending school, and absence of parental and social support (Lowenthal et al., 2014). Adherence to HAART remains problematic with this population as adolescents are often challenged with maintaining strict routines and this is often linked to mental health problems (Mellins et al., 2004; Murphy et al., 2003; Merzel et al., 2008; Rudy et al., 2009; Ferrand et al., 2010). Delayed disclosure of HIV status to the adolescent, and a resultant lack of autonomy, substantially affect adherence (Close, 2003). Good adherence to an antiretroviral regimen is associated with an adolescent's knowledge of their HIV status, valuable social support, and having a strong relationship with parents or caregivers (Lowenthal et al., 2014). When this support is scant, especially in the case of orphans, adherence becomes increasingly challenging (Bernays et al., 2014). In fact, lack of a parent or caregiver at an adolescent's clinic visit is powerfully related to HIV virologic failure indicating that identifying adolescents who attend clinics on their own might assist the most vulnerable youth with HIV and other chronic diseases (Lowenthal et al, 2015).

However, even for adolescents with the ostensible advantages of knowing their status and having consistent support, social and structural barriers of stigma and poverty still impact on adherence. The stigma that surrounds HIV leads adolescents to take their treatment in secret which is difficult in busy school and weekend environments. Taking treatment every day of their lives is made more difficult within the context of poverty, where they might be living in crowded households with little privacy and access to food (Bernays et al, 2014). Since adherence means not only following dosing regimens but also being able to refill prescriptions, and since prescriptions are refilled as part of routine follow-up visits in Africa, barriers to adherence and retention overlap. Travel distance to clinic sites and associated costs, stigma and fear of disclosure, competing demands for scarce resources, religious and cultural beliefs, and unanticipated obligations and events (e.g., attending a family funeral) are key adherence barriers identified through previous research that also bear upon retention (Davies et al., 2013; Agwu & Fairlie, 2013).

The desire for conformity with peers during adolescence, and a fear of stigmatization, greatly affects treatment adherence. Transition of adolescents from paediatric to adult HIV care services might further disrupt adherence, because the time available for counselling is diminished and healthcare providers have little experience of addressing adolescent-specific concerns (Lowenthal et al., 2014). Without an enhanced understanding of how to achieve adherence and consistent access to potent ARVs, LMICs are in danger of running out of options for perintally infected adolescent transitioning into adulthood (Sohn & Hazra, 2013).

Stigma

A major distinction between HIV/AIDS and other chronic or terminal illnesses is the stigma associated with the disease. Stigma is known to be a key driver of the HIV epidemic by operating as a means of reinforcing existing power structures, HIV's association with debilitation, death, lost capacity to work, and behaviour that may be considered socially 'deviant' (Treves-Kagan et al, 2016). HIV-related stigma has mired intervention efforts, led to delays in testing, decreased engagement in care, and reduced adherence to treatment and care regimens (Katz et al, 2013). Although impressive advancements have been made in creating stigma reduction interventions (Stangl et al, 2013), HIV stigma remains a major barrier to reducing HIV incidence and mortality.



- Whose home were you living in?
- Who was the person who looked after you most?
- Why did things change?

I was born on (date) 05/05/1999
Where? BARA
Whose home did I live in? mother
Who looked after me most? mother & father

Her parents threw her birthday party

Her mothe got sick and died, she stayed with her aunt and uncle.

Her fathe was hit by a car and died.

She tryed to comite suicide but her aunt took her for counselling.

uncle told her she was H.I.V+

she started A.R.T.

She got sick and was hospitalysed for two weeks. She was dischaged but other kids treated her bad at school

She gat sick again with skin problem and was back at hospital for one week. other kids mistreated her at school.

Her uncle chased her sister away it was the most difficult time for her because she was writting exams and her sisters were sleeping on the street.

Figure 6. Road of Life Map detailing stigma (Female, 16 years old at time of interview in 2013).

'She got sick and was hospitalized for two weeks. She was discharged but other kids treated her bad at school [at age 11yrs]. She got sick again with a skin problem and was back at hospital for one week. Other kids mistreated her at school [at age 12yrs].'

This stigma often stems from lack of knowledge about HIV and how it is transmitted; which can adversely affect adolescents and their caregivers in ways that have long-term negative psychological and social consequences (Close, 2003). HIV positive patients often have to endure the stigma and discrimination they feel from the community or service providers, but also, especially during adolescence, experience ‘self-stigma’(or ‘internalized stigma’) where an individual takes on the perceived stigma of others and stigmatizes themselves (Livingston & Boyd, 2010). This form of stigma has consequences for mental health, particularly depression, and negative impacts on HIV care and treatment uptake (Lee et al, 2002; Simbayi et al, 2007). Internalized stigma has a large effect on the paediatric population through its influence on caregiver’s decisions to disclose. If parents or caregivers have internalized the stigma and negative views of HIV/AIDS, their likelihood of telling the child or adolescent about his or her diagnosis decreases significantly (Close, 2003; Vreeman et al, 2013). This may create fear in adolescents disclosing their status to others and they may feel shameful regarding their HIV diagnosis (Hogwood et al, 2013; Fair & Albright, 2012). Obviously, these factors have an enormous influence that can have a negative impact on interpersonal relationships, self-esteem and the practice of safe sex where honestly talking about sexual transmission and protection is crucial. Indeed, HIV stigma has been linked to intensified psychological distress, weak physical health and quality of life, poor social support, and risky health behaviours such as medication hiding and non-adherence to ART, sexual risk-taking and non- disclosure of HIV status to sexual partners (Mutumba et al, 2015).

In addition, exposure to stigma has a profound effect on adolescents growing up with HIV. Their HIV status often physically manifests with visible scars of skin disease, a smaller and physically weaker physique than their peers and having delayed puberty. As is common amoung young people, the desire to conform with peers could inadvertently lead them not only to stop treatment or disclose their status, but can also instill in them a pronounced sense of social isolation by being marked out as different, which creates a heavy psychological burden (Bernays et al., 2014). Hence biomedical interventions to address HIV in isolation are profoundly insufficient and do not meet the challenges that this population faces.

Medical independence and transition to adult clinics

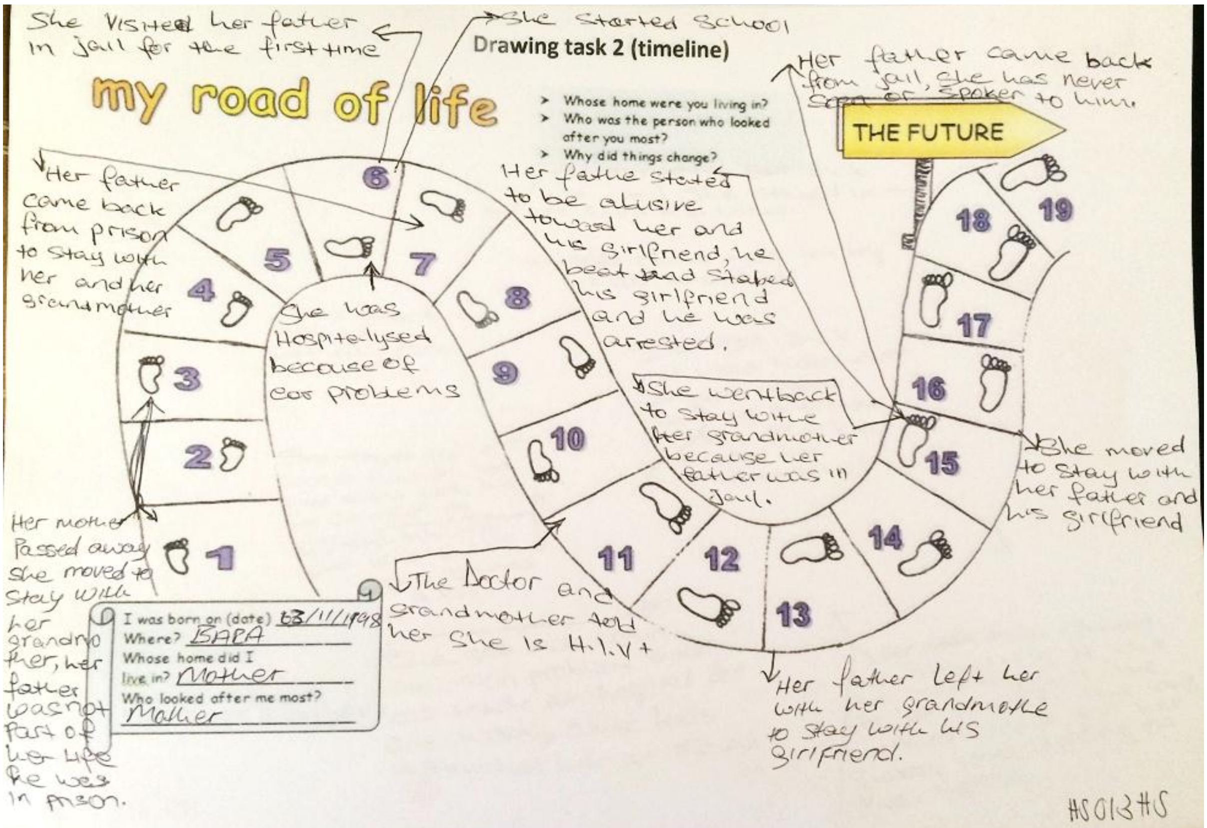
For adolescents living with a chronic illness, transitioning to adulthood includes an important shift towards medical independence. Health service involvement decreases in adolescence at the same time that family involvement in young people’s healthcare also declines. This situation can have serious implications for an adolescent’s health and decision making such as missing doses and clinic appointments and so on (Lowenthal et al, 2014, 2015). Often, adolescents need to transition to a new clinic as they age as many paediatric clinics do not have funding or capacity to keep youth as they age into adulthood (Agwu & Fairlie, 2013; Close, 2003). The extent that young people with HIV are dropping out of adult healthcare in LMICs after transferring from specialist paediatric services has become increasingly apparent, leading to failure in adherence to ART and greater risks to self and others (Patton et al, 2016). In South Africa, adolescent patients are typically transitioned from paediatric clinics, where they get a great deal of investment from clinical teams, to adult clinics at the age of approximately 12yrs where they are expected to navigate complex systems independently (SANAC, 2011). It is unsurprising, therefore, that most of these patients are lost in these systems and their treatment and care suffers greatly (Hussen et al, 2015). Some studies reveal very high morbidity and mortality rates amoung adolescents who are transitioned out of paediatric care (Pearlstein et al, 2013; Fish et al, 2014; Hussen et al, 2015).

As many adolescents are not treatment literate and some do not have a sophisticated understanding of their medical histories, healthcare providers should teach adolescents to cope with specific tasks such as managing their medication, scheduling their appointments, and discussing their healthcare concerns directly with their providers. As adolescents transition between paediatric and adult clinical venues, healthcare providers need to have a thorough understanding of the multi-faceted issues including complicated treatment histories, complex psychosocial dynamics and development stage, in order to effectively manage adolescents living with HIV and optimize outcomes after the transfer (Agwu & Fairlie, 2013). Regrettably, youth friendly services are not extensively accessible in the public health sector in South Africa (SANAC, 2011; Tylee et al, 2007), with children either staying with their paediatrician well past adolescence or transitioned out of paediatric services with little preparation resulting in adolescents getting dropped in adult systems of care or falling out of care as a result of their necessities not being met. Youth friendly healthcare is patient-centred care with an emphasis on respect, coordination of care, appropriate provision of information, high-quality communication, involvement in decisions about care, and the ability of healthcare providers to listen to adolescent needs (Patton et al, 2016). The healthcare professionals who interact with adolescents need to be appropriate and informed of youth friendly ways of working, and held accountable to appropriate care for all patients. Obtaining adolescent-sensitive care services from sexual healthcare providers at clinics is related to decreased rates of unprotected sex and substantiates reports on the negative effect of inferior clinic care on adolescent sexual and reproductive health (Toska et al, 2016).

The success of the transition process from paediatric to adult healthcare settings will greatly impact the success of ART in adolescents and young adults. The transition of care involves complex changes of clinics, models of care, and healthcare providers. If this transition is not well conducted, there is a high risk of non-adherence to ART, emergence of viral resistance and loss to follow-up, with implications for individual patients as well as for the overall epidemic (Dahourou et al, 2017). Whilst this population is unheeded and their clinical, psychological and social needs continue to be poorly understood, adolescents (including those on ART) will remain one of the most vulnerable populations affected by the HIV pandemic. Our failure to attend to this vulnerability jeopardizes the lives of these youth and threatens the successes of paediatric HIV treatment efforts to date (Bernays et al., 2014).

Violence and sexual reproductive health

Violence is a leading cause of death in South Africa, where rates of fatal violence are 5 and 8 times higher than the global average (Seedat et al, 2009; Matzopoulas et al, 2010). Much of this violence is interpersonal in nature and experienced in the home, community and at school (Nothling et al, 2016; Jewkes et al, 2002, 2009).



- Whose home were you living in?
- Who was the person who looked after you most?
- Why did things change?

She visited her father in jail for the first time

She started school

Her father came back from jail, she has never seen or spoken to him.

Her father came back from prison to stay with her and her grandmother

Her father started to be abusive toward her and his girlfriend, he beat ~~had~~ stabed his girlfriend and he was arrested.

She was hospitalysed because of ear problems

She went back to stay with her grandmother because her father was in jail.

She moved to stay with her father and his girlfriend

Her mother passed away she moved to stay with her grandmother, her father wasn't part of her life he was in prison.

The Doctor and grandmother told her She is H.I.V+

Her father left her with her grandmothe to stay with his girlfriend.

I was born on (date) 13/11/1998
Where? BAPA
Whose home did I live in? Mother
Who looked after me most? Mother

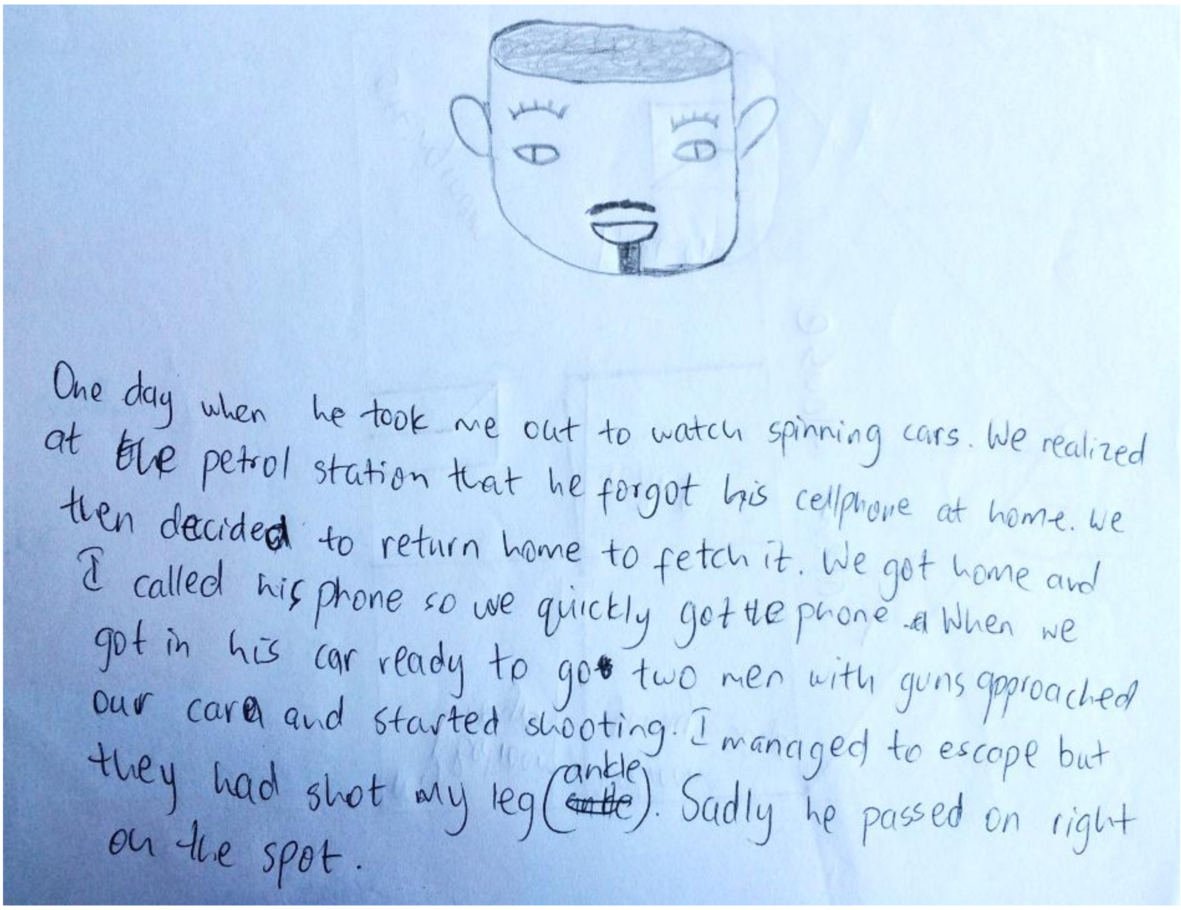
Figure 7. Road of Life Map detailing domestic violence (Female, 17 years old at time of interview in 2013).

'Her father started to be abusive towards her and his girlfriend. He beat and stabbed his girlfriend and was arrested [at age 15yrs].'

Worldwide, an estimated 1 billion children experience abuse each year with the highest rated in LMICs (Hillis et al, 2016). Recent local studies suggest increases in abuse in adolescence (Burton et al, 2015) with rates of violence victimization increasing not only within the home, but also in school and community settings (Finkelhor et al, 2013; Devries 2016). Local research reveals prevalence rates of 56.3% for lifetime physical abuse, 35.5% for lifetime emotional abuse and 9% for lifetime sexual abuse in youth (Meinck et al, 2016). Youth with perinatal HIV report a high prevalence of violence that is associated with poor virological and immunological outcomes (Kacanek et al, 2016). Exposure to violence also forecasts lower educational outcomes in youth in South Africa (Sherr et al, 2016).

There is a large body of literature documenting the manner in which dominant social constructions of gender lead to poor sexual health for young South Africans (Pettifor et al., 2005, Jewkes et al., 2006; Pettifor et al., 2012). Gender inequality and violence are crucial structural determinants of women and girls vulnerability to HIV infection in South Africa (Jewkes et al, 2010; Watts & Seeley, 2014). As stated previously, HIV incidence continues to be most problematic for 15-24yr olds, with approximately 40% of horizontal transmission occurring within this age group (UNICEF, 2013) so adolescents need information to protect themselves and make informed choices about their sexual and reproductive health. The transmission of interpersonal violence takes shape as adolescents begin to experiment within their own relationships as they get older. Adolescents are at high risk of intimate partner violence (IPV) (Decker et al, 2014). Their immature age and comparative inexperience can limit their power in relationships and incur risk, particularly for females engaged with older men (Decker et al, 2014). Abuse during this time can also set young women on a trajectory for future violence and sexual risk behaviour (Woollett & Thomson, 2016). Unfortunately, evidence of the effectiveness of interventions for preventing intimate partner violence and sexual violence in adolesents and young adults is largely lacking. In most part as a result of studies of poor quality with small sample sizes, varied outcome measures, and short follow-up periods, especially in LMICs (Patton et al, 2016).

Boys are also at high risk for violence exposure and experience. In a recent local study it was found that child trauma (including child abuse) is a risk factor for both low mental health and male-perpetrated IPV amid men in Gauteng (Machisa et al, 2016). Child abuse experiences of men intensify adult male-perpetrated IPV therefore prevention interventions for male-perpetrated IPV in South Africa must include strategies and therapies to address poor mental health. Verification from a recent study investigating gender differences in children living in elevated HIV-affected communities in South Africa and Malawi recognised that boys self-reported significantly inferior average quality of life than girls and were significantly more frequently found to be subjected to violence (Hensels et al, 2016). Indeed, a more extensive approach to child development might be necessary to guarantee that the needs of both girls and boys are considered, and that boys are not overlooked.



One day when he took me out to watch spinning cars. We realized at the petrol station that he forgot his cellphone at home. We then decided to return home to fetch it. We got home and I called his phone so we quickly got the phone ~~a~~ When we got in his car ready to go two men with guns approached our car and started shooting. I managed to escape but they had shot my leg(ankle ~~ankle~~). Sadly he passed on right on the spot.

Figure 8. Written account of death of uncle (Male, 18 years old at time of interview in 2014)

'One day when he [uncle] took me out to watch spinning cars. We realized at the petrol station that he forgot his cellphone at home. We then decided to return home to fetch it. We got home and I called his phone so we quickly got the phone. When we got in his car ready to go, two men with guns approached our car and started shooting. I managed to escape but they had shot my ankle. Sadly he [uncle] passed on right on the spot [17 years old at time].'

Traumatized youth should routinely be screened for a history of abuse and particularly exposure to community or school violence, given their strong association with PTSD (Nothling et al, 2016). Educational programmes that target both genders to discuss gender inequality in public and private spheres and how violence leads to unhealthy outcomes for all are required. While gender socialisation starts at birth, early adolescence is a critical point of intensification in personal gender attitudes, as puberty reshapes male and female self-perceptions as well as social expectations from others (e.g. family members, peers) (Woollett & Thomson, 2016). Early adolescence is therefore seen as an exceptional period to address gender attitudes before they become more entrenched (Kagestan et al, 2016). An opportunity to do this exists at different healthcare levels. There is also increasingly evidence to suggest that HIV, intimate partner violence and mental health are intersecting epidemics highlighting that dealing with one of these issues behooves managing the related and associated comorbidities (Woollett & Hatcher, 2016).

Early sexual debut, having multiple sex partners, being at high risk of sexual violence, and adolescent girls engaging in transactional sex with older men, put adolescents at especially high risk of transmitting HIV infection (Cluver et al, 2011; Lowenthal et al, 2014). A study on transactional sex conducted in South Africa highlighted that adolescents “dually” affected by AIDS orphanhood and caregiver sickness showed a 3-fold likelihood of experiencing severe emotional and physical abuse and, amoungst girls, a 6-fold likelihood of transactional sexual exploitation, compared with those in healthy families (Cluver et al, 2011). The effects of familial AIDS, food insecurity, and exposure to abuse raised prevalence of transactional sex amoungst girls from 1% to 57% (Cluver et al, 2011).

Violence, its dynamic of power and control, and the fact that young women are targets of gender based violence (GBV) impacts on teen pregnancy rates and consequent child and maternal mortality and morbidity. Adolescent pregnancy is a crucial public health issue in South Africa, where pregnancy rates escalate exponentially for girls after the age of 15 years: 1% of girls aged under 15 years report ever being pregnant however this rate increases to 27% of 15 to 19 year-olds (MacLeod, 2010). Adolescent pregnancy is connected with poorer access to antenatal services and postnatal care (MacLeod, 2010), and other deleterious socioeconomic outcomes for adolescent mothers, including dropping out of school (Grant & Hallman, 2008) risk of HIV infection and reinfection (Pettifor et al, 2004; Jewkes et al, 2001) and death (Keesbury et al, 2010). The failure to negotiate condom use in age-disparate sexual relationships also drives adolescent pregnancy in this context (Toska et al, 2015).

Awareness and understanding about reproductive health, HIV transmission, and contraceptive methods is limited amoung HIV-infected adolescents (WHO, 2013). Inconsistency between the information given by healthcare providers and the genuine needs of HIV-infected adolescents is common, with the interests of young people sometimes not taken into account (Lowenthal et al., 2014). Healthcare providers need to recognize that young people perinatally infected with HIV are sexually active or anticipate being so in the future.

Furthermore, an array of social protection provisions have been found to be strongly linked to reduced unprotected sex amoung HIV positive adolescents: access to schools, good parental supervision, and adolescent-sensitive sexual health care at clinics (Toska et al, 2016). Helping adolescent girls outside of the home setting, at school and clinics, will not only guarantee they reach services critical to their long-term wellbeing, but also encourage them to engage in safer sex (Toska et al, 2016).

Resilience – a concept of particular value in understanding perinatally infected adolescents

'Resilience' is a relatively novel and decidedly multifaceted concept (Ungar, 2013; Cicchetti, 2010; Windle, 2011; Masten, 2014; Zolkoski & Bullock, 2012). Although there are many various definitions of resilience, they are generally similar and mean the positive adaptation of people to difficult situations (Skovdal & Daniel, 2012). Resilience in the context of the HIV epidemic amoung children and adolescents is important, as it is well known that HIV adds a significant burden to development and that those infected are likely to suffer increased mental health problems and psychosocial stress (Betancourt et al, 2013; Cluver et al, 2012; Li et al, 2008; Mutumba et al, 2015; Sherr & Mueller, 2009; Pienaar et al, 2011).

Amoung PIA, resilience may be a particularly important construct, as a result of th the significant burden of HIV in adolescents (2.1 million young people aged 10-19 years living with HIV globally (UNAIDS, 2013) as stated previously). In addition, the psychological and social risks of this population pose serious vulnerabilities that increase the risk of secondary transmission (as stated previously). Mitigating risk by improving mental health outcomes, particularly resilience, would be in the public health interest but more research is required to understand this construct in this population.

Research suggests that individual traits, resources, and competencies — including age, cognitive capacity, sense of purpose, and belief in a positive future — influence resilience; encouraging and accepting environmental circumstances help form resilience by mitigating the detrimental effects of adversity (Amzel et al, 2013).

Resilience in HIV-infected adolescents is also shaped by the complex interaction between individual-level factors, family-level factors such as caregiver well being or illness, institutional-level factors such as access and engagement with health services and education, and societal factors such as stigma (Amzel et al, 2013; Betancourt et al, 2011). In addition, literature regarding HIV orphans (of which many are perinatally infected) has explored aspects that contribute to their particular vulnerabilities. These are often linked to coping with the illness or loss of a parent, exacerbated by associated stigma, trauma and bereavement, and financial hardship (Wood et al, 2006; Daniel et al, 2007, Collishaw et al 2015, Li et al, 2015).

Masten (2001) coined the term ‘ordinary magic’ to refer to resilience as something fostered by everyday resources, common to individuals, families, communities and cultures. These conventional sources of resilience suggest that resilience is not rare and that active strides can be taken to develop and maintain resilience amoung young people who are placed at risk by ordinary and extraordinary hardship (Theron & Theron, 2010).

In a recent study of PIA, “actively seeking support from others, higher self-concept, and less internalized stigma were all correlated with better mental health” (Bhana et al, 2016, pg.67). The development of a healthy sense of self (self concept) and increased acceptance of their HIV status has been found to be significant in other vulnerable youth (Ungar et al, 2007) and thus may also be valuable to promoting resilience in PIA (Bhana et al, 2016). Parental supervision and communication, youth self-esteem and low internalized stigma are characteristics that may advance resilience in PIA (Bhana et al, 2016).

Whilst progress has been made in identifying and managing risk factors for HIV positive children and adolescents, little is known about how HIV positive adolescents demonstrate resilience and how the healthcare environment can be utilized as an agent of resilience for young people.

Opportunities for the health system to impact on mental health in this patient population.

Adolescence is a period of transformation of the adolescent-caregiver relationship as young people create relationships with peers and significant others outside the family, they meet with numerous challenges that could impact their wellbeing and also broaden their range of coping skills and resources (Mutumba et al, 2016). Local research indicates that perceived support both from peers (Cluver et al, 2009) and from caring adults (Cheng et al, 2014) has significant positive effects on adolescent mental health. Therefore, healthcare personnel are well placed to have a positive and perceptibly supportive impact on young people who access them regularly. HIV positive paediatric patients tend to have long standing relationships with their providers, accessing the healthcare system throughout their development. Thus, this attachment is conducive to containing the emotional aspects of patients, where trust and safety are already established. Although the physical environment presents many challenges and risks for adolescents living with HIV, the health system could be utilized to counter these effects. In addition, support groups at facility level hold promise in curbing mental health problems in HIV positive adolescents; social support may help protect youth against the damaging effects of stressors and nurture more positive mental health outcomes (Mupambireyi et al, 2014; Cheng et al, 2014).

Interventions to meet the mental health challenges of HIV infected young people are gaining traction with varying success, in neighbouring African countries (Mavhu et al, 2013; Strasser & Gibbons, 2014) and locally (Bhana et al, 2014). However, the inconsistencies in risk factors for this population accentuates the need for a nuanced life course approach (Cluver et al, 2012), recognizing that young people are a population in transition, facing fluid challenges and opportunities which demand developing new skills. Thus, dynamic and adaptable interventions that strive to identify and address emerging threats and opportunities are needed (Mutumba et al, 2016).

In addition, there are considerable challenges to implementing mental health interventions at public healthcare level that need to be thoroughly addressed for optimum impact. These include lack of skilled mental health professionals available to intervene and the need to utilize and upskill lay counsellors to meet the demand ethically with targeted training and consistent expert supervision (Patel et al, 2011;

Petersen et al, 2011; Breuer et al, 2011; Ventevogel, 2014; Mendenhall et al, 2014). Screening for mental health can lead to increased access to treatment but it is necessary to invest in screening instruments with high specificity, validity and reliability; that are short and can be administered easily in multiple languages (Kagee et al, 2013).

Problem statement and justification for research

Adolescents are attending public health clinics relatively consistently if they are perinatally infected. If they are stable on treatment, they attend clinics at least every three months to fill their prescriptions and have a check up visit. If they are unwell, they attend more regularly. It is highly probable that this population is at risk for common mental health problems that are largely unrecognized and unaddressed.

There needs to be evidence to assess what the mental health issues are for this growing population of HIV positive adolescents retained in care. In addition, the relationship between their mental health and other risk factors (such as orphan status, disclosure, adherence, violence and sexual reproductive health etc.) needs to be understood and documented. Without the research, mental health interventions will not be targeted or strategic. Evidence of this population's resilience needs to be verified in tandem so that this mental health resource can be maximized and fostered in public health settings.

Addressing mental health problems for adolescents will have consequent gains for HIV care and treatment, health system strengthening, and individual and family health improvements. As the burden of disease has fallen to this vulnerable group, health priorities can ill afford not to concentrate on adolescent specific issues, such as mental health. Currently, there is no literature on the mental health of HIV positive adolescents retained in care in South Africa – this thesis aims to fill this gap and create evidence for policy reform.

CHAPTER 3

Methodology – how the studies were conducted

Introduction

This thesis will include five published papers. This chapter provides a description of the methodology for the 3 studies that comprise this PhD. Study 1 addressed objective 1 of the thesis (description of mental health outcomes), study 2 was used to address objective 3 of this thesis (resilience) while data from the third study was used for objective 2 (impact of bereavement).

Ethical consideration

Paper 1 gives consideration to the ethical issues this research raised and covers all three studies discussed below. An application to the University of the Witwatersrand Medical Human Research Ethics Committee (HREC) was made in February 2013. The South African National Health Act states that 'for health research with minors (<18 year olds), consent from a legal parent or guardian for research with children must be obtained' (Section 71, 2012). Our population was composed of vulnerable children in Johannesburg, South Africa, most of whom were speculated to not be living with a parent or legal guardian and hence we were not be in the position to obtain parental consent. As such, the medical HREC advised approaching the South African courts for permission to enroll participants in the study. This entailed: securing an advocate to appear in the South Gauteng High Court; securing a law firm to brief this advocate; drafting affidavits and serving them on all facilities where the research was to take place (Harriet Shezi Clinic at Chris Hani Baragwanath Academic Hospital, Ward 21 of Hillbrow Community Health Center (CHC), Ward 274 of Charlotte Maxeke Academic Hospital, Faranani Clinic of Natalspruit Hospital and Essellen Street Clinic in Hillbrow). These were also served on all research committees required for this study (Chris Hani Baragwanath Academic Hospital research committee, Charlotte Maxeke Academic Hospital research committee, Gauteng Provincial Department of Health research committee, Johnnesburg District Department of Health research committee) and both the National Minister and the MEC for health, giving more than three and a half weeks' notice of the application. There were no oppositions to this order. The case was managed by Fluxman's Attorneys and presented by Advocate John Peter SC to Honourable Judge Molefe on

31st July, 2013. The court order was granted on the same day (Appendix A) which led to full ethics clearance and permission to interview volunteers without parental or guardian consent (M130258) on 31st July from the University of Witwatersrand Medical HREC (Appendix B). Following this, permission to undertake this research was also permitted by all research committees listed above (Appendix C).

Study 1: Prevalence of mental health outcomes in HIV positive adolescents accessing treatment in Johannesburg

Background and question

What are the levels of common mental health problems (depression, anxiety, PTSD, suicidality) in HIV positive adolescents (13-19yrs) accessing care and treatment in Johannesburg?

Study design

A cross sectional observational study was undertaken at 5 paediatric ARV clinics in Johannesburg with HIV positive adolescents aged 13-19 years. Adolescents were invited to participate in a questionnaire (Appendix D) administered on tablet computers when they came to the clinic for their regular appointment. The data was collected by research counsellors over a period of 8 months from August 2013-April 2014.

Study sites and sample (sample size calculations table)

HIV positive adolescents between the ages of 13 and 19yrs attending these clinics for their HIV care were recruited for this study: Harriet Shezi Clinic of Chris Hani Baragwanath Academic Hospital, Ward 21 of Hillbrow CHC, Ward 274 of Charlotte Maxeke Academic Hospital, Faranani Clinic of Natalspruit Hospital and Essellen Street Clinic in Hillbrow. All these clinics offer routine clinical care except Harriet Shezi Clinic that offers specialized paediatric HIV care. This is a convenient sample as patient records were easily available and research counsellors had an active presence in these facilities either running support groups or employed there permanently as lay counsellors.

Harriet Shezi Children's Clinic: The Harriet Shezi Children's Clinic (HSCC) is the paediatric HIV clinic at Chris Hani Baragwanath Academic Hospital in Soweto.

Currently, HSCC is one of the largest clinics devoted to paediatric HIV services in the country. The clinic was opened in 2000 (this was the first paediatric roll out clinic for ARVs to children in the country), and currently there are over 4488 patients receiving antiretroviral therapy. HSCC has a strong multi-disciplinary team delivering tertiary level clinical services to children and adolescents in the greater Soweto region.

Faranani Clinic, Natalspruit Hospital: The Faranani Clinic at the Natalspruit Hospital has a large cohort of youth accessing services and Wits RHI had been offering paediatric support at this facility for approximately 6 years. Natalspruit Hospital attends to a large underserved population in Ekurhuleni District and Faranani is the ARV clinic.

Youth Friendly Clinic: The City of Johannesburg's Esselen Street Clinic in Hillbrow managed tuberculosis, sexually transmitted infections, family planning and HIV counselling and testing. The clinic, a partnership between the City and the Wits RHI, saw up to 350 people daily particularly vulnerable and marginalised groups such as sex workers and youth within the Esselen Street Clinic. This clinic was closed by the city shortly after recruitment was completed for large scale renovations. It remains closed at present.

Ward 21 of Hillbrow CHC: Wits RHI has a close working relationship with Hillbrow CHC and Ward 21. Prior to 2014, this relationship was largely undertaken through collaboration with Wits RHI lay counsellors offering adolescent specific services at the clinic. However, the Ward was renovated by Wits RHI and became a fully functioning adolescent friendly clinic in 2014, attracting more adolescents to the site for care and treatment. Currently there are 483 adolescents on treatment for HIV.

Ward 274 of Charlotte Maxeke Academic Hospital: The Charlotte Maxeke Academic Hospital is an accredited central hospital with 1088 beds providing patients from across the Gauteng province and neighboring provinces with services. It offers inpatient and specialist outpatient's services. Ward 274 is the paediatric HIV wing and currently accommodates many inner city adolescents seeking care and treatment. There are currently 698 adolescents on HIV treatment.

Study population

All participants were Black African and spoke English with ease, although their home language was an African language. HIV infected adolescents access these clinics at least every 3 months if they are stable on treatment for check ups and to fill their prescriptions for ARVs. Most adolescents were found to have been on treatment for most of their life, typically accessing the facility since early childhood. Most adolescents knew the clinics and their providers well having seen them regularly over a number of years. Whilst caregivers might have been accompanying children to the clinic, it was very unusual to see a caregiver accompanying an adolescent. As such, most of the adolescents recruited for this study were managing their medical treatment independently. Although it was the intention of this study to compare vertically and horizontally infected HIV positive adolescents, what transpired was that very few adolescents accessing these facilities were *not* vertically infected. Horizontally infected youth may not be accessing treatment at facilities and may not know their HIV status as they may have become recently infected and are most likely in good health.

Data collection

Prior to data collection 9 lay counsellors were recruited to participate in the research. These counsellors worked at the sites regularly, were trained in paediatric HIV, pre and post test counselling, adherence counselling, disclosure and had advanced counselling skills. This training had been completed before the counsellors engaged in the current study and was the basis of their work as counsellors in the clinics. All were interested in conducting this research. Five were female and four were male, ranging in age from their late twenties (5) to mid fifties. All were fluent in various African languages (Zulu, Xhosa, Setswana, Sesotho) as well as English. Counsellors were trained for an additional 5 days on the study protocol and objectives, distress protocols and management of crisis situations (such as disclosure of rape or suicide), duties and responsibilities as research counsellors and appropriate conduct in undertaking the research. They also received specialized training on using non verbal ways of working with children and adolescents, and how to utilize materials for the study. A manual was developed for fieldworkers to reference as needed. The data collection tools were explained in detail for each variable including how data should be completed, where to obtain the information from and how to interpret the information. Extensive training was undertaken on how to utilize the tablet computer and conduct the questionnaires using these devices.

Research counsellors were debriefed weekly by a registered therapist and any data collection queries were addressed in a timely fashion. The primary investigator checked the completed questionnaires on a weekly basis to ensure quality control and any errors were addressed within a 2 week period of follow up directly with participants. If suicidal patients were identified, the research counsellor called the primary investigator immediately and the situation was managed by following the protocol to refer them for immediate care. There were 17 participants screened out of the study on account of active suicidality. They were all managed with active referral to the inpatient care at the hospital and their providers and caregivers made aware of their mental health concerns. These participants required some follow up case management to ensure they were taken care of appropriately and were subsequently safe.

The questionnaire was loaded on tablet computers. The questionnaire was piloted on the tablet for four weeks and all ‘bugs’ identified and worked out of the system to ensure quality data was collected and questions asked optimally. Adolescents were encouraged by research counsellors to ‘play’ with the tablet before the interview began (many had not seen or engaged with a tablet before). If the adolescent was familiar with the instrument, they undertook the questionnaire on their own with the research counsellor present to answer questions. If not, the research counsellor, together with the adolescent, administered the questionnaire.

The questionnaire comprised a variety of questions (HIV related, sexual reproductive health, violence exposure, etc.), screening tools (for common mental health problems) and drawing tasks. Adolescent’s knowledge of their own HIV positive status was assessed initially through healthcare providers’ report and with additional checks using a screening on whether adolescents knew why they were coming to the clinic to avoid unintentional disclosure. Adolescents who did not know why they were coming to the clinic, or reported they were coming for other reasons than HIV treatment (such as attending clinics for their vitamins) were not asked the HIV related questions in the questionnaire.

A community advisory board (CAB) was initiated for this research and comprised 9 adolescents from Harriet Shezi Clinic, Faranani Clinic, Ward 21 and Ward 274. These adolescents were active participants of the adolescent support groups held at the facilities they utilized and conducted by the research counsellors. All adolescents knew their HIV status and had disclosed it to at least one other person. They were invited to join the CAB, giving informed consent (Appendix E) to do so and to use the picture below. The CAB were consulted on the questionnaire's relevance and whether the questions were clear; participant reimbursement in the form of a gift voucher at a major retailer was their idea as well as what snacks to provide participants. They endorsed the referral card and were able to say which referrals were helpful in their neighbourhoods. All their feedback was incorporated into the study design and implementation.

Figure 9: Community Advisory Board (CAB) participants and lay counsellors

MY BODY, MY LIFE, MY FUTURE!

TRAUMA

Family Life Center
@ City Center: 011 833 2057
@ Soweto: 011 984 0266

Child, Adolescent, Family Unit
@ Charlotte Maxeke Hospital
011 481 5103

Nthabiseng Clinic @ Chris Hani
011 933 1206

Sinakekelwe Clinic @ Natalspruit
011 909 5832

Medico Legal Clinic @ Hillbrow
011 694 3803

LEGAL ADVICE

Lawyers Against Abuse (LvA)
011 717 8655

Teddy Bear Clinic
011 484 4554

Child Welfare
011 492 2888

Emthonjeni Centre
011 717 4513

COUNSELING

Ctr for Psychological Svcs
+ Career Development
@ Doornfontein: 011 559 6042
@ Soweto: 011 559 5752

Ekupholeni MH + Trauma Ctr
011 909 2929

Joburg Parent + Child Counselling
011 484 1734/6

Ububele
011 786 5085

SA Depr + Anxiety Group
011 262 6396

Lefika la Phodiso Art Therapy
011 484 4672

Childline
011 645 2000

SHELTER

The House Shelter
011 680 2913

Home of Hope
011 331 4467

Usindiso Ministries
011 334 1143

Sunlight Safe House
011 645 2000

Ikhaya Lethemba
011 242 3000

HOTLINES

Suicide Crisis Line
0800 567 567
SMS 31393

Lifeline
0861 322 322

Childline
08000 55555

LoveLife
0800 121 900

Child Welfare
0861 4 CHILD (24453)

AIDS + TB Helpline
0800 012 322

Figure 10. Referral card

Data collection tools

Measures

Sociodemographic information

Items originated from the South African census and included age, gender, ethnicity, household composition, formal/informal housing, highest school grade achieved, and orphanhood status.

Mental health measures

Mental health was measured using standardized scales utilized previously with youth in South Africa (Cluver et al, 2012).

Table 1. Description of mental health scales

Depressive symptoms: The Child Depression Inventory (short form) (Kovaks, 1992) (10 items). This scale is highly correlated with the full scale (r 0.89; Kovacs, 1992) and in our sample showed an acceptable internal consistency of α=.70. The CDI has strong psychometric properties, and has been used in multiple South African populations (Cluver, 2009; Suliman, 2002); internal consistency ranges from .71 to .94 (Kovaks, 1992; Saylor, 1984)
Anxiety symptoms: Children's Manifest Anxiety Scale – Revised (14 items). Anxiety was measured using an abbreviated version of the 28-item Revised Children's Manifest Anxiety Scale (Reynolds & Paget, 1983), which has been validated for use in South Africa (Boyes & Cluver, 2013) and in our sample showed an α=.75. Cluver showed an α.80, and the reduced scale showed α .75 (2006) and .80 (2009). The RCMAS has been standardized in US populations, shows good internal consistency and test-retest reliability (.68 after 9 months) (Reynolds & Richmond, 1978; Gerard & Reynolds, 2014).
Post-traumatic stress symptoms: Child PTSD Checklist (28 items) (Amaya-Jackson, 1995). Posttraumatic stress symptoms were measured using the Child PTSD Checklist that has been validated in South Africa (Boyes et al, 2012) and in our sample showed an acceptable α=.89. Cluver used this in studies of AIDS-orphanhood, and showed α.94. The Child PTSD Checklist has been used more than any other PTSD scale with Black African youth in South Africa (Seedat et al, 2000; Seedat et al, 2004). On US populations, the scale shows α .82-.95. Test-retest reliability at one week was r=.91 (Amaya-Jackson et al, 2000). The scale corresponds to DSM-IV diagnostic criteria.
Suicidal symptoms: MINI International Psychiatric Interview (5 items) (Sheehan et al, 2004). Suicidal behaviour was measured with the MINI International Psychiatric Interview for children and adolescents suicide scale. This scale is well validated, showing strong internal consistency and test-retest reliability (Lecrubier et al, 1997); in our sample an α=.75.
Substance abuse symptoms: National survey of HIV and risk behaviour amoungst young South Africans (Pettifor et al, 2004) (4 items). This is a widely referenced and acknowledged national survey of risk behaviours in youth.

Western-validated clinical scores must be interpreted with caution, and to date no clinical cut-offs have been validated in Africa. Resultantly a symptomatic group was identified as adolescents who experienced >50% of the symptoms on any of the depression, anxiety or PTSD scales. These methods, although imperfect, have been used in Africa to measure symptomatology with scales validated in other contexts. Murray et al (2015) used a PTSD measure in Zambia and to maximize sensitivity implemented that a response of 1 or more per item would be indicative of symptoms appropriate for trauma focused cognitive behaviour therapy. Similarly Seedat et al (2004) in South Africa utilized a PTSD measure and used a conservative threshold score of 2 (‘most of the time’) to endorse the presence of a symptom. Although our scoring method identified a lower threshold than cut-off scoring, it was more likely to capture those participants possibly at risk.

Data analysis

Data from questionnaires were entered into MS Excel from tablet computers and imported into Statistica v13 for statistical analysis. Data was cleaned and entries with missing data were excluded from the analysis. The following new variables were generated from the collected data: ‘Depression Score’, ‘Anxiety Score’, ‘PTSD Score’, ‘Peer Victimisation Score’, and ‘Suicidality Score’. These variables were obtained by adding the responses to the questions related to each section after reversing scores where necessary. The following group variables were also created to look at differences between groups: ‘Symptomatic for Suicidality’, ‘Symptomatic for Depression’, ‘Symptomatic for Anxiety’, ‘Symptomatic for PTSD’, and ‘Symptomatic’. Respondents who responded “yes” to any of the five questions related to suicidal thoughts or behaviours in the last month were included in the ‘Symptomatic for Suicidality’ group. There were ten questions assessing depression each with a scale of 0, 1, or 2. Respondents who scored 1 or 2 on five items or more were included in the ‘Symptomatic for Depression’ group. Anxiety was assessed using 14 questions which respondents could either respond “yes” (1) or “no” (0) to. Respondents who scored 1 on seven items or more were included in the ‘Symptomatic for Anxiety’ group. There were 28 questions assessing PTSD each with a scale of 0, 1, 2, or 3. Respondents who scored 2 or 3 on fourteen items or more were included in the ‘Symptomatic for PTSD’ group. Any respondent that belonged to at least one of the symptomatic groups was included in a broader ‘Symptomatic’ group.

Both descriptive and bivariate statistics were conducted to examine the distribution of all variables and assess relationships between variables. Significance testing was undertaken using a 95% confidence interval. Frequency distributions were run on all variables as a starting point. Measures of central tendency and spread were done using a number of statistics, including the mode, median, mean, minimum, maximum, and standard deviation. Normality was assessed using the Kolmogorov-Smirnov and Shapiro-Wild tests and histograms were generated for graphical confirmation.

Pearson's *r* was used to measure the correlation between continuous variables such as age, number of losses experienced, years knowing HIV status and PTSD scores. T-tests were used to compare differences between groups, such as gender, violence exposure, feeling of belonging, and control for the future in relation to the mental health outcomes assessed. Chi-squared tests were used to determine statistically significant differences in response to categorical variables, such as gender, suicidality and exposure to violence. Relative risks and 95% confidence intervals were calculated using Altman's formula to understand if a group was more at risk than another in relation to mental health outcomes. All analyses were used to facilitate identification of at-risk groups. These findings are detailed in chapter 6.

Multiple regression analyses were used to predict the value of depression, anxiety, and PTSD scores based on the value of variables and to determine the overall fit of the model and the relative contribution of each of the predictors to the total variance explained. Below are tables from the regression analysis for depression, anxiety and PTSD scores – only significant variables are represented:

Table 2. Regression summary for depression score

	Regression Summary for Dependent Variable: Depression Score R= ,71207103 R^2= ,50704516 Adjusted R^2= ,47128677 F(14,193)=14,180 p<0,0000 Std.Error of estimate: 2,1768						
N=208	**b***	**Std.Err. of b***	**b**	**Std.Err. of b**	**t(193)**	**p-value**	**Valid N**
Intercept			0,509197	1,634237	0,31158	0,755696	
DaysHungry	0,179572	0,053986	0,705440	0,212082	3,32626	0,001054	343
SuicidalityScore	0,178427	0,055291	0,501673	0,155458	3,22707	0,001469	337
PTSDScore	0,222530	0,065541	0,055733	0,016415	3,39530	0,000832	325

Table 3. ANOVA for depression score

Effect	Analysis of Variance; DV: Depression Score				
	Sums of Squares	**df**	**Mean Squares**	**F**	**p-value**

Effect	Analysis of Variance; DV: Depression Score				
	Sums of Squares	**df**	**Mean Squares**	**F**	**p-value**
Regress.	940,695	14	67,19253	14,17976	0,000000
Residual	914,554	193	4,73862		
Total	1855,250				

Table 4. Regression summary for anxiety score

	Regression Summary for Dependant Variable: Anxiety Score R=,74831840 R^2 = ,55998043 Adjusted R^2 =,45608692 F(51,216)=5,3899 p<,00000 Std Error of estimate: 2,1334					
N=268	**b***	**Std.Err of b***	**b**	**Std Err of b**	**T(216)**	**p-value**
Intercept			-0,29375	4,559668	-0,06442	0,948693
Look after younger	-0,113680	0,051451	-0,67602	0,305965	-2,20948	0,028192
Depression score	0,322866	0,067152	0,33223	0,069101	4,80796	0,000003
PeerVic Score	0,158825	0,062270	0,09971	0,039094	2,55057	0,011447
PTSD Score	0,225499	0,066716	0,05571	0,016482	3,38000	0,000860
Been Hospitalised	0,108445	0,051147	0,65615	0,309467	2,12026	0,035125

Table 5. ANOVA for anxiety score

	Analysis of Variance; DV Anxiety Score				
Effect	**Sums of Square**	**DF**	**Mean squares**	**F**	**p-value**
Regress	1251,136	51	24,53208	5,389946	0,000000
Residual	983,114	216	4,55145		
Total	2234,250				

Table 6. Regression summary for PTSD score

	Regression Summary for Dependant Variable: PTSD Score R=,75187151 R^2 =,56531077 Adjusted R^2 =,46267581 F(51,216)=5,5080 p<,00000 Std Error of estimate: 8,5831					
N=268	**b***	**Std.Err of b***	**b**	**Std Err of b**	**T(216)**	**p-value**
Intercept			19,39748	18,29698	1,06015	0,290262
Sex (M/F)	-0,138436	0,053278	-3,23914	1,25128	-2,58867	0,010289
Depression score	0,207636	0,068789	0,86484	0,28652	3,01843	0,002846
PeerVic Score	0,174380	0,061686	0,44314	0,15676	2,82687	0,005142
ExpViol Times Things Stolen	-0,115474	0,052691	-1,14286	0,52150	-2,19151	0,029484
ExpViol Private Parts Touched	-0,119013	0,054630	-8,17357	3,75186	-2,17854	0,030448
What Status	0,109259	0,051905	6,17442	2,93324	2,10498	0,036449
Know Other HIV	-0,109437	0,052505	-2,72356	1,30668	-2,08433	0,038306
Control Future	0,107945	0,050712	6,35899	2,98743	2,12859	0,034421
Have Dream	0,145008	0,054006	9,95882	3,70904	2,68501	0,007816
Anxiety Score	0,222768	0,065908	0,90171	0,26678	3,38000	0,000860

Table 7. ANOVA for PTSD score

	Analysis of Variance; DV PTSD Score				
Effect	**Sums of Square**	**df**	**Mean squares**	**F**	**p-value**
Regress	20694,26	51	405,7698	5,507975	0,000000
Residual	15912,62	216	73,6695		
Total	36606,88				

Multiple regression analysis was used to test which variable significantly predicted participants' mental health outcomes (depression, anxiety PTSD). The results of the regression indicated that three predictors explained 50.7% of the variance in depression (R^2 = 0.47, F(14)=14.18, p<.01). It was found that number of days hungry (β = .18, p<.01), suicidality score (beta = .18, p<.01), PTSD score (β = .22, p<01) significantly predicted depression score. Five predictors explained 55.9% of the variance in anxiety (R^2 = 0.46, F(51)=5.39, p<.01). It was found that looking after children in the home (β = -.11, p<.05), whether one had been recently hospitalized (β = .011, p<.05), depression score (β = .32, p<.01) and PTSD score (β = .23, p<.01) significantly predicted anxiety score. Similarly, ten predictors explained 56.5% of the variance in PTSD (R^2 = 0.46, F(51)=5.51, p<.01). Knowing others who are HIV positive (β = -.12, p<.05), peer victimization score (β = .17, p<.01), depression score (β = .21, p<.01) and anxiety score (β = .22, p<.01) significantly predicted PTSD score.

Ethical consideration

Three hundred and fourty three adolescents gave verbal assent and written consent to participate in the research, and all participation was sought on the basis of good clinical practice guidelines (Verma, 2013).

Confidentiality was maintained except where participants were at risk of significant harm, including being actively suicidal or currently experiencing abuse, in which case interviews were stopped and immediate referrals were made to child protection and health services in accordance with mandatory reporting legislation in South Africa (Children's Act, 2005). Where prior abuse or rape was no longer occurring, referrals were made to support and counselling services.

Interviews were conducted at facilities, adolescents invited to participate in the waiting room or during support groups. Confidential space was negotiated with the facility managers for these interviews ahead of time and privacy was resultantly assured. Most interviews occurred during regular clinic times but on four occasions, recruitment occurred on a Saturday with permission granted in advance to utilize the clinic space from the facility manager and her superiors. Interviews lasted approximately 60-90 minutes and were accommodated by facility staff. Participants were given a pocket sized card with active referrals for services in their neighbourhood including counselling, legal and crisis resources. Upon completion of the interview, participants received reimbursement for travel; a snack; and a gift voucher for R50 (US $4) at a local clothing retailer.

Limitations

Although there was significant training and oversight of the study team in terms of helping adolescents both with the tablet and engaging in the drawing tasks, research counsellors may not have offered every participant with full opportunities to engage. Some participants may have curtailed their engagement on account of social desirability bias. However, tablet computers were utilized which have been shown to reduce reporting bias on sensitive questions. Participants were recruited from healthcare facilities in an urban setting and conveniently sampled so findings may not be generalizable to adolescents in other contexts. All psychological measures should be interpreted with caution in different cultures as noted above. There is a need for standardized scores and instruments for the South African context as the current instruments may not be capturing the full range of symptoms in this population. Also, there was no comparison group of HIV negative adolescents for this study to assess the role of HIV in mental health problems.

(Appendix F: information sheet; Appendix G: distress protocol; Appendix H: SOP distress management)

Study 2: Exploring resilience in HIV positive adolescents accessing treatment in Johannesburg

Background and question

What are the characteristics of resilience amoung HIV positive adolescents (13-19yrs) accessing HIV treatment in Johannesburg?

Study design

The qualitative studies (2 and 3 detailed below) of this PhD were nested in the quantitative study described above. Participants for study 2 were recruited purposively by research counsellors familiar to them based on consent and willingness to engage in in-depth interviews. High functioning adolescents (i.e. scoring moderate to low on the standardized mental health measures indicating ‘good’ mental health) were chosen because their resilience was being investigated, i.e. these participants' reported difficulties and adverse life experiences that did not seem to be impacting negatively on their mental health functioning as assessed through their questionnaire responses. These adolescents were invited to participate in study 2 when they had completed the questionnaire and the research counsellor with them had speculated on their potential resilience. The adolescents who agreed, were followed up by the research counsellors and primary researcher to establish a convenient time to meet at the clinic to conduct study 2. All data was collected by the primary researcher between February-April 2014.

Study sites and sample

There was an attempt to recruit participants in relatively equal proportions from all five study sites and by gender to ensure balance and variety in findings. Of the 25 participants recruited, 15 were female; median age was 16yrs ranging from 13-19 years. Fourteen participants were from Harriet Shezi Clinic, six from Faranani Clinic, three from Ward 274 and two from Ward 21.

Data collection

Twenty-five adolescents were interviewed face-to-face for 60 minutes using a semi-structured interview guide when they visited the clinic for their regular appointment. The interviews were digitally recorded with participant consent and conducted in English as all participants spoke English comfortably. The semi structured interview guide explored the following themes: how did participants understand resilience? What helped them cope in their lives? What were some of the difficulties they had experienced in their lives and how did they manage them? What could the health system offer to enable them to cope better both with their HIV disease as well as other concerns they may have? If they could address other young HIV infected children and adolescents, what messages would they have for them?

Data collection tools

An in depth semi structured interview guide (Appendix I) was developed in consultation and collaboration with the research counsellors, as well as social worker, a psychologist and a senior researcher that assisted with data analysis. The guide was appraised continuously to ensure that questions being asked reflected the area of study comprehensively. Interviews followed an emergent design (Dahlgren et al, 2004) issues of interest that came up in one interview were probed further in subsequent interviews until such a subject was saturated. This process continued throughout the data collection period. Interviews were concluded when no new information came up in any of the areas of inquiry or research questions, i.e. when data saturation was reached.

Data analysis

All interviews were transcribed verbatim in English by professional transcriptionists. Each transcript was reviewed to ensure clarity and rectify errors. Data were managed in QSR NVivo 10, a qualitative analysis software package, constructing an analytical framework of broad codes by creating a ‘start list’ of possible themes and building upon the research questions. This final framework of thematic codes was imported into NVivo along with code definitions. Each broad code, or wide thematic basket of ideas (Creswell, 2014), was applied to each transcript and ‘fine codes’ were developed using an inductive approach deriving meaning from the data itself rather than imposing pre-formed ideas (Hutchinson et al, 2010). The fine codes were constantly compared with the broad code definition—ensuring that finer themes related to the question of interest. This process was crucial for analytical rigor as it allowed the opportunity for seeking out disconfirming evidence (Miles & Huberman, 1994), and for adding to the preliminary “audit trail” of decisions made by the research team (Lincoln & Guba, 1985). To ensure intercoder agreement, fine codes were developed by 4 researchers competent in qualitative data analysis by printing out a full set of excerpts (from each data set) related to each code for each transcript and identifying sub-themes emerging from the data. Two researchers applied the thematic code to each transcript, a technique called ‘double coding’. The focus of double-coding was to ensure that code application was consistent across transcripts and that code definitions were robust. An analytical summary was developed on each study objective using illustrative quotes to support key emerging conclusions. The findings and analytical reports were critiqued by the group to guarantee research findings; highlighting the reality of the transcripts rather than simply one researcher's view of the data. During analysis, we found that data did reach a point of saturation, which leads us to believe the sample size was sufficient.

Ethical consideration

All interviews were conducted in a private space at the clinic, negotiated with the facility manager ahead of time to ensure confidentiality. Participants were given reimbursement for travel; a snack; and an additional gift voucher for R50 ($3) at a clothing retailer for each interview they attended. All data collection materials were stored in a locked file cabinet and electronic voice files and transcripts were password protected and stored on an encrypted server. All identifying information regarding the participant or clinic setting was removed and transcripts were saved by a file name with no personal identifiers. Pseudonyms unrelated to participants real name were assigned to each transcript for ease of analysis and data presentation.

Limitations

Similar limitations apply to this study as to study 1 described above due to the same population being sampled. Firstly, the adolescents were purposively recruited from clinics based on their responses to a questionnaire and the view of the counsellor administering the tool, thus the sample may overrepresent resilience amoung a population that may, more typically, face major barriers to resilience and mental health. Secondly, there was no comparison group of adolescents who were not coping and thus potential significant differences in what made some adolescents more resilient than others could not be assessed. Thirdly, this was a clinic-based sample in an urban environment and it is likely that participants may not reflect the broader adolescent population – futher research is needed with rural adolescents and those not accessing healthcare. Lastly, it was not the intention of this study to analyse the concept of resilience but merely to describe resilient characteristics found in this particular population.

Study 3: The impact of bereavement on HIV positive adolescents accessing treatment in Johannesburg

Background and question

How do drawings or writing of HIV positive adolescents' depictions of loss connect to mental health outcomes? Can drawing tasks be utilized by lay counsellors in public health clinics to understand bereavement in adolescent patients?

Study design

This qualitative study was also nested in the qualitative study (study 1) described above. This study examined the use of drawings completed by participants who undertook the questionnaire. These drawings were facilitated by research counsellors as a means of engaging in the experience of loss of the adolescents. The most symptomatic (i.e. those with highest mental health scores indicating poorer mental health) participants' drawings/written accounts to the drawing task '*draw a picture of someone close to you who died'* were compared with the least symptomatic participants' accounts through facilitated focus group discussions. The data was collected by the primary researcher in April 2014.

Data collection

Drawings of the most symptomatic and the least symptomatic participants on overall mental health scores were retrieved for comparison after analysing the mental health scores of the entire sample (n=343). This led to 26 responses to the drawing task: '*draw a picture of someone close to you who died*' being selected for analysis. Seven of these were written accounts and 19 were drawn images. Some participants chose to write instead of draw. The instruction for this task was given about midway in the questionnaire when rapport had been established, conversations around life histories and mental health were completed, and less emotionally loaded drawing tasks such as '*draw where you sleep at home'* had been completed. Thus participants were familiar with completing drawings in the questionnaire at this point. The participants were offered a variety of drawing tools: pencils, coloured pencils, felt tip pens, pens and paper to employ for this task. Study 3 participants were different to study 2 participants.

These drawings/written accounts were then assessed through 3 focus group discussions (FGDs) with professionals working with adolescents in the public health sector (art therapists, psychologists, social worker, counsellors). For each FGD, all drawings and written accounts were exhibited on the walls of the room for easy access to the visual material. Participants were invited to view all the imagery before the FGDs commenced. All FGDs were digitally recorded with participant consent and lasted approximately 1 hour. The first focus group was conducted with four registered art therapists to reflect on the drawings/written accounts selected. These therapists worked with disenfranchised children/adolescents in urban community settings using art as the basis for therapeutic engagement. The second focus group was conducted with two psychologists and a social worker who worked with the population being studied in primary healthcare environments to similarly reflect on the drawings chosen. The last focus group was conducted with six research counsellors and a study coordinator undertaking the data collection for this research study. The semi structured interview guide explored the following themes: was it clear which group was more or less symptomatic? What were the reflections and responses to the imagery and written accounts presented? Knowing the population and their experience of loss, what do the images tell us about the adolescents as well as the health system? What recommendations would be of importance with this population based on these images?

There was no reimbursement provided for study participation.

Data collection tools

Similar to study 2, an in depth semi structured interview guide was developed and appraised continuously to ensure that questions being asked reflected the area of study. Emerging themes were explored consistently in FGDs until saturation was achieved.

Data analysis

Mental health was measured using standardized scales for depression, anxiety and PTSD as described above. Descriptive and bivariate analysis identified the most symptomatic (20 respondents that met the criteria for being symptomatic for depression and anxiety, and had the highest PTSD scores) and least symptomatic (20 respondents that did not meet the criteria for being symptomatic for depression and anxiety, and had the lowest PTSD scores) participants for overall mental health scores. From this group n=26 participants were identified for further analysis.

The three FGDs were recorded and transcribed verbatim by professional transcriptionists. Each transcript was reviewed to ensure clarity and rectify errors.

Data were interrogated building an analytical framework of broad codes by creating a 'start list' of possible themes and building upon the research questions. New ideas were added and combined, whenever possible, to capture main themes emerging from the transcripts. Each broad code, or wide thematic basket of ideas, was applied to each transcript and 'fine codes' were developed using an inductive approach deriving meaning from the data itself rather than imposing pre-formed ideas (Creswell, 2014). To ensure intercoder reliability, fine codes were developed by three researchers competent in qualitative data analysis for each transcript, identifying sub-themes emerging from the data. Results were critiqued to guarantee research findings via a series of skype calls to refine codes until consensus was reached. Drawings/written accounts presented were selected by the same three researchers to ensure themes were properly represented through the imagery identified and examined. Trustworthiness of findings was ensured by the team approach to data analysis, coding discussion meetings, and by presenting initial findings to groups of colleagues and peers.

Ethical consideration

All data collection materials were stored in a locked file cabinet and electronic voice files and transcripts were password protected and stored on an encrypted server. All identifying characteristics were coded or removed. Pseudonyms unrelated to participants real name were assigned to each transcript for ease of analysis and data presentation. Similarly, confidentiality was maintained and no identifying information was evident on work displayed to the focus group participants.

Limitations

It was not the intention to analyse the drawings represented in this study in a mechanistic, intellectualised approach to pictorial analysis. The drawings were processed with the research counsellors and participants gave voice in this containing relationship to their imagery and narratives. An intuitive response, which may be considered as unreliable and subjective, was undertaken through participants in the focus group discussions. All participants had a keen aesthetic sensitivity, strong affinity and responsiveness to the visual images and it is believed they were able to appreciate and experience the aesthetic dynamics intrinsic to each image. However, it may be possible that a different group would perceive alternative findings.

This limitation must be interpreted in light of others in this study. There was no control group and no comparator for visual imagery of this population, thus claims and conclusions based on these drawings are merely speculative and warrant further investigation. Participants were conveniently sampled and recruited from primary healthcare facilities in an urban setting so findings may not be generalisable to adolescents in other contexts. Drawings were requested in a quantitative questionnaire and were not overtly introduced as therapeutic per se. There may have been compliance or permission seeking on the part of participants leading to curbed expression in their drawings. The study relied on self-report that may have led to social desirability bias.

Finally, in this study and the others in this PhD, it must be stated that there is currently no precise test to determine perinatal infection (for those who were not tested at birth), especially in resource poor settings where accurate clinical records are a challenge to obtain, so symptoms, time of first hospitalization and timing of ART initiation are used as guides (Ferrand et al, 2009). Resultantly, some adolescents assumed to be perinatally infected in this thesis may not have been.

CHAPTER 4

Results - Enrolling HIV-positive adolescents in mental health research: a case study reflecting on legal and ethical complexities

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Introduction

Adolescent burden of HIV

Adolescents living with HIV are an emerging group in the global HIV/AIDS epidemic. In 2012, there were 2.1 million HIV infected adolescents in Low and Middle Income Countries (LMICs); globally there were 3.2 million HIV infected children aged under 15 years, 90% of whom were living in sub-Saharan Africa[1, 2]. Nearly one-sixth of all new HIV infections are in adolescents aged 15 – 19 years[3] making this group the most vulnerable incident infection population in South Africa[4]. In addition, due to significant improvement in accessing antiretroviral therapy (ART), children born with HIV are growing into adolescence in large numbers, especially in LMICs[5,6].

Worldwide, adolescents are the only age group in which AIDS-related deaths are not decreasing[3]. In 2013, there were more than 9,500 South African deaths among HIV-infected adolescents[7]. Local studies contrasting adolescents with adults, indicate lower retention and viral suppression among youth[8,9]. The cohort of sexually active, HIV infected and viremic youth presents a significant impact on HIV transmission rates warranting public health investment consideration. Adolescents engagement is critical to a meaningful HIV response.

Approximately 15 million children in sub-Saharan Africa have lost one or both parents to AIDS; 2.5 million in South Africa[10]. An orphanhood epidemic has matured alongside the HIV epidemic with high rates of adolescent orphans. In 2012, the overall national level of orphans under 18 years of age was 16.9% (maternal, 4.4%; paternal, 9.3%; double, 3.2%)[4]. Families of HIV positive children and adolescents have high levels of mobility and migration, with inconsistent guardianship, care and supervision[11-13]. Typically when biological parents die, their children are taken into care by extended family or friends. Unless a child is placed in formal institutional care, the formal appointment of a legal guardian is extremely rare. Legal guardianship is often not meaningful to African families[14].

Rates of mental health problems in adolescents

In both developed and less developed countries almost 50% of people living with HIV/AIDS have a diagnosable mental disorder – in some instances a rate threefold higher than the general population[15-18]. Reasons for this include pre-morbid mental conditions, the effect of HIV on the central nervous system, the psychological impact of living with HIV/AIDS, side-effects of medication, social stigma and discrimination[15]. Mental health disorders occur with increased frequency among HIV infected children and adolescents in developed contexts[12,19,20]. In LMICs there is a paucity of research on this population and mental health outcomes. Studies in western countries, measuring the association between HIV and mental health outcomes in adolescents, are not always comparable with African populations, where adolescents are subjected to multiple additional risks and vulnerabilities. Poor mental health is strongly related to other health and development concerns in young people – lower educational achievements, neurocognitive delay, substance abuse, violence, and poor reproductive and sexual health[21-25]. Examination of the impact of HIV on mental health outcomes in adolescents locally is critical; mental health is likely to affect HIV care and treatment, consequential adult burden of disease and secondary transmission.

Difficulties with undertaking research for this group

South African legislation requiring parental or guardian's consent presents a significant barrier to research on HIV infected adolescents aged under 18 years. Using a study of mental health outcomes of HIV infected adolescents in Johannesburg as a case study, we explore legal and ethical issues related to conducting adolescent mental health research.

Legal framework

National Health Act, 2003 (NHA)

Prior to March 2012, the South African framework governing research permitted children (under 18 years) to consent independently to take part in research[26]. Where the research posed minimal risk and no community objection was anticipated, national ethical guidelines permitted a dispensation from parental or guardian's consent for participation in health research by older children[14,27].

On 1 March 2012, section 71 of the NHA came into effect, which has four prerequisites for research or experimentation on a minor for therapeutic purposes: (a) the best interests of the minor; (b) conformity with the manner and conditions prescribed; (c) consent of the parent or guardian; and (d) consent of the minor where capable of understanding. Non-therapeutic research and experimentation requires additional ministerial consent[28].

On 19 September 2014, *Regulations Relating to Research with Human Participants* were promulgated completing the new legal framework for regulating health research established by the NHA[29]. These regulations address three general issues relating to children. First, minors are considered a vulnerable population. Health Research Ethics Committees (HRECs) are required to balance child protection and research facilitation and pay special attention to protocols, recognising children as deserving beneficiaries of research outcomes[30]. Second, the participation of minors must be scientifically indispensable to the study design[30]. Third, minors can only participate in research when they will be exposed to particular low levels of risk, an approach that corresponds with the risk categories described in national ethical guidelines[29].

The regulations define "therapeutic research" as research that holds out the prospect of direct benefit to the participant. Neither the NHA nor the regulations define “research”.

Impractical for researchers: case study Woollett

This case study (a description of the mental health of HIV positive adolescents accessing care in Johannesburg) highlights the legal process undertaken to facilitate research on vulnerable South African adolescents. It could not be done with parental or guardian’s consent – proposed participants would be orphans without legal guardians. Approval was initially refused by the University of the Witwatersrand Medical HREC. In July 2013, the principal investigator applied to the High Court, Johannesburg, in its capacity as upper guardian of minors, for consent for the research. The application was served on the facility managers of the five clinics concerned, the provincial and district research committees, Chris Hani Baragwanath and Charlotte Maxeke Academic Hospital research committees, the provincial Health MEC and the Health Minister. Upon the order being granted, the university HREC granted unconditional approval of the study (M130258) as did the other research committees. This process took eight months and without pro bono legal assistance would have been impossible.

The study integrated qualitative and quantitative methods in design and implementation. It took place in five clinics serving HIV infected adolescents in Johannesburg. A survey was undertaken of 343 HIV infected adolescents aged 13 – 19 years. It contained standard assessments for depression, anxiety, post-traumatic stress disorder (PTSD) and suicide and captured HIV, sexual reproductive health, adherence, disclosure and demographic information.

Of the 343 participants, 74% were orphaned and did not have legal guardians. Most were likely perinatally infected. Twenty seven percent were symptomatic for depression, anxiety or PTSD, 24% participants indicated signs of suicidality (excluding 17 adolescents excluded for active suicidality). Almost 90% did not feel that they belonged within the family fostering them, 90% did not receive praise from those they lived with and 85% were not given the same things as other children in the home. But for the High Court order, most of the sample would likely not have participated in this research.

Issues related to parental consent

Much debate has taken place over allowing children to consent to health research[14,26,31,32]. South African HIV research is still abundant and the greatest burden of disease has moved to vulnerable groups, including adolescents. Research on adolescents is critical but inhibited by requiring parental consent.

- *Exclusion of most Orphaned and Vulnerable Children and Youth (OVCY)*

The adverse outcomes of being orphaned include loss of effective guidance and supervision, inconsistent care, loss of educational opportunities, impoverishment, increased sexual vulnerability, high rates of risk taking, psychological distress and significant mental health problems[19]. There is higher prevalence of HIV infection among orphans than non-orphans and orphans of non-AIDS causes, earlier sexual debut, increased risk of intergenerational sex, and increased family violence and exploitation[10,33-36].

OVCYs are increasingly recognized as a special population for HIV risk and transmission[34]. OVCYs, child-headed households, and those without an official guardian are a unique and contemporary issue placing many South African institutions (including government) under tremendous pressure. Innovation and responsiveness are key factors to counter these challenges. This vulnerable group can ill afford to be neglected by research, which could assist in HIV prevention and yield effective treatment interventions.

Parental consent is impossible for minors not living with, or having access to, their parents and orphans who comprise a significant proportion of HIV infected children. Section 71 has the effect of impeding research on child-headed households and OVCYs.

- Inconsistent and confusing legal policy

Section 129 of the Children's Act, 2005[37] permits independent autonomous consent to general medical treatment by a child over the age of 12 years, including HIV counselling and testing. The Choice on Termination of Pregnancy Act, 1996[38] provides for autonomous decision-making by a pregnant child with no minimum age requirement. Policy recognises an adolescent capacity in children to make decisions concerning themselves. An adolescent child may independently consent to an HIV test and receive medical treatment but cannot consent to the observation of such for research to improve the quality of, or access to, treatment. Excluding autonomous participation in observational research of a low risk nature undermines this policy.

- Inadvertent harm or silence to voices that most need to be heard

Adolescents may opt not to seek care because they want to avoid telling their parents about their health problems and sexual activity[1]. The Children's Act facilitates confidentiality from parents avoiding stigma, discrimination and potential punishment. Requiring parental consent for research removes confidentiality. Children unable to obtain parental consent to participate are often those most in need of mental health information and resources. Requiring parental consent excludes their experiences and needs from research findings[39].

Research identifying harm to children, might expose the parents and caretakers as the perpetrators of such harm. Parental consent in these circumstances is highly likely to be refused and the harm undetected. South African prevalence rates for abuse in adolescents are 56.3% for lifetime physical abuse, 35.5% for lifetime emotional abuse and 9% for lifetime sexual abuse[24]. Historically, a requirement for parental consent in all cases would have precluded the ground breaking research by radiologists correlating paediatric head trauma with long bone fractures identifying child abuse[40].

- *Requiring parental consent may be inconsistent with principles of justice, inclusiveness and autonomy*

Requiring parental consent, implicitly assumes the parents' ability to understand research and assess risk is always superior to their children's. Parents' opinions are often informed by their own experience of adolescence rather than the realities of their children[39]. Mental health is highly stigmatized, difficult to communicate and often not discussed in families.

Most school-aged children are capable of meaningful assent for participation in many types of research studies. Adolescents from 14 years may be as capable as adults of making competent decisions about research participation, according to more stringent legal standards of competency[41]. South African adolescents view participation in research, particularly HIV vaccine trials, to be beneficial and would participate; their reasons ranging from altruism to direct benefit[31,42]. Adolescents report marginal levels of distress when self-reporting violence and suicidality[43,44]. In our study the overwhelming majority of adolescents expressed relief and gratitude in being able to tell their story and did not report experiencing the interview as stressful – echoing findings in other studies of HIV affected children[45-47].

The African Charter on the Rights and Responsibilities of the Child recognises rights to enjoy the best attainable state of physical, mental and spiritual health and scientific research. The right to life and the right to access to healthcare ranks among the most fundamental of the human rights guaranteed by international human rights[48]. Excluding adolescent children from health research infringes on their constitutional rights to both basic healthcare and access to healthcare services[49].

Recommendations for mental health research with adolescents arising from this study

To promote ethical integrity, the following were implemented and are examples that may be helpful to other studies:

A Community Advisory Board (CAB) that can advise on all aspects of the research, including proposal, protocol, survey, informed consent and a dissemination plan can ensure youth-friendliness and relevance if constituted by adolescents who utilise services. This is effective in addressing complex health disparities and facilitates local acceptability of the research practices.

Research staff need a balance of research, community, and clinical experience. Lay counsellors, with experience in the clinics managing issues of adherence, disclosure, stigma and HIV counselling, and additional training that emphasises adolescent rights, the distinction between researchers and counsellors, modelling interview techniques, with practice sessions on dealing with informed consent processes etc. are recommended. Staff also need weekly debriefing and supervision from a registered therapist.

Consent procedures disclosed that confidentiality might be broken by the mandatory reporting requirements, relating to suspected ill-treatment, abuse or neglect of children (section 42 of the Children's Act[37], section 4 of the Prevention of Family Violence Act, 1993[50] and sexual offences against children (section 54 of the Criminal Law (Sexual Offences and Related Matters) Amendment Act 2007[51]). Study staff need training to identify reporting obligations, and understand and manage the processes triggered.

Researchers must be mindful that there is evidence that adolescents when compared to adults are less likely to spontaneously consider risks and benefits, are less likely to evaluate long-term consequences of decisions, are more likely to place weight on benefit than risk, are more likely to be short-term focused, and are less likely to recognize the vested interests of others[42]. Thus recognition of immature decision-making is necessary and researchers should try to enhance adolescent understanding to the fullest extent possible. To assess understanding, our informed consent contained both multiple choice questions and open ended probing questions.

The latent power dynamic between researchers and adolescent participants must be managed. Contextually obedience to and respect for adults are values strongly emphasised; children seldom speak up or voice their opinions to adults[52]. Time needs to be provided for the adolescents to acquire trust in the researchers and the research process. Research counsellors were able to speak all the local languages, increasing their ability to answer all questions posed and alleviate potential anxiety of the participants.

Authenticity in child participatory research is crucial: without it, the validity of what is reported is inevitably questionable and, at the level of tokenism, it is fundamentally unethical[52]. Research utilising non-verbal methods, such as drawings, can offer research subjects active participation in the research process, authenticating their voice through their engagement, offering more developmentally appropriate means of accessing data, diminishing stress in the child/adolescent-adult interaction and providing a more comfortable method of engagement than language[52-55].

Engaging youth in research can be more easily facilitated with the use of mobile and computer devices, known to be appealing. Data was collected on tablet computers to improve reporting of sensitive questions[56,57].

HRECs reviewing adolescent protocols should consult with one another to facilitate uniformity in response to similar research protocols[42].

Discussion and recommendations

Evidence regarding the mental health of HIV infected adolescents is fundamental to inform policy. In this case study, 27% of HIV positive adolescents accessing treatment were experiencing common mental health problems, previously unrecognised and could be treated in the public health system. But for a court order, this evidence would not have been available. Vulnerable groups, like adolescents, are typically the last to benefit from research, and often need it the most.

Laws, such as the NHA, were developed to safeguard children and in many cases do. Section 71 has the policy objective to protect them. Where the parental consent requirement is inappropriate or impossible it operates to exclude children from research, further increasing their vulnerability and failing its policy objective.

Research ethics legislation is vital and welcomed, but a balance is needed between protection from exploitation and access to benefits of research. Excessive regulation to protect adolescents from exploitative research may impede on their human rights and autonomy as individuals and circumvents research being undertaken to improve access to care and treatment and reform national policy[26]. It is also likely to delay their access to any improvement based on adult research undertaken[58]. Provision should be made for rigorous review by HRECs and promoting clear communication to adolescents rather than restrictions that reduce research participation[29]. The NHA and its regulations ought to take into account the social contexts of South African adolescents. A rights-based approach is necessary in managing these tensions[59]. As Mann (in Kirby, 2004) highlights "health and human rights are complementary approaches to the central problem of advancing human well-being" [48].

The failure to address mental health problems in terms of prevention and treatment, including developmental and intellectual disorders, in childhood and adolescents in low-resource settings, is a public health issue with far reaching consequences. A substantial proportion of adult mental health problems originate early in life, such failure has long-lasting effects beyond childhood and adolescence[59]; and impedes the achievement of basic development goals in LMICs.

A commitment to evidence-based healthcare requires more, not less, effort to encourage research and clear evaluation of services. Service and research entities need to assess whether their services/interventions are helping children/adolescents and how they can be improved. Excluding the most vulnerable adolescents risks biasing the research capacity to assess their needs and services to them.

These findings suggest the importance of considering an amendment to Section 71 of the NHA, in order to facilitate valuable and necessary research concerning HIV infected and orphaned children. A mechanism ought to be introduced to permit research on children where parental or guardians' consent is either not practicable or inappropriate. "Research" ought to be defined. A distinction should be made to cater for HRECs to allow a dispensation from parental consent for classes of research that present minimal risk of harm to child participants and an age threshold introduced for children to give autonomous consent. Further practical examples of how to address the challenges related to this work in diverse contexts are needed, in order to build a consensus on best practices.

Conclusion

Ethical and sound health research is essential to promoting the health of highly vulnerable HIV infected and affected adolescents. If research results are to be targeted to adolescents, it is essential that adolescents be included so study outcomes are relevant to them. Healthcare policy is best improved based on the evidence to meet the mental health needs of this population more effectively.

Requiring parental consent for particular research does not necessarily give effect to policy. For the vast majority of HIV infected adolescents such consent is simply impossible. The result is the most vulnerable are excluded from research that may yield great benefit. Resort to the High Court is practically unworkable and legislative amendment is urgently required.

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CHAPTER 5

Results - Identifying risks for mental health problems in HIV positive adolescents accessing HIV treatment in Johannesburg

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Introduction

Mental health needs of children and adolescents globally do not get the attention and resources required, but are severely underserved in low and middle-income countries (LMICs) (Cortina et al, 2012; Becker & Kleinman, 2013; Gore et al, 2011; Patel et al, 2007; Kieling et al, 2011). Mental disorders account for a large proportion of disease burden and mortality in young people in all societies, but especially so for youth in LMICs as a result of scarce resources and strong associations with social determinants of health, such as poverty, food insecurity, violence, poor access to education and healthcare etc. (Patel et al, 2007). The HIV pandemic has increasingly brought attention to the unmet mental health needs of children and adolescents (Breuer et al, 2011), highlighting the necessity to integrate HIV and mental health care as positive mental health is critical in the management of HIV disease (Mellins & Malee, 2013; Lowenthal et al, 2014; Sherr et al, 2014; Stein et al, 2014).

Children and adolescents make up a significant proportion of the population in LMICs; many of whom are HIV infected. Approximately 2.1 million adolescents in LMICs were living with HIV in 2012, and of the estimated 3.2 million children under the age of 15 years infected with HIV globally, 90% are living in sub-Saharan Africa (WHO, 2013; UNAIDS, 2014). In 2012 it was estimated that there were approximately 369,000 adolescents under the age of 14 years and 720,000 15 to 24 year olds living with HIV in South Africa (Simbayi et al, 2014). In addition, nearly one-sixth of all new HIV infections are among adolescents 15 to 19 years (UNICEF, 2013). As antiretroviral therapy (ART) continues to be scaled up in LMICs to improve morbidity and mortality outcomes associated with HIV infection, prevention of new HIV infections among adolescents is critical (Davies & Pinto, 2015). Increased efforts are required to understand the *global* health needs of this population (including mental health needs) to mitigate and prevent secondary transmission, and manage consequent adult burden of disease as they transition from adolescence.

Although there is a dearth of information on the mental health of HIV positive adolescents in South Africa, major depression is highly prevalent among HIV-positive patients, ranging between 18% and 81% depending on population and methodology of the study (Arseniou et al, 2013). Depression amongst AIDS-orphaned children is significantly higher than among other orphaned children (Kumar et al, 2014). This is also true for PTSD. Cluver (2012) reported that in South Africa, children orphaned by AIDS were 67% more likely to suffer from PTSD than children orphaned by other causes.

Evidence suggests increases in abuse in adolescence (Burton et al, 2015) with rates of violence victimization escalating at home, school and within community settings (Finkelhor et al, 2013; Devries 2016). Local studies reveal prevalence rates of 56.3% for lifetime physical abuse, 35.5% for lifetime emotional abuse and 9% for lifetime sexual abuse in youth (Meinck et al, 2016). Exposure to violence also predicts poor educational outcomes in youth in South Africa (Sherr et al, 2016).

Research indicates that perinatally infected HIV positive adolescents tend to have high levels of common mental health problems (Lowenthal, 2014) and that this has direct negative effects on adherence to ART (Kim et al 2014; Hudelson & Cluver, 2015; Nel & Kagee, 2011), retention in care (Lowenthal, 2014; Agwu & Fairlie, 2013), and high risk sexual behaviors (Mellins et al, 2011; Gadow et al, 2012). These factors lead to risk for secondary transmission. Evidence suggests that mental health in this population is significantly related to exposure to violence (Skeen et al, 2016); levels of connectedness, future orientation and hope (Petersen et al, 2010; Bernays et al, 2007); and disclosure of HIV status (Lowenthal et al, 2014). There have been consistent calls to improve prevention and research efforts regarding adolescent mental health and HIV (Ordonez & Collins, 2015; Mofenson & Cotton, 2013) in attempts to further policy recommendations and strengthen the evidence base of mental health needs of youth in South Africa. Little is known of the mental health of perinatally infected HIV positive adolescents accessing treatment within the healthcare system.

As a consequence of the combined neuropathological effects of HIV and the environmental context, the most common psychiatric disorders found amongst HIV positive adolescents globally and locally are depression, anxiety, suicidality and post-traumatic stress disorder (PTSD) (Lowenthal et al., 2014; Gadow et al, 2012; Cluver et al, 2007, 2009; Thom, 2009; Petersen et al, 2014). This study investigated the common mental health problems evident (depression, anxiety, post traumatic stress disorder (PTSD), suicidality) in perinatally infected adolescents retained in care in Johannesburg.

Methods

Participants and procedures

We assessed the mental health of n=343 HIV positive adolescents accessing five convenience sampled pediatric ARV clinics serving adolescents in Johannesburg. Three clinics were hospital based; one was a community health center and one a primary healthcare clinic. All provided routine care except one hospital based ‘flagship’ clinic that offered specialized pediatric ARV services. All were located in urban settings characterized by poverty, violence and poor infrastructure. Data was collected over a period of eight months. Participants were aged between 13 and 19 years, the majority on treatment for HIV (92%) and most had been attending the clinics since early childhood. Although it was challenging to distinguish source of HIV infection, most had lived with HIV for as long as they remembered and hence were categorized as perinatally infected. Clinic records also categorized these participants as infected perinatally. However, it is possible that a proportion was infected through blood transfusion or rape in childhood and four participants were known to be horizontally infected (1%). Study participants consented to participate in responding to a 90 minute structured questionnaire administered on tablet computers. Research counsellors facilitated the questionnaires, were known to the adolescents and routinely provided direct services to them as clinic counsellors. Trained in pediatric HIV and advanced counselling, these counsellors were willing to participate in the research, engaging in principles of ethical research with minors (Clacherty & Donald, 2007). They received an additional five day training for this study, with an emphasis on distress protocol management and had weekly supervisory debriefing from a registered therapist throughout the course of data collection.

All data collected were identified by a unique participant number and kept in confidential files and tablet computers with no identifying information. Confidentiality was maintained unless participants reported abuse or were at risk of significant harm. Where prior abuse or rape had occurred (n=4), referrals were made to support and counselling services. Where there was active suicidality (n=17), participants were screened out of the study with referrals made for immediate care.

Participants were given a pocket sized card with referrals for services in their neighbourhood including counselling, legal and crisis resources. Upon completion of the interview, participants received reimbursement for travel; a snack; and a gift voucher for R50 ($4) at a clothing retailer. These items were endorsed and recommended by the adolescent community advisory board (CAB) instituted for this research.

Ethical consideration

The South African National Health Act states that ‘for health research with minors (<18 year olds), consent from a legal parent or guardian for research with children must be obtained’ (Section 71, 2012). This sample was speculated to not have “legal” guardians from whom to obtain consent, it being well known that perinatally infected adolescents are frequently orphaned and in the care of extended family members who are seldom legal guardians. As such, the medical research ethics committee of the University of the Witwatersrand advised obtaining a court order which was granted and led to full ethics clearance and permission to interview volunteers without parental or guardian consent (M130258). Permission was also granted from Gauteng Provincial Department of Health, Johannesburg District Department of Health, and the research committees of facilities. Adolescents gave verbal assent and written consent to participate in the research, and all participation was sought on the basis of good clinical practice guidelines (Verma, 2013).

Measures

Sociodemographic information

Items were derived from the South African census and included age, gender, ethnicity, household composition, formal/informal housing, highest school grade achieved, and orphanhood status.

Mental health measures

Mental health was measured using standardized scales utilized previously with youth in South Africa (Cluver et al, 2012). Depression was measured with the 10-item Child Depression Inventory Short Form (Kovacs, 1992), highly correlated with the full scale (r 0.89; Kovacs, 1992); α=.70. Anxiety was measured using an abbreviated version of the 28-item Revised Children's Manifest Anxiety Scale (Reynolds & Paget, 1983), which has been validated for use in South Africa (Boyes & Cluver, 2012); α=.75. Posttraumatic stress symptoms were measured using the Child PTSD Checklist (Amaya-Jackson, 1995) that has been validated in South Africa (Boyes et al, 2012); α=.89. Suicidal behavior was measured with the MINI International Psychiatric Interview for children and adolescents suicide scale (Sheehan et al, 2004). This scale is well validated, showing strong internal consistency and test-retest reliability (Lecrubier et al, 1997); α=.75.

Western-validated clinical scores must be interpreted with caution, and to date no clinical cut-offs have been validated in Africa. Resultantly a symptomatic group was identified as adolescents who experienced >50% of the symptoms on any of the depression, anxiety or PTSD scales. These methods, although imperfect, have been used in Africa to measure symptomatology with scales validated in other contexts. Murray et al (2015) used a PTSD measure in Zambia and to maximize sensitivity implemented that a response of 1 or more per item would be indicative of symptoms appropriate for trauma focused cognitive behavior therapy. Similarly Seedat et al (2004) in South Africa utilized a PTSD measure and used a conservative threshold score of 2 ('most of the time') to endorse the presence of a symptom. Although our scoring method identified a lower threshold than cut-off scoring, it was more likely to capture those participants possibly at risk.

Hypothesized intervening variables were identified by literature review as linked to HIV/AIDS and/or child outcomes and are summarized in table 8

Table 8. Hypothesized intervening variables

Variable	Measurement	Description of assessment	Reference
Poverty	South African National Food Consumption Survey	• past-week hunger at the child level • past-week insufficient food at the household level • lack of any employment in the household	Labadarios et al., 2003
Child abuse	UNICEF scales for sub-Saharan Africa	• physical abuse was described as beating with an object or deliberate harm • emotional abuse was exposure to verbal abuse • sexual abuse was unwanted genital contact or rape • exposure to domestic conflict was verbal and physical violence between adults in the household and whether the adolescent felt safe at home	Snider & Dawes, 2006
Community violence	Child Exposure to Community Violence Checklist	• adapted to reflect most common community traumas for children in South Africa, as identified by national police statistics (SAPS 2005): assault, robbery and witnessing of stabbings and shootings	Richters & Martinez, 1993
Bullying	Peer Victimization Scale	• items include: being called names, being hit or threatened and having possessions broken or stolen	Mynard & Joseph, 2000
Sexual health risk	National Survey of HIV and Risk Behaviour amongst Young South Africans and the South African Demographic and Health Survey	• checklist of items	Pettifor et al., 2003 Department of Health & Medical Research Council, 2007
Future outlook		• do you have a dream for yourself and your future? • do you feel you can control your future?	

Analysis strategy

Data were analysed using Statistica v13. Descriptive and bivariate analyses were conducted to examine the distribution of all variables at each time point and assess relationships between variables. Descriptive analyses were run on all variables. Normality was assessed using Kolmogorov-Smirnov and the Shapiro-Wild tests and histograms generated for graphical confirmation. Pearson's *r* was used to measure the correlation between continuous variables such as age, number of losses experienced, years knowing status and PTSD scores. T-tests were used to compare differences between groups, such as gender, violence exposure, feeling of belonging and control for the future in relation to the mental health outcomes assessed. Chi-squared tests were used to determine statistically significant differences in responses to categorical variables, such as gender, suicidality and exposure to violence. Relative risks and 95% confidence intervals were calculated using Altman's formula (Altman, 1991) to understand if a group was more at risk than another in relation to mental health outcomes. All analyses were used to facilitate identification of at-risk groups.

Table 9. Sociodemographics

Table 9: Descriptive statistics of sample (n=343)

Characteristics	Number or median	Percentage or IQR*
Sociodemographics		
Age	16 years	(12-19)
Female	181	(52%)
Grade	10	(23%)
Attending school	336	(98%)
Orphaned	243	(73%)
Home: house, brick, concrete	262	(76%)
Cellphone	318	(92%)
Home life characteristics		
Look after younger children	127	(37%)
Look after sick	184	(53%)
Feel don't belong in family	305	(89%)
Don't get praise at home	309	(90%)
Violence-related characteristics		
Peer victimization outside school	169	(49%)
Peer victimization in school	240	(70%)
Seen someone shot	57	(17%)
Seen someone stabbed	96	(28%)
Inappropriately touched	53	(15%)
Mental health characteristics		
Significant bereavement*	279	(82%)
Suicidality	81	(24%)
Depression	49	(14%)
Anxiety	84	(25%)
Experienced traumatic event	164	(49%)
Post traumatic stress disorder (PTSD)	16	(5%)
Symtpomatic*	93	(27%)
HIV-related characteristics		
Know HIV status	304	(89%)
Know how contracted HIV	174	(51%)
Taking ARVs*	301	(88%)
Disclosed status to others	91	(27%)

*IQR: interquartile range; Sig bereavement: parent, sibling, primary caregiver; Symptomatic: depression, anxiety and/or PTSD; ARVs: Antiretroviral Treatment

The mean age of participants was 16 years, and 52% were female. The majority was orphaned (73%; 32% double orphans) and living either with extended family members (285 participants, 83%) or in children’s homes (5 participants, 1.5%). Eighty nine percent of participants reported they did not feel they belonged in the family they were being raised in, 90% reported that they did not get praise from those they live with, and 85% reported they did not get the same things as other children in the home. Of those who reportedly knew their status (89%), mean age of disclosure was 12 years. Although they had been disclosed to, only 51% reportedly knew how they contracted HIV.

Around one third (27%) of the sample was symptomatic for depression, anxiety or PTSD; 24% of the sample indicated signs of suicidality answering yes to questions such as: *in the past month did you wish you were dead? Did you want to hurt yourself? Did you think of killing yourself? Did you think of a way to kill yourself?* Seventeen participants (5%) reported attempting suicide in the past month.

Table 10. Significant variables in relation to Depression, Anxiety, and PTSD

Variable	**Depression**		**Anxiety**		**PTSD**	
Pearson's	Correlation	p	Correlation	p	Correlation	p
Grade	-0,05	0,33	-0,07	0,24	0,11	0,05*
Age	0,01	0,80	0,01	0,83	0,11	0,05*
Days Hungry	0,35	0,00**	0,26	0,00**	0,18	0,00**
Highest Grade	-0,04	0,47	0,06	0,28	0,13	0,016*
Depression Score	-	-	0,61	0,00**	0,52	0,00**
Anxiety Score	0,61	0,00**	-	-	0,54	0,00**
Peer Violence Score	0,32	0,00**	0,39	0,00**	0,38	0,00**
Number of losses	-0,01	0,80	0,04	0,51	0,12	0,03*
PTSD Score	0,52	0,00**	0,54	0,00**	-	-
T-tests	Mean	p	Mean	p	Mean	p
Gender						
f	3,31	0,00**	4,76	0,01*	19,45	0,00**
m	2,39		3,86		14,36	
Look After Sick						
yes	2,57	0,04*	4,36	0,81	16,36	0,32
no	3,25		4,28		17,70	
Feel Belong						
yes	5,71	0,00**	6,49	0,00**	23,85	0,00**
no	2,53		4,03		16,10	
Gets Praise						
yes	4,53	0,00**	5,17	0,10	22,07	0,01*
no	2,69		4,22		16,44	
Get Same Things						
yes	5,07	0,00**	5,51	0,01*	22,17	0,00**
no	2,55		4,22		16,49	
Suicidality						
yes	4,73	0,00**	6,24	0,00**	23,23	0,00**
no	2,27		3,77		15,25	
Peer Violence Inside and Outside of School						
yes	3,20	0,01*	4,74	0,02*	20,35	0,00**
no	2,38		3,97		14,58	
Experienced Violence – Inappropriate Touch						
yes	3,70	0,01*	5,51	0,00**	22,58	0,00**
no	2,53		4,05		15,90	
Experienced Violence – Been Hit						
yes	3,63	0,00**	5,52	0,00**	21,98	0,00**
no	2,49		3,99		15,77	
Experienced Violence – Feel Safe at Home	2,54	0,00**	4,13	0,00**	16,29	0,00**

Variable	Depression		Anxiety		PTSD	
yes	5,67		6,94		28,94	
no						
Know their Status						
yes	2,61	0,00**	4,16	0,00**	16,59	0,02*
no	4,41		6,09		22,50	
Control Future						
yes	2,53	0,00**	4,04	0,00**	16,35	0,00**
no	5,15		7,15		29,08	
Have Dream						
yes	2,58	0,00**	4,19	0,01*	16,37	0,00**
no	6,00		6,46		30,77	

*p<0,05
**p<0,005

Table 10 indicates significant variables related to depression, anxiety and PTSD. Days hungry was significantly correlated to all mental health problems. Results show high rates of comorbidity amongst depression, anxiety and PTSD. Females scored significantly higher for depression (p<.001), anxiety (p<.01), and PTSD (p<.001) than males. Those reporting suicidality also reported significantly higher on all three mental health scales suggesting that suicidal individuals are more likely to present with higher levels of depression (p<.001), anxiety (p<.001) and PTSD (p<.001). Experiencing peer violence inside and outside of school, being inappropriately touched, being hit, and not feeling safe at home, all resulted in significantly higher depression, anxiety, and PTSD. Knowing one’s status was protective in terms of mental health with lower scores for depression (p<.001), anxiety (p<.001) and PTSD (p<.05). Participants who reported being able to control their future and have dreams for their future were significantly less symptomatic compared to those who did not report this.

Table 11. Significant results for symptomatic group

Variable	Symptomatic for Depression, Anxiety, or PTSD	Not Symptomatic for Depression, Anxiety, or PTSD	p value
T-test	Mean	Mean	p
Age	15,6	15,8	0,48
Days Hungry	0,48	0,18	0,00**
Depression Score	5,57	1,57	0,00**
Anxiety Score	7,92	2,81	0,00**
Peer Violence Score	8,70	5,24	0,00**
Number of losses	1,13	1,00	0,18
Years since loss	6,73	6,72	0,97
PTSD Score	26,18	13,22	0,00**
Years knowing status	4,42	4,34	0,85
Number of grants	1,16	1,02	0,20
Chi-Square X^2	% and n	% and n	p
Female	60% (56)	48% (111)	0,05
Look after younger children in home	43% (38)	38% (82)	0,46
Look after a sick people in home	51% (47)	57% (130)	0,35
Feel that they belong	21% (19)	6% (14)	0,00**
Get praise	12% (11)	8% (18)	0,24
Someone in their home has a job	26% (24)	22% (51)	0,42

Variable	Symptomatic for Depression, Anxiety, or PTSD	Not Symptomatic for Depression, Anxiety, or PTSD	p value
Get the same things	21% (19)	10% (22)	0,01*
Wish they were dead	20% (19)	6% (13)	0,00**
Want to hurt self	14% (13)	6% (13)	0,02*
Think about killing self	20% (19)	10% (22)	0,01*
Think about a way of killing self	14% (13)	5% (11)	0,00**
Try to kill self	10% (9)	2% (5)	0,00**
Any suicidality	37% (34)	16% (36)	0,00**
Has had sex	19% (18)	20% (45)	0,98
Peer Victimisation inside of School	79% (73)	71% (164)	0,17
Peer Victimisation outside of School	63% (59)	47% (108)	0,01*
Peer Victimisation inside and outside of school	52% (48)	38% (87)	0,02*
Been sick this year	46% (43)	33% (76)	0,02*
Been inappropriately touched	28% (26)	12% (27)	0,00**
Been hit or attacked	33% (31)	14% (33)	0,00**
Been hit at home	58% (18)	36% (12)	0,08
Seen someone shot	15% (14)	18% (42)	0,50
Seen someone stabbed	29% (27)	71% (163)	0,94
Been treated badly because someone in family is sick	17% (16)	9% (21)	0,04*
Has lost someone close	79% (73)	81% (187)	0,62
Has not talked about loss	57% (53)	55% (128)	0,80
Have a safe place for adolescents in the community	44% (41)	70% (161)	0,00**
Know how they become HIV Positive	54% (45)	58% (127)	0,55
Has had TB	37% (31)	45% (98)	0,25
Has been hospitalised	68% (56)	65% (142)	0,67
Has disclosed status	36% (30)	28% (61)	0,16
Receive no grants	16% (15)	16% (36)	0,91

*p<0,05
**p<0,005

In an attempt to understand the symptomatic group within the larger sample, analysis was conducted comparing the symptomatic to the non-symptomatic group. Results are highlighted in table 11 on a range of significant variables. Experiencing hunger (p<.001) and peer violence (p<.001) were significantly related to being symptomatic. Significantly higher number of those in the symptomatic group (63%) than those in the other (47%) experienced peer victimization both in and outside of school (p<.05). High levels of exposure to violence were present with 16% reportedly seeing someone shot and 28% reportedly seeing someone stabbed.

Those in the symptomatic group were significantly more likely to report having been sick in the past year as opposed to the non-symptomatic group (46% vs 33% respectively, p=.02). Being treated badly as a result of someone being sick in the home was reported by a significantly higher portion of those in the symptomatic group than those in the non-symptomatic group (17% vs 9% respectively, p=.04).

Table 12. Relative risk of being symptomatic

Variable	**Are this times more likely to become symptomatic for Depression**		**Are this times more likely to become symptomatic for Anxiety**		**Are this times more likely to become symptomatic for PTSD**		**Are this times more likely to become symptomatic for any**	
	Relative Risk	**p**	**Relative Risk**	**p**	**Relative Risk**	**p**	**Relative Risk**	**p**
Are female	1,69	0, 06	1,38	0, 09	2,06	0,17	1,42	0,05
Been hit	1,97	0,02*	2,00	0,00	1,85	0,24	2,03	0,00
Been inappropriately touched	2,22	0,01**	1,77	0,00**	3,08	0,02*	1,98	0,00
Do not feel like they control their future	2,55	0,04*	2,75	0,00**	8,11	0,00**	2,37	0,00**
Do not feel safe at home	5,17	0,00**	2,92	0,00**	3,94	0,02*	2,76	0,00**
Do not have a dream	4,62	0,00**	2,25	0,00**	7,92	0,00**	2,57	0,00**
Do not have a safe place in the community for adolescents	2,31	0,00**	2,02	0,00**	3,66	0,01*	2,10	0,00**
Experienced forced sex	3,55	0,02*	3,01	0,01*	2,38	0,40	1,90	0,17
Experienced peer violence at school					2,56	0,21	1,34	0,18
Experienced peer violence outside of school	2,16	0,01*	1,62	0,02*	2,80	0,07	1,63	0,01**
Experienced peer violence at school and outside	1,77	0,04	1,34	0,13	4,17	0,01*	1,49	0,02*
Report any form of suicidality	3,44	0,00**	2,35	0,01**	3,58	0,01**	2,09	0,00**
Think about a way to kill themselves	3,54	0,00**	2,23	0,00**	4,18	0,01**	2,03	0,00**
Think about killing themselves	3,22	0,00**	1,95	0,00**	5,39	0,00**	1,77	0,00**
Try to kill themselves	3,76	0,00**	2,52	0,00**	3,17	0,10	2,37	0,00**
Want to hurt themselves	2,74	0,00**	1,97	0,00**	3,54	0,02*	1,79	0,01**
Wish they were dead	3,71	0,00**	2,54	0,00**	2,11	0,22	2,34	0,00**

*p<0,05
**p<0,005

Table 12 indicates the unadjusted relative risk of being symptomatic for 4 categories: depression, anxiety, PTSD or any of the 3 diagnoses. Being inappropriately touched increased the risk for being symptomatic for depression (RR=2.22, p=.01, 95% CI), PTSD (RR=3.08, p=.02, 95% CI), and anxiety (RR=1.77, p=.00, 95% CI). Experiencing forced sex led to a significantly higher relative risk of experiencing depression (RR=3.55, p=.02, 95% CI), anxiety (RR=3.01, p=.01, 95% CI), and PTSD (RR=2.38, p=.04, 95% CI). Experiencing peer violence at school increased the risk of experiencing PTSD (RR=2.56, p=.21, 95% CI) but not depression or anxiety. However, experiencing peer violence outside of school increased the risk of experiencing depression (RR=2.16, p=.01, 95% CI), anxiety (RR=1.62, p=.02, 95% CI) and PTSD (RR=2.80, p=.07, 95% CI). There was a quantitative difference in the experience of violence in and out of school.

Those that did not feel safe at home showed a significantly higher risk of all three mental health disorders – depression (RR=5.17, p=.00); anxiety (RR=2.92, p=.00); and PTSD (RR=3.94, p=.02) all 95% CI. This was similar (depression RR=2.31, p=.00; anxiety RR=2.02, p=.00; PTSD RR=3.66, p=.01 all 95% CI) for those who reported that there was no safe place in the community for adolescents.

Discussion

This study described the mental health (depression, anxiety, PTSD, suicidality) of HIV positive adolescents accessing care in Johannesburg, finding approximately a third (27%) of these participants symptomatic for any of these mental health disorders over the threshold. Our findings indicate being HIV positive may be an important predictor of mental health problems in this population. This is a ‘non-clinical’ sample, i.e. they are not accessing healthcare for mental health, but rather HIV care and treatment. Broadening the scope of intervention the health facility could be offering to curb the comorbid mental health problems of youth is warranted. Our study recommends that policy and public health practice integrate HIV and mental health care for young people.

Suicidality and suicidal ideation was high in this population (24% in the sample with 5% screened out at the start). This is not surprising as suicide is a major risk factor in adolescence both nationally and internationally. South African suicide rates range from 11.5 per 100 000 to 25 per 100 000 of the population; and on average 9.5% of non-natural deaths in young people are due to suicide (Schlebusch, 2012). Cluver et al (2015) have shown that suicide rates tend to increase among South African adolescents, as their exposure to adverse childhood events (e.g. parental death by AIDS or homicide, abuse, and exposure to community violence) accumulate. It is unclear what the attribution of orphan status and HIV diagnosis are to outcomes of suicidality, but these are arguably additional adverse childhood events that further the risk of suicidality. Of concern is that most of the adolescents in this sample had not been asked about suicide before. Screening in such a high risk group seems necessary and a missed opportunity in linking them to appropriate care.

Evidence suggests that violence exposure is also related to suicidal behavior (Sorsdahl et al, 2011). The experience of violence, both directly and indirectly, at school, in the home and community had significant implications for mental health in this sample. Exposure to violence was strongly related to PTSD, but also to anxiety and depression to a lesser degree. Peer victimization in and outside of school was powerfully associated with poor mental health outcomes indicating the need to address violence not only at community but at school level and especially amongst adolescent peers. Most violence prevention efforts do not take into account levels of violence experienced by youth at school or amongst peers (Devries, 2016; Thumann et al, 2016; Gevers et al, 2012; Choe et al, 2012) and this exposure has consequent negative effects on mental health. There are recent evidence based interventions that show promise to reduce violence at school (Devries et al, 2015) and parenting interventions that reduce violence in the home (Cluver et al, 2016; Knerr et al, 2013; Cooper et al, 2009). Reducing community violence remains a challenge, but one that requires continued research and attempts to solve.

Findings suggest the need for increased stigma reduction at the adolescent level related to ill health, particularly HIV. Poor relationships with peers, feelings of lack of security, and negative life events may increase the risk of mental disorders in adolescents (Cheng et al, 2014). Unfortunately, although violence is an important risk factor for adverse mental health (Seedat et al, 2009), it is rarely screened for in young people who require protection. Most mental health research describing HIV positive patients tends to focus on depression and anxiety (Arseniou et al, 2013; Gutierrez et al, 2013); this research highlights the need to manage PTSD equally. In addition, gender was strongly linked to poorer mental health outcomes in this sample, indicating a gendered screening approach is likely to identify those most at risk.

Although 78% of our sample reported having been disclosed to, just 50% knew how they became infected, and only 23% reported to disclosing their status to someone else. Adolescents need more reliable and comprehensive information regarding vertical transmission. Early and full disclosure (i.e. disclosure as a process over time) is strongly associated with improved adherence amongst ART-initiated adolescents (Cluver et al, 2015; Vas et al 2010). Adolescents who have been told their HIV status and understand their diagnosis are significantly less anxious than those who haven’t and those that know their status for longer report higher intentions to self-disclose to potential sex partners (Santamaria et al, 2011). Disclosure may be an essential tool in improving adolescent adherence and reducing mortality and onwards transmission. Our study also suggests that disclosure is protective against mental health problems in adolescence; a compelling reason to support both families and healthcare providers to engage in disclosure with youth in their care (Santamaria et al, 2011; Kidia et al, 2014; Cluver et al, 2015). Empowered young patients who know their status and have improved agency as a result of it (Kidia, 2014), may more easily be able to think about their future and dream into it. These elements were found to be protective against mental health problems.

Almost 90% of this sample revealed they did not feel they belonged in the family they were being raised in. Ninety percent reported that they did not get praise from those they live with, and 85% reported they did not get the same things as other children in the home. Given that these adolescents are being raised outside of their nuclear families, and live in environments characterized by high levels of migrancy, urban poverty, violence, and lack of family structure, these factors all exacerbate the burden of being infected. Emotional bonds to those taking care of them appear to be tenuous. In addition, adolescents who did not feel safe in their homes or communities showed higher mental health problems, indicating the need for increased social protection of this vulnerable population and recognition of this link to mental health problems.

Implications for practice:

Adolescence is a time for transformation of the adolescent-caregiver relationship; as adolescents establish relationships with peers and significant others outside the family, they expand their repertoire of coping skills and resources (Mutumba et al, 2016). Local research indicates that perceived support both from peers (Cluver et al, 2009) and from caring adults (Cheng et al, 2014) has significant positive effects on adolescent mental health. Therefore, healthcare personnel are well placed to have a positive and perceptibly supportive impact on young people who access them regularly. Although the physical environment presents many challenges and risks for adolescents living with HIV, the health system could be utilized to counter these effects through safe and reliable relationships. In addition, support groups at facility level hold promise in curbing mental health problems in HIV positive adolescents (Mupambireyi et al, 2014; Cheng et al, 2014).

There are some critical indicators of mental health risk that could be incorporated into screening for adolescents at primary healthcare level. These include assessing if patients are hungry and whether they have been sick or hospitalized in the last year. There was a high probability that adolescents would be struggling with mental health problems if they did not feel they controlled their future or if they did not have a dream for the future. These questions could easily be asked in patient care and could lead to screening and referral for high risk patients.

Interventions to meet the mental health challenges of HIV infected young people are gaining traction with varying success, in neighbouring African countries (Mavhu et al, 2013; Strasser & Gibbons, 2014) and locally (Bhana et al, 2014). However, the variations in risk factors for this population underscores the need for a nuanced life course approach (Cluver et al, 2012), recognizing that young people are a population in transition. Dynamic and flexible interventions that seek to identify and address emerging threats and opportunities are required (Mutumba et al, 2016).

There are considerable challenges to implementing mental health interventions at public healthcare level that need to be thoroughly addressed for optimum impact. These include lack of skilled mental health professionals available to intervene and the need to utilize and upskill lay counselors to meet the demand ethically with targeted training and consistent expert supervision (Patel et al, 2011; Petersen et al, 2011; Breuer et al, 2011; Ventevogel, 2014; Mendenhall et al, 2014). Screening for mental health can lead to increased access to treatment but it is necessary to invest in screening instruments with high specificity, validity and reliability; that are short and can be administered easily in multiple languages (Kagee et al, 2013).

These findings should be interpreted within the limitations of the study. Participants were recruited from healthcare facilities in an urban setting that was convenience sampled so findings may not be generalizable to adolescents in other contexts. Also, most adolescents do not typically receive this suitable a level of care, so problems are likely to be worse than in the population sampled. The study used self-report instruments susceptible to reporting bias and there may have been underreporting due to social desirability bias or stigma. However, tablet computers were utilized which have been shown to reduce reporting bias on sensitive questions (Gorbach et al., 2013; Jaspan et al., 2007; Toska, 2015). All psychological measures should be interpreted with caution in different cultures. There is a need for standardized scores and instruments for this context as the current instruments may not be capturing the full range of symptoms. There was no comparison group of HIV negative adolescents to assess the role of HIV in mental health problems. There is currently no precise test to determine perinatal infection, especially in resource poor settings where accurate clinical records are a challenge to obtain, so symptoms, time of first hospitalization and timing of ART initiation are used as guides (Ferrand et al, 2009). Resultantly, some adolescents assumed to be perinatally infected in this study may not have been. Despite these limitations, our findings have several important clinical and policy implications. They highlight that young people accessing treatment are at risk for common mental health problems that are largely unrecognized and untreated and could be addressed within the health system.

Conclusion

Our findings underscore the need to improve efforts to identify and reduce mental health problems in adolescents accessing treatment for HIV in public health settings. This sample was not deemed 'hard to reach' a term often associated with adolescent patients. Patients generally accessed care at least once every 3 months and were 'captive' in terms of the ability to influence their health outcomes. Not addressing the mental health concerns latent within the population speaks to gross missed opportunity. Not only in terms of impacting their current mental health and consequent benefits to their HIV care, but also in terms of curbing the poor adult outcomes likely to present later in more extreme forms as a result of untreated and unprevented early onset in adolescence (Das-Munshi et al, 2016; Patton et al, 2014). Promoting support, violence protection and access to mental health interventions at facility level could have positive effects on mitigating risk in a vulnerable population. Policies that recognize this and support training for healthcare workers would strengthen the overall health of patients and maximize the value of the healthcare system in protecting young people in South Africa.

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CHAPTER 6

Results - Reticence in disclosure of HIV infection and reasons for bereavement: impact on perinatally infected adolescents' mental health and understanding of HIV treatment and prevention in Johannesburg, South Africa

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Introduction

Due to dramatic improvements in access to antiretroviral therapy (ART), children born with perinatal HIV infection are growing into adolescence in large numbers, especially in low and middle income countries (LMICs) (Ferrand et al, 2009; Idele et al, 2014). Adolescents are typically defined as 10-19 yr olds (WHO, 2014). Approximately 2.1 million adolescents in LMICs were living with HIV in 2012, and of the approximately 3.2 million children under the age of 15 years infected with HIV globally, 90% are living in sub-Saharan Africa (WHO, 2013; UNAIDS, 2014). Thus, adolescents are considered a key population contextually for HIV prevention, care and treatment (UNAIDS, 2011) as their engagement is critical to a successful and meaningful HIV response.

Vertical transmission rates have reduced to less than 3% nationally in South Africa (Goga et al, 2012), however, the prevention of mother-to-child HIV transmission (PMTCT) programmes were only rolled out in the public health sector around 2004 (Meyers et al, 2007) impacting on the current population of HIV positive children and adolescents. In 2012 it was estimated that there were approximately 369,000 0-14 year old children and adolescents and 720,000 15-24 year olds living with HIV (Shisana et al, 2014). It is unclear how many perinatally infected HIV-positive adolescents (PIA) are on treatment and engaged in care. There is currently no precise way to determine perinatal infection, especially in resource poor settings where accurate clinical records are a challenge to obtain, so symptoms and time of first hospitalization are used as guides (Ferrand et al, 2009).

Adolescence is a period of profound physical, cognitive and psychological development but PIA have a host of additional issues to manage. For many, their childhoods have been characterized by frequent illness, hospitalizations, multiple losses, and poor school attendance (Mavhu et al, 2013). Identity formation, accepting their HIV status and the influence of stigma can be difficult to manage (Mutumba et al, 2015). Issues of disclosure both to those infected and then later to friends and partners are daunting (Vaz et al, 2010; Pinzon-Iregui et al, 2013); and many encounter challenges with mental health (Gadow et al, 2012; Mavhu et al, 2013; Mellins & Malee, 2013; Bernays et al, 2014; Lowenthal et al, 2014), often as a consequence of being orphaned (Cluver et al, 2012).

Many adolescents, especially orphans, are faced with the major undertaking of bereavement which is a risk to mental health. Much like the process of physical recovery after injury, there is evidence to suggest that the grieving process consists of a series of tasks that one must work through before fully adjusting to the loss (Li et al, 2008) and include: accepting the reality and fully experiencing the emotional distress of the loss; adjusting to one's environment and sense of self without the loved one; finding meaning in the loved one's death; and becoming engaged with other adults who can provide ongoing comfort, security and nurturance (Mannarino & Cohen, 2011). Research suggests that if these tasks are not successfully completed, individuals will suffer complicated grief which includes (1) a sense of disbelief regarding the death; (2) anger and bitterness over the death; (3) recurrent pangs of painful emotions with intense yearning and longing for the deceased; and (4) preoccupation with thoughts of the loved one, often including distressing intrusive thoughts related to the death (Shear et al, 2005). Those who suffer complicated grief are 'stuck' in their grieving and experience difficulty integrating the event in their lives. This is accentuated in South Africa, where there is a culture of silence experienced by children and adolescents, who are not encouraged to ask questions and adults rarely explain what has happened and why (Wood et al, 2006). PIA have to negotiate the complex demands of treatment, social pressures, and vulnerable health within the context of bereavement and disrupted care, without having necessarily developed the skills to manage these circumstances and without community support to enable speedier recovery (Bernays et al, 2014).

It is important not to underestimate the potential psychological effects of the awareness of their own HIV status on their wellbeing, which is reinforced through taking daily treatment and witnessing HIV-related deaths within the household – a daily reminder of their own infection and a potential trigger for mental health challenges (Bernays et al, 2014). In addition, it is probable that at the time of diagnosis for these adolescents, they were likely considered terminal (Small et al, 2014) and consequently, they may have feared their own death growing up. Little is known about how bereavement impacts on HIV positive adolescents' worldview, their beliefs regarding their own HIV infection, and access to HIV prevention options in the public health sector.

Disclosure of one's HIV status, both to others and how the status has been disclosed to oneself, is affected by these life events and most studies reveal that the majority of HIV-infected children and adolescents in resource-limited settings are unaware of their HIV status (Vreeman et al, 2013) despite the positive consequences of HIV disclosure including: improved identity formation; adherence to treatment; and retention in HIV care (Santamaria et al, 2011; Kidia et al, 2014; Cluver et al, 2015). If disclosure doesn't occur spontaneously between family members, it is reportedly undertaken via two alternate routes: hospitalization for serious illness with subsequent HIV testing and consequent disclosure, or, for those on treatment for years, a deliberate request from the child/adolescent to understand their diagnosis as a result of regular clinic visits and the ongoing need for treatment adherence. Those hospitalized for serious illness tend to be slow progressors (sometimes defined as having no progression of disease in the first ten years of life or CD4 cell percentages at or above 25% at 10 years (Ofori-Mante et al, 2007), or as median survival of 12 to 13 years (Ferrand et al, 2009). Depending on the definition, 3-25% of all children can be defined as slow progressors (Warszawski et al, 2007; Ferrand et al, 2009). Disclosure is increasingly understood not as a single event, but as a complex and dynamic process over time where accurate information regarding HIV acquisition is communicated and understood; also named complete disclosure (Cluver et al, 2015). Little is known about how children or adolescents' disclosure (or lack of it) has impacted on their understanding of HIV infection, the emotional process of coming to terms with their HIV status, the challenges of becoming resilient, and their view of their own reproductive future.

We examined the perceptions of PIA attending clinics in Johannesburg with respect to their own infection, how they were disclosed to and their mental health state using qualitative research methodology. These adolescents were known to be retained in care for many years, knew their HIV status, and were expected to be treatment literate and 'resilient' by the research counsellors who were engaged in their care.

Methods

Participants and procedures

Study participants were recruited from paediatric antiretroviral (ARV) clinics in Johannesburg; three were hospital based; one was a community health centre and one a primary healthcare clinic. Staff in these clinics served HIV infected children and adolescent patients and their caregivers. Counsellors were employed at all facilities to offer routine HIV counselling and testing, adherence and disclosure counselling. Research counsellors, who routinely provided direct services to the adolescents as counsellors and were trained in paediatric HIV and advanced counselling, participated willingly in the research, engaging in principles of ethical research with minors (Clacherty & Donald, 2007). Research counsellors received an additional 5-day training for this study, with an emphasis on distress protocol management (i.e. managing suicidality, reported abuse, rape or violence), as well as weekly debriefing and supervision from a registered therapist throughout the course of data collection.

All adolescents were on treatment for HIV and most had been attending clinics for many years. Most participants were found to be infected at birth and had all lived with HIV for as long as they remembered, but there may be a small proportion that were infected through blood transfusion or rape in early childhood, although there is little data documenting this. This qualitative study was linked to a quantitative study (n=343) that utilised a 90 minute structured questionnaire and will be reported elsewhere. Participants for the qualitative study were recruited purposively by a research counsellor familiar to the adolescent. Recruitment was based on consent and willingness to engage in in-depth interviews. Research counsellors who administered the questionnaire identified study participants, who scored moderate to low on standard mental health measures (for depression, anxiety, post traumatic stress disorder and suicidality) whilst they also reported significant difficult life experiences, for the qualitative study. These adolescents were chosen because their resilience was being investigated, i.e. their reported difficulties and adverse life experiences did not seem to be impacting negatively on their mental health functioning.

Twenty-five adolescents aged 13-19 years (mean 16 years; 15 female) were interviewed for 60 minutes by the principal researcher using a semi-structured interview guide when they visited the clinic for their regular appointment. The interviews were recorded with participant consent and conducted in English as all participants spoke English comfortably.

Table 13. Descriptive information on HIV positive adolescents

Name (pseudonyms)	Gender	Age	Disclosed to?	Know how became infected?	Orphan status	Living arrangement
Jabulile	F	15	Yes	No	Double	Grandmother
Jafta	M	18	Yes	Yes	Double	Children's home
Banele	M	18	Yes	No	Double	Grandmother
Lindakuhle	F	16	Yes	No	Double	Foster home
Nobuhle	F	19	Yes	Yes	Double	Aunt
Buhle	F	15	Yes	No	Single	Grandmother (biological father alive no relationship)
Thabisile	F	17	Yes	Yes	Double	Grandmother
Sindiswa	F	16	Yes	No	Single	Biological father and stepmother
Phindile	F	16	Yes	No	Double	Aunt
Zodwa	F	18	Yes	Yes	Non	Biological mother (biological father alive no relationship)
Lesedi	M	13	Yes	Yes	Double	Great grandmother
Tebogo	F	18	Yes	Yes	Single	Biological mother
Tshepo	M	18	Yes	Yes	Non	Biological mother (biological father alive no relationship)
Sithembile	M	18	Yes	No	Double	Grandmother
Nomphumelelo	F	17	Yes	No	Double	Grandmother
Ntokoza	M	13	Yes	No	Double	Grandmother
Palesa	F	14	Yes	Yes	Single	Grandmother (biological mother alive poor relationship)
Sharon	F	18	Yes	Yes	Non	Biological mother (biological father alive poor relationship)
Mahlatsi	M	17	Yes	No	Single	Biological mother
Siphomandla	M	16	Yes	Yes	Double	Children's home
Ntombi	F	14	Yes	No	Single	Biological mother
Nthuli	F	18	Yes	Yes	Double	Aunt
Mathi	F	18	Yes	Yes	Double	Grandmother
Bongani	M	18	Yes	No	Single	Biological father
Siphiwe	M	18	Yes	No	Non	Bio mother (bio father alive no relationship)

Participants were given a pocket sized card with active referrals for services in their neighbourhood including counselling, legal and crisis resources; reimbursement for travel; a snack; and a gift voucher for R50 ($3) at a clothing retailer for each interview they attended. These items were recommended by the adolescent community advisory board (CAB) instituted for this research.

Ethical consideration

As it was likely that many of the potential participants aged <18 years would not have “legal” guardians from whom to obtain consent, a court order was sought for this research as a result of the National Health Act, section 71 which came into effect 1st March 2012 regulating that ‘for health research with minors (<18 year olds) consent from a legal parent or guardian for research with children be obtained'. The University of the Witwatersrand human research and ethics committee advised approaching the court for permission. Permission to conduct the study was granted in July 2013 with ethical clearance given to interview volunteers without parental or guardian consent (M130258). Where this was the case (n=343) adolescents gave verbal assent and written consent to participate in the research, and all participation was sought on the basis of good clinical practice guidelines (Verma, 2013). Permission was also granted from Gauteng Provincial Department of Health, Johannesburg District Department of Health, and the research committees of facilities.

Confidentiality was maintained except where participants were at risk of significant harm, including being actively suicidal or currently experiencing abuse, in which case interviews were stopped and immediate referrals were made to child protection and health services in accordance with mandatory reporting legislation in South Africa (Children's Act, 2005). Seventeen participants in the quantitative study were screened out on account of being suicidal as measured by a standardized suicide scale and given immediate care. Four participants reported rapes in the past that had been previously reported so immediate care was not necessary and they were not excluded from the study. No participants were screened out of the current qualitative study.

Data analysis

Interviews were transcribed verbatim. All identifying characterisitcs were coded or removed. Data were managed in QSR NVivo 10, building an analytical framework of broad codes by creating a 'start list' of possible themes and building upon the research questions. Each broad code, or wide thematic basket of ideas (Creswell, 2014), was applied to each transcript and 'fine codes' were developed using an inductive approach deriving meaning from the data itself rather than imposing pre-formed ideas (Hutchinson et al, 2010). To ensure intercoder reliability, fine codes were developed by four researchers competent in qualitative data analysis by printing out a full set of excerpts (from each data set) related to each code for each transcript and identifying sub-themes emerging from the data. Two researchers applied the thematic code to each transcript, a technique called 'double coding'. The findings for each transcript were critiqued by at least 3 of the 4 researchers to guarantee research findings.

Table 14. Qualitative Report Themes

Themes	Broad code	Definition/ Research Question
Challenges of HIV positive adolescents	Adherence	What helps you remember to take your medication? Are there times that you haven't or don't take your meds? What happens? You know that actress on Generations that recently died because she stopped taking her ARVs? She believed she didn't need them. What do you think of that?
	Bereavement	How have you managed losing significant people in your life? What were you told about how they died? What do you remember? Can you tell me about the time when someone important died and what happened?
	Disclosure	When were you disclosed to and by whom? What age do you think HIV positive children should be disclosed to? Why? Have you ever disclosed your status to someone else? What happened?
	Mental health	In your opinion, what kinds of mental health problems do HIV positive adolescents face? (A mental health problem is something like depression, trauma, alcohol abuse etc.) Do you think these mental health problems are different in HIV positive adolescents as opposed to HIV negative adolescents? How come? What behaviours normally show that people are having a hard time managing their feelings?
	Stigma	Do you think there is stigma around HIV? Explain Have you ever experienced stigma regarding being HIV positive? What happened?
Coping/ Resilience	Role models	What do you think HIV positive adolescents need from others for life to turn out well? Are there people in your life you can go to when life gets tough? Who are these people and what do they offer you? Who do you look up to and why?
	Strategies for coping	For adolescents who have a great deal of difficulty that they have managed (e.g. parent dies, get separated from siblings, get very sick, school is tough, people discriminate against them because of their status etc.) what helps them cope and come out of the situation okay? What sorts of things help you manage life and its stress?
HIV disease	Feelings about HIV	How do you feel about being HIV positive?
	Knowledge	Do you know how you became infected? Do you understand how to manage your disease? Do you have any questions about HIV that you would like answers to?
Health care	Messages for youth	If there were some other younger HIV positive children or adolescents here, what would you like to say to them?
	Recommendations for health system	What do HIV positive adolescents need from the healthcare system (by healthcare system I mean hospitals, clinics, or any health facility one goes to when sick)? How can the healthcare system be improved to help adolescents more? If the minsiter of health was here with us, what would you recommend he do for HIV positive adolescents in our country?

Results

The main themes that emerged from the data included the significant role of lack of, or incomplete disclosure on consequent grief and understanding of HIV. This understanding negatively influenced treatment adherence with poor comprehension of PMTCT and vertical transmission. Secrecy around death, particularly of primary caregivers/parents, impacted on understanding one's own HIV status and compounded difficulties in dealing with it. Grieving was complicated and had consequent negative impacts on mental health and resilience.

The influence of unprocessed loss and consequent grief: impact on emotional development and treatment adherence

Of the 25 participants interviewed, 21 were orphaned, with 14 being double orphans and seven single orphans who were not living with their remaining biological parent. Experience of loss was prevalent among the group and most participants described complicated grieving with very little support from family and friends. In many cases, the loss of a caregiver led to other significant losses such as the loss of home (most children/adolescents went to live with relatives in other parts of the country), loss of siblings (typically siblings were split between family relatives and provinces); loss of friends, schools and neighborhoods. Multiple losses, both relational and contextual, largely as a result of HIV did not allow time to properly mourn or develop emotional resources such as resilience, and added to fear of the disease.

One participant described that after first losing a 'healthy uncle' (at age 8; he witnessed him being shot), he lost his brother within two months (to HIV/AIDS) and three years later his mother (at age 11; also to HIV/AIDS) and another uncle (at age 13; to violence):

> "*Yeah and afterwards, after like three years my mom died. I was like 'I'm the next, I'm the next, I'm the chosen one'. Then my uncle dies and I was like 'shit'…this shit is a really huge measure thing. Over fast, like you're going down…"*

On being asked whether treatment makes a difference to mortality the same participant states:

> "*I don't know, this thing keep on telling me that [I will die], I don't know why, so yeah…Yeah, it's like they are beating me up with a five pound hammer, you see, shot after shot, shot after shot, so yeah"* – Male, 18 years

Participants said that they received very little explanation about the death of their caregivers (who had most probably died from HIV/AIDS). Consequently little guidance was offered to frame and resolve their grieving, few opportunities given to direct ways of remembering the dead, and their perceptions on the cause of death not addressed. Another participant recalls:

> Interviewee: *They said to me my mom is dead but I don't know what happened to her. I was crying the whole day and the whole night [participant was 10 years old at the time].*
>
> Interviewer: *And nobody explained what happened?*
>
> Interviewee: *No*
>
> Interviewer: *Do you know how your mom died now [8 years later]?*
>
> Interviewee: *No* – Female, 18 years

Many participants both witnessed the death and had significant responsibilities in caretaking of the sick but were, ironically, excluded from protective community rituals of dealing with death as a result of being considered 'children'. This exclusion leads young people to manage significant losses on their own, without the benefit of community - a risk to their mental health and emotional development. With regard to the 'culture of silence', a 13 year old informant's description of his grandmother's passing graphically illustrates the pain experienced by children. He lost his mother when he was eight years old, his father when he was 10, his stepmother when he was 12, and two months prior to the interview, he lost his grandmother (all of whom he was living with up until their deaths). His experience of the death of his grandmother is the following:

> *"Everyday her friend took her to the clinic, everyday, everyday, so she was sick in front of me. Then that day of the 9th of April I was not in the house, I was at school. So when I come back there were a lot of people in the house and they said I must play. I went to play, I see an ambulance getting in the house, I wondered why and when my great grandma sister passed away it*

> *was like that too. I wondered why, I just played cards. Then the fire brigade came in the driveway and I wait in the driveway, I throw the cards down and my feet shook and shook. My friend asked me, "what is going on?" and I said "she's gone". Then I cried….They arranged a funeral and her birthday was on the 13th April, so her birthday passed looking at her picture saying 'happy birthday mom' and then on the 20th we went to the Eastern Cape because that is where they buried her. I didn't go to the graveyard for the funeral because they said 'children don't go to the graveyard' but I went the next day. Then I was crying and said "rest in peace mom, you will always be in my heart, beloved by me". Then I went back home"* – Male, 13 years

Reasons for poor treatment adherence include bereavement and complicated grieving and were described by many participants. Shortly after the participants' bereavement cited above, he was having problems with adherence to his medication. He was labelled a 'poor adherer' and given multiple adherence sessions with a counsellor at the clinic. These sessions can be punitive (adolescents often struggle with adherence and are judged and criticised about this) but are meant to improve adherence. The medical staff did not know about his bereavement and he did not tell them about it; he did not recognise the link between his grief and his difficulties adhering to his medication and these psychosocial influences were not accounted for in his clinical care.

Many of the participants were still grieving the losses they had experienced, years after they had occurred, longing for relationships they never got to experience.

> *"Not knowing my parents, that's the hardest part"* – Female, 16 years

> *"It's that every child wants to have a dad and a mother at the same time…growing up having a dad and a mother because it's really sad seeing some of my friends having their families and telling me they went out with their dads, then I knew that I didn't have a dad…so many children do suffer from that thing because you all want parents, both parents"* – Male, 17 years

Impact of incomplete disclosure on (mis)understanding HIV transmission

All participants described shock and confusion at the time of disclosure regardless of their age; particularly slow progressors as they had no idea they were HIV positive. Some who had been on treatment had suspicions of being HIV positive. Many participants described feeling fearful of death at disclosure, immediately linking HIV with death (especially those who had experienced multiple bereavements; which were assumed by the adolescents to be a consequence of HIV/AIDS).

> *"At first I was scared, nervous, I thought that maybe God is calling me now, it's my time to die"* – Male, 18 years.

Another participant disclosed to by a doctor when he was hospitalised for tuberculosis was reminded of his mother's death:

> *"Ja [yes], it was the first time. I was surprised. I start thinking that my mother passed away in 2004 ... and my uncles, started like 'oh my mother was killed by HIV' but then the doctor told me that you were born with the disease'. I just say okay maar [but] I cried the first time when I found out ja. I was very painful"* – Female, 16 years

Often the disclosure of their own HIV status was the point that they realized their own parents had died from the disease; many participants had not been told the cause of death of their parents.

> *"I'm very inquisitive so I ask a lot. I'd be asking questions 'why I'd be taking medicine?' and she [clinic counsellor] would be like 'Okay you're HIV positive, you got infected in this manner', so everything started to make sense for me. That's when I realized my mom died of this virus so I'm not going to be the second victim in my family"* – Male, 18 years

This adolescent responded to the disclosure of his status by being determined not to die of HIV like his mother showing that disclosure can have positive benefits.

Many times participants were the only family member, other than their mothers, who were HIV positive with subsequent siblings born HIV negative. These participants did not understand why they were HIV positive when their siblings were not. They did not understand vertical transmission:

> *"I cried and asked myself 'why me?' because every time, most the things that happened to me, then my other little brothers, why are my little brothers safe and I'm not fine? How can I be not fine?"* – Female, 18 years

Incomplete disclosure’s effect on acceptance of HIV diagnosis, identity formation and stigma management

For most disclosure was a one time, finite occurrence with little consequent discussion or engagement with disclosure again through development. Incomplete disclosure and lack of engagement from family and clinic staff had negative effects on adolescents’ abilities to come to terms with their HIV status. Many participants reported having difficult feelings about their disease, its management and integrating being HIV positive into their identity; identity formation being one of the developmental milestones for the developmental phase of adolescence:

> ”*Like this thing man, just pop up from nowhere, I will be like ‘hey dog, I’m HIV…shit’, then I get mad…from nowhere, I don’t know what causes that...I don’t know why I have this, why me?”* – Male, 18 years (known his status for 6 years)

This can also be attributed to the fears they harbour around the disease:

> “*Ja [yes], it’s only to accept my status, that’s the thing, always change my mood…Yes, because I feel like so painful because me and that person having the same thing, then when he dies, it’s like I’m next”* – Male, 18 years

Acceptance of the diagnosis is a process, especially for those perinatally infected:

> *“I ask myself why, then my mind told me why, like it told me I was born with it, it wasn’t my fault that I was doing wrong things, no, I was born with it, so I have to heal myself inside and say ‘I do accept’”* – Female, 18 years

Many participants also reported levels of pervasive stigma and ignorance regarding HIV in their communities, and especially amongst their peers making it even more challenging to disclose one’s HIV status:

> “*When you have friends who don’t have this sickness, you feel left out because some of them tell you that ‘if we find out one of our friends has HIV then we will stop going with this guy’, so things like that, yes…that’s what most teenagers face”* – Male, 17 years

In addition, most participants shared that if they disclosed their status, transmission would be assumed to have been through sex and this was stigmatizing as well:

> "*I mean in my community where I stay, they call me 'cheese girl' if you understand, a girl who wears the most expensive clothes. So if I could be open about my status and tell some of my friends, they would say that's why I have such expensive clothes, it's because of my status. They'd say I'm HIV and they going to treat me badly in that way"* – Female, 16 years

Implicit in this quote is the notion that the participant became positive as a result of engaging in transactional sex; indicating ignorance that transmission of HIV could have been the result of mother-to-child transmission perhaps because of known high rates of sexual transmission in this context.

Knowledge does not account for understanding

Disclosure seemed a fractured process: information only partially communicated and comprehended. Even though all participants were aware of their HIV status and described being disclosed to, only one knew *how* they became infected.

> Interviewer: *So do you know how you contracted HIV?*
>
> Interviewee: *Not really, but by him [doctor] he thinks maybe I got it at birth. But I think if I got it at birth maybe I would have been dead by now, so I am not sure, so I don't know how I got it* – Male, 18 years

Even for those participants who knew they were born with the virus they actually didn't fully comprehend transmission:

> Interviewer: *Do you know how you got infected?*
>
> Interviewee: *I don't know but the thing I am highly sure of it that I was born with it* – Female, 18 years

So even though adolescents might know they were born with the virus, they do not know how they contracted it:

> " *No I don't [know how I got the virus] but she [mother] told me I was born with it"* – Male, 17 years

Secrecy's tenacious undermining of development

Many participants describe the secrecy and lack of direct communication both around the death of their biological parents as well as disclosure of their HIV status. One participant describes the lies within her family that have left her feeling both confused and sad:

> Interviewee: *I don't know because before my mother died we ask her that how come I am HIV positive, she said that she doesn't have HIV, she just has sugar diabetes, maybe I have sugar diabetes too.*
>
> Interviewer: *Do you think your mom was telling the truth?*
>
> Interviewee: *No. It makes me feel bad because I don't know where do I receive HIV from?* – Female, 16 years.

Another participant recommended asking clinic staff for the truth when family members were not forthcoming:

> *"I think they must ask their parents, 'how did I get it?', so if the parent doesn't tell her or him what's happening, talk to the counsellor; tell the counsellor 'I don't know how did I get it, so what must I do to calm myself because I can't even think or concentrate…I just think of this: how did I get it while my other sisters didn't get it?' So it's like that"* – Female, 18 years

Adolescents are left with many unanswered questions

Although secrecy appeared pervasive, many participants suspected their caregivers died of HIV/AIDS, and whilst parental death resulting from HIV was understood, actual means of transmission of the virus to the adolescent was not at all understood. The researcher explained PMTCT to all participants but one who already understood this prevention method as well as vertical transmission. Typical responses to learning about PMTCT included the following:

> Interviewee: *That used to freak me out, just thinking of the fact that if I would just get pregnant, what if I also do the same thing to my own child? Maybe my own child wouldn't forgive me, would always be angry like I am to my mom, so ja [yes]*
>
> Interviewer: *What does it feel like to know you have these options and that the chances of transmitting the virus are low?*
>
> Interviewee: *It's kind of relieving, so ja* – Female, 17 years

Discussion

This study examined the perceptions of perinatally infected adolescents (PIA) with regard to HIV and their own infection, as well as their mental health state. The limitations of disclosure, both with regards to their HIV status as well as how their parents died, was a central theme that emerged to impact their understanding of their diagnosis and was the foundation of their mental health difficulties. In addition, their bereavements and management of losses over time highlighted a pattern of complicated grieving.

Although these participants were recruited because they were assumed to be knowledgeable and adherent, both through provider and self report, they actually were not. In addition, the outward appearance of the PIAs on treatment projects a mental health state that may not be a true reflection of the internal turmoil they have gone/are going through. These participants had both a lack of understanding of PMTCT and future reproductive health options, as well as unreliable comprehension of how they contracted HIV and pathways to vertical transmission. Of all 25 participants, only 1 knew about vertical transmission. This was a startling finding from a group of treatment literate patients who were engaged in care at the clinics and interfaced with medical professionals frequently and typically over many years.

Cultural silence around both death and disclosure, although intended to be protective to children and adolescents, has deleterious consequences for PIA. The majority of the sample described this ‘culture’ in the interview. Loss of family members, irrespective of cause of death, and in addition to loss of parent(s) is a key finding in our investigation of factors affecting the mental health and wellbeing of PIA. Perceptions of the value of treatment depend on experience and interpretations of these deaths. The denial inherent in this silence and its formulation over time and through development leads to poor understanding of one’s disease and reinforces stigma around HIV with costs to mental health functioning (Daniel et al, 2007). It should also be highlighted that even ‘resilient’ adolescents continue to grieve and struggle to come to terms with their loss/losses.

There seemed to be two critical moments of distress for this sample of PIA in their struggles to come to terms with their HIV status throughout their development – when their parents died (Li et al, 2008; Mannarino & Cohen, 2011) and when they found out they were HIV positive (Dorrell & Katz, 2013). It is suggested that these two events are inextricably linked. As a result of not being told the truth about the death of their primary caregivers/parents, they came to their own conclusions, and described assuming HIV/AIDS was the cause of death. When they found out their own status, they similarly assumed they would die like their parents did. Our findings affirm that orphans are significantly disadvantaged by social norms that exclude them from the truth about death which in turn leaves them to grieve privately and unsupported (Wood et al, 2006; van der Heijden & Swartz, 2010) but we also offer a closer examination of the nature of the grief and some of the emotional effects on individuals. Adolescents in this study reported to feeling uncared for and confused about the death of their loved ones; they were struggling with these feelings and grieving still many years after their losses. Many participants came to conclusions about the cause of death of their primary caregivers on their own, often at the point of disclosure of their own status. HIV related death is compounded by the stigma of the disease, leading to further silence and secrecy, and with potential increased internalized stigma on the part of the HIV positive adolescent. When these participants discovered they were HIV positive, they presumed they would die and were still struggling to accept that they might not die in the foreseeable future. This highlights a pattern of incomplete disclosure, i.e. a lack of discussing disclosure over the course of development, giving opportunity to fully understand HIV transmission and disease management. Lack of detection and treatment of these misunderstandings and consequent unresolved feelings can lead to more longstanding mental health problems that may become exacerbated in adolescence and are currently unaddressed (Sherr & Mueller, 2009).

Disclosure is fundamental to managing experiences of loss and mental health and when disclosure (either of the death of a primary caregiver/parent or of HIV status) is not engaged with appropriately or sensitively, it leads to dismal consequences that cannot be underestimated. Disclosure needs to be recognised as a process, requiring discussion over time to enable adolescents to work through their grief and fully understand HIV, addressing any worries or concerns they may have. Lack of comprehension has dire consequences for adolescents especially when they age out of paediatric care and where assumptions may be made about their knowledge and understanding. Studies have found very high morbidity and mortality rates among adolescents who are transitioned out of paediatric care; reasons include lack of relationship with adult providers, absence of youth-friendly adult providers, poor psychosocial service provision and inadequate detection of mental health concerns, ‘quick’ transitions with little preparation and poor collaboration between clinics, lack of independence on the part of the adolescent, often being ill prepared for self management of the HIV disease (Pearlstein et al, 2013; Fish et al, 2014; Hussen et al, 2015). Our findings would also suggest that PIAs project a different image of health status to what they are actually experiencing and health services do not provide ongoing support for a sufficient time after a professional has informed PIA of his/her status.

Our participants had no reliable and accurate understanding of PMTCT and its value in their own lives. Unfortunately, even adults do not have comprehensive understanding of PMTCT (Craft et al, 2007) and awareness of and knowledge about reproductive health, HIV transmission, and contraceptive methods is poor among HIV-infected adolescents (Lowenthal et al, 2014). When asked if they knew how they contracted HIV, these participants would respond by saying they were born with the virus, thereby implying they comprehended vertical transmission. Unfortunately, as a consequence of the misperception of their understanding, undoubtedly many opportunities to educate this group about prevention options such as PMTCT and sexual transmission to uninfected partners were lost. As Terblanche & Stellenberg (2014) discovered in their research with 200 adult patients on ARVs at a community health centre in Cape Town, knowledge of HIV and ART was poor and this is likely to be the same with adolescents. Conveying comprehensive understanding of complex concepts requires both repetition and reinforcement (Kidia et al, 2014). Consistent and continuous messaging around HIV and ART is needed to ensure care and treatment is optimal, especially for key populations at high risk. HIV care programmes should provide age-appropriate information on prevention of HIV transmission and family-planning and give support about disclosure of HIV status to partners and contraceptive services (Lowenthal et al, 2014).

The findings from this study are limited in several ways. First, the adolescents were purposively recruited from clinics based on their responses to a questionnaire and the view of the research counsellor administering the tool, thus this sample cannot be viewed as representing all HIV positive adolescents accessing healthcare and limits generalizability. Second, this was a clinic based sample in an urban environment and it is likely that participants may not reflect issues in the broader adolescent population. A study that incorporated views from marginalized, rural communities and non-clinical settings would have provided a sample with greater variety of perspectives. This sample was however identified as being resilient that may imply that others face greater challenges and may present with worse mental health. Lastly, bereavement and measures for this were not explicitly assessed in the interview thus the role of bereavement in understanding the nature of infection and disclosure among HIV positive adolescents is merely speculative and warrants further investigation.

Despite these limitations, the findings are important in directing healthcare for HIV positive adolescents within the public healthcare system. Improving messaging around PMTCT and vertical transmission, having more explicit guidance regarding disclosure of HIV status as well as death to young people, and managing mental health with specific reference to pervasive complicated grieving of those who lose their primary caregivers at a young age would be recommended.

Conclusion

Disclosure has more complex effects on individuals than is commonly recognized. When perinatally infected children become adolescents and learn more fully about why they are on medication, they suffer further grief that is not just about losing a parent(s). In addition, as a result of lack of full disclosure, many adolescents experience complicated grieving. Comprehensive disclosure, managed consistently over time, including up to date messaging around sexual reproductive health options are necessary both to facilitate better adherence but also to enhance self-management skills that are critical for HIV positive adolescents to transition out of paediatric health facilities and improve mental health. Perinatally infected HIV-positive adolescents accessing care and treatment in public health facilities in Johannesburg have poor understanding of PMTCT with limited comprehension of vertical transmission. Health services need to incorporate understanding of these effects in PIA treatment programs.

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CHAPTER 7

Results - "To be HIV positive is not the end of the world": Resilience amongst perinatally infected HIV positive adolescents in Johannesburg

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Introduction

'Resilience' is a relatively novel and decidedly complex concept (Ungar, 2013; Cicchetti, 2010; Windle, 2011; Masten, 2014; Zolkoski & Bullock, 2012). Although there are many different definitions of resilience, they are broadly similar and refer to the positive adaptation of people to difficult situations (Skovdal & Daniel, 2012). Resilience in the context of the HIV epidemic among children and adolescents is important, as it is well known that HIV adds a significant burden to development and that those infected are likely to suffer increased mental health problems and psychosocial stress (Betancourt et al, 2013; Cluver et al, 2012; Li et al, 2008; Mutumba et al, 2015; Sherr & Mueller, 2009; Pienaar et al, 2011).

Among perinatally infected adolescents, resilience may be a particularly important construct. There is a significant burden of HIV in adolescents with 2.1 million adolescents aged 10-19 years living with HIV globally (UNAIDS, 2013). These adolescents tend to experience enduring adversity (multiple losses and bereavement, numerous sickness and hospitalization, poor school attendance, increased poverty and exposure to violence, stigma and discrimination, disclosure challenges) as well as low levels of physical, psychological and social resources which puts them at risk for developing mental health problems (Mavhu et al, 2013; Bernays et al, 2014; Lowenthal et al, 2014). Perinatally infected adolescents are also more likely to struggle with adherence to treatment (Agwu & Fairlie, 2013; Kacanek et al, 2015; Lowenthal et al, 2014; Cluver et al, 2015) and may engage in unsafe sexual activity (Agwu & Fairlie, 2013; Cluver et al, 2011). They are similarly at higher risk of sexual coercion and peer pressure (Kim et al, 2014), increasing the risk of secondary transmission. Indeed, nearly one-sixth of all new HIV infections are in adolescents aged 15-19 years (UNICEF, 2013) making this age group the most vulnerable incident infection population in South Africa (Shisana et al, 2014). Mitigating risk by improving mental health outcomes, particularly resilience, would be in the public health interest but more research is required to understand this construct in this population.

Studies indicate that individual characteristics, resources, and competencies — including age, cognitive capacity, sense of purpose, and belief in a positive future — contribute to resilience; supportive and accepting environmental conditions help shape resilience by mitigating the negative effects of adversity (Amzel et al, 2013). Resilience in HIV-infected adolescents is also influenced by the complex interplay between individual-level factors, family-level factors such as caregiver well being or illness, institutional-level factors such as access and engagement with health services and education, and societal factors such as stigma (Amzel et al, 2013; Betancourt et al, 2011). In addition, literature regarding HIV orphans (of which many are perinatally infected) has explored factors that contribute to their unique vulnerabilities. These are often associated with coping with the illness or loss of a parent, compounded by associated stigma, trauma and bereavement, and financial hardship (Wood et al, 2006; Daniel et al, 2007, Collishaw et al 2015, Li et al, 2015).

Masten (2001) coined the term 'ordinary magic' to refer to resilience as something nurtured by everyday resources, common to individuals, families, communities and cultures. These conventional roots of resilience suggest that resilience is not rare and that active steps can be taken to develop and sustain resilience among young people who are placed at risk by ordinary and extraordinary hardship (Theron & Theron, 2010).

Whilst progress has been made in identifying and managing risk factors for HIV positive children and adolescents, little is known about how HIV positive adolescents demonstrate resilience and how the healthcare environment can be utilized as an agent of resilience for young people. We conducted qualitative research to explore the views of HIV positive adolescents attending clinics in Johannesburg regarding resilience and mental health.

Methods

Participants and procedures

The study nested qualitative research into an observational adolescent study conducted in five HIV clinics serving adolescents in Johannesburg, South Africa (n=25/343). Three of the clinics were hospital based; one was a community health center and one a primary healthcare clinic. All offered routine care except 1 hospital based ‘flagship’ clinic that offered specialized pediatric ARV services.

Participants for this analysis were recruited purposively by research counsellors familiar to the adolescent based on consent and willingness to engage in in-depth interviews. Research counsellors were trained in pediatric HIV and advanced counselling, and volunteered to participate in the research, engaging in principles of ethical research with minors. They received an additional 5 day training for this study as well as weekly debriefing and supervision throughout the course of data collection. High functioning adolescents (i.e. scoring moderate to low on standardized mental health measures indicating ‘good’ mental health) were chosen because their resilience was being investigated, i.e. these participants’ reported difficulties and adverse life experiences did not seem to be impacting negatively on their mental health functioning. All participants reported experience of being disclosed to about their HIV-status, were on treatment for HIV and had been attending clinics for many years. A total of 62 adolescents were identified as high functioning. The 25 participants chosen from this sample characterized a range from all 5 facilities recruited from. Twenty-five adolescents between 13 – 19yrs (mean 16yrs; 15 female) were interviewed for approximately 60 minutes each by the principal researcher of the study using a semi-structured interview guide when they visited the clinic for their regular appointment. The interviews were recorded with participant consent and conducted in English as all participants spoke English fluently.

Participants were presumed to be infected at birth and had all lived with HIV for as long as they remembered, but it is possible that a small proportion were infected through blood transfusion or rape in childhood, although there is little data documenting this.

Participants were given a pocket sized card with active referrals for services in their neighbourhood including counselling, legal and crisis resources. Upon completion of the interview, participants received reimbursement for travel; a snack; and a gift voucher for R50 (US $4) at a local clothing retailer. These items were endorsed and recommended by the adolescent community advisory board (CAB) instituted for this research.

Ethics consideration

The South African National Health Act states that ‘for health research with minors (<18 year olds), consent from a legal parent or guardian for research with children must be obtained’ (Section 71, 2012). This sample was speculated to possibly not have legal guardians from whom to obtain consent. As such, the ethics committee of the University of the Witwatersrand advised approaching the court for permission to enroll participants in the study by obtaining a court order which was granted and led to full ethics clearance and permission to interview volunteers without parental or guardian consent (M130258). Where this was the case (n=343) adolescents gave verbal assent and written consent to participate in the research, and all participation was sought on the basis of good clinical practice guidelines (Verma, 2013). Permission was also granted from Gauteng Provincial Department of Health, Johannesburg District Department of Health, and the research committees of facilities.

Confidentiality was maintained except where participants were at risk of significant harm, including being actively suicidal or currently experiencing abuse, in which case interviews were stopped and immediate referrals were made to child protection and health services in accordance with mandatory reporting legislation in South Africa (Children’s Act, 2005). Seventeen participants were screened out of the quantitative sample for active suicidality and four participants reported historic rapes, none in the current qualitative sample. Where prior abuse or rape was no longer occurring, referrals were made to support and counselling services, again none in the current qualitative sample.

Data analysis

All interviews were transcribed verbatim in English. All identifying information regarding the participant or clinic setting was removed and transcripts were saved by a file name with no personal identifiers. Data were managed in QSR NVivo 10, a qualitative analysis software package, constructing an analytical framework of broad codes by creating a ‘start list’ of possible themes and building upon the research questions. Each broad code, or wide thematic basket of ideas (Creswell, 2014), was applied to each transcript and ‘fine codes’ were developed using an inductive approach deriving meaning from the data itself rather than imposing pre-formed ideas (Hutchinson et al, 2010). To ensure intercoder agreement, fine codes were developed by 4 researchers competent in qualitative data analysis by printing out a full set of excerpts (from each data set) related to each code for each transcript and identifying sub-themes emerging from the data. Two researchers applied the thematic code to each transcript, a technique called ‘double coding’. The findings were critiqued by the group to guarantee research findings, highlighted the reality of the transcripts rather than simply one researcher’s view of the data. During analysis, we found that data did reach a point of saturation, which leads us to believe the sample size was sufficient.

Findings

Of the 25 adolescents interviewed, 15 were female. All had been disclosed to, and most had known their HIV status for many years. All participants reported they had been attending clinics since early childhood (and most likely being treated for HIV). Four participants were not orphaned, 7 were single orphans and 14 (56%) were double orphans. Three of the participants lived in a children’s home, 13 participants (52%) lived with extended family members, mainly grandmothers, and the remainder lived with biological parents.

Beliefs underpinning resiliency

A strong theme emerging from adolescent participants was the idea that their own belief systems set the stage for their ability to be resilient. Many participants demonstrated a belief in fate with a comfort in the conviction that one is on the path one should be:

> *‘So you know they say God throws challenges at you to make you stronger; God does not throw things that He knows that you cannot handle? He throws things at you that He knows that you can handle...so that’s what keeps me going and to me like that’s what tells me everything happens for a reason. There is a reason it happened [becoming HIV positive] and cannot be changed now and if I want to continue to live, I have to take my tablets and all that...so that’s what keeps me going’ (male, 18yrs)*

This quote highlights another central theme that emerged regarding the value of challenges in life as a measure of personal resilience and validation of coping ability:

> *'Yes and like in life, all the things that you face, once you face them, you might find out that you're the strongest person...stronger than the person sitting next to you' (male, 18yrs)*

Many participants were orphaned, the loss of their parents being one of the most profound challenges facing their development. However, one participant highlighted this 'risk' enabled him to recognize his strengths in coping:

> *'Ja but there's an upside too. It teaches you well; without your parents you can learn about life on your own, make your mistakes, learn from your mistakes and soldier on. Many people complain 'I don't have a parent, okay nothing's going to go my way'; they have a negative attitude believing nothing is going to ever work out without their parents around. I always did things on my own and even if there were hard times, I made it through' (double orphan, male, 17yrs)*

Another participant drew attention to the particular challenges perinatally infected HIV positive children and adolescents manage:

> *'I would say when they grow up [children infected at birth with HIV] they will be stronger than what they were because they know responsibilities and that stuff other kids don't have to deal with' (female, 16yrs)*

Character traits as internalised resiliency

Several character traits were important for the resilience and coping of adolescents. Many of the respondents had a flexible and pragmatic acceptance about their lives which helped them cope with their realities:

> *'I easily accept things as they are. I never look too deep into things that 'why did it have to happen now?' and ask myself unanswerable questions. I just accept things — 'ok my uncle has died life goes on, that's just how it is with me' (double orphan who recently lost uncle who was primary caregiver at the time, male 17yrs)*

One young woman described how accepting her own parents' death was difficult, but something that she was compelled to "deal with":

> *'It was a bit harder [dealing with parents' death and consequent HIV disclosure] but as time goes by I was accepting that this is me so I have to deal with it' (female, 16yrs)*

This pragmatism translated into understanding and accepting their HIV diagnosis with consequent improved management of the disease.

> *...you do have medication and treatment, there's no use [need] for you to die because you have these things. Why should you die from HIV...to be HIV is not the end of the world' (male, 17yrs).*

The following participant was a double orphan, living in a children's home who had accepted many hard realities in his life, including his HIV status:

> *'A lot' of children come to me and say 'how do you deal with this?' [being HIV positive] and I say 'it is easy'. I ask them how they deal with their lives. I ask them 'okay if you are ill and then the doctor said to you take this medicine for this month, would you do it or wouldn't you do it?' and they say to me 'I will do it'. And then I ask them why and they say 'because I'd like to be well and healthy'. And then I say 'okay, I'd also like to be healthy. I'm taking my medication every day so that's no big deal about that' and then they say 'okay so it's not a big deal' (male, 16yrs).*

Many respondents spoke openly about the need to take responsibility for one's life and health, indicating an internal locus of control which had a direct impact on improved health outcomes.

> *'They will have to face the reality [HIV positive adolescents]…at the end of the day you will be the one to be happy about your health, at least you will be doing something. What's going on with your health, inside and outside your body, is your own responsibility…ja' (male, 16yrs)*

This responsibility was also demonstrated in sexual relationships with a strong sense of safe sex practices utilized by participants:

> *'I have disclosed to my boyfriend and he is negative. Every time we have sex we use condom. Always' (female, 18yrs)*

Although most participants discussed the need to be especially mindful regarding safe sex given their status, many were particular in their decisions about when to engage in sexual relationships:

> *'Well, okay at first I used to date a guy who was HIV positive like me so it was actually an easy relationship because we would get to speak about our status and all that. So, ja, since I've been dating the HIV negative guy it's been kind of hard because we don't get to speak that much but we do have fun but we don't have sexual intercourse and all that because I find it very risky for my life so ja' (female, 17yrs)*

Most participants exhibited a robust self-esteem and were able to identify the need for this particularly in overcoming HIV stigma that is still rife in communities.

> *'It's like a natural thing; you have to learn how to be strong. Without your self-esteem, maybe, you know people come to you and say 'you are HIV, ag we don't want to play with you and so on'. You just say 'okay thank you for that word but I will not take it seriously' and then move on with your life. Forget about that a long time ago and move on and say 'okay I'm HIV positive. I've got friends who are HIV and I've got friends who are negative, so why should I worry about them? I don't care what they are or who they are'. So for me self-esteem plays a big role but as far as I'm concerned no one should come to me with negative words and so forth because I don't think I deserve it, ja, I don't think I deserve it and I don't think anybody deserves it' (male, 16yrs)*

Participants reported experiences of rejection on account of being HIV positive and the need to actively manage discrimination. One young woman described her coping techniques for dealing with insults and misconceptions around HIV:

> *'I think they [HIV positive adolescents] need a positive self-esteem; tell themselves positive things every time. Whenever a person insults you or say something stupid about HIV while you're listening to that person you must tell yourself in your head 'ag, whatever...I'm the person' and keep your head forward just continue telling yourself you are this person and you are not going to be what they say out there' (female, 17yrs)*

Being self-assured and accepting oneself were the basis of this self-esteem:

> *'Well a lot of people think or say that I'm ignorant, I'm cocky you know like, but I'm just a simple person who wants to enjoy life and that's just full of courage. Even though the situation might be suppressing [oppressive], there's always a positive at the end of the tunnel. So yeah, courage drives me to see positive in negative' (male, 18yrs)*

In addition, many participants demonstrated self-reliance that was key to self-esteem:

> *'If you don't believe in yourself, who will? Some people might see you as crap but hey you're believing in you for yourself and you see yourself as the greatest guy on earth. Successful, living life the way you wanted to live life with a family, children and so forth and if you're going to keep degrading yourself then everybody is going to keep looking down on you. So take down that balcony that they keep looking down on you from and be on the balcony that everybody can look up to you' (male 17yrs)*

Many respondents reported being considered in their problem-solving, noting that with enough thought, they could come to a solution to problems.

> *'Use your head and not your feelings' that's all I can say because our emotions always make us make the wrong decisions but when you use your head you can actually manoeuvre through things...turn the bad into an advantage for you' (male, 18yrs)*

Most participants were goal oriented and had plans for their futures coupled with a conviction of their future success.

> *'In the future I have a good plan and I do my schoolwork and stuff. So I know that I'm going to live this good life' (male, 18yrs)*

> *'I've told myself this is not the end of the world, I can live. I can do anything that I want to be and I thought I would die. I would never be a tour manager. So I said 'no, I'm going to be a tour manager when I grow up' (female, 14yrs)*

Social behaviours as actioned resiliency

While accepting and acknowledging the challenges in their lives, for example being orphaned, most participants reported actively pursuing and accessing adults and parental role models to meet their developmental needs and obtain support where they could, demonstrating agency in effectively utilizing resources available for their own gain.

> *'...everyone in life, every father, every mother, every stepdad, every stepmom, every grandmother is a father to me, is a mother to me so I don't regret that. I don't feel pain that I don't have a mother or father of my own because I've got so many mothers and fathers on earth...so I'm good' (male, 18yrs)*

This participant highlights his ability to relate to others, being flexible in his worldview and accomodating to his circumstances:

> *'I randomly meet people every day so I get talking with the person and I just share 'okay if you were in this situation as I am and so forth what would you do?' and then they would share lives. I take it a bit of what they told me and put it into the way that I see things and that would eventually help me in my life' (male, 17yrs)*

In addition to accessing adults, another participant emphasises the need for uptake of healthcare services that are widely available in the country:

> *'I would advise them [other HIV positive adolescents] and teach them about ARV's and that they still have a chance to live. Having HIV doesn't mean that they are going to die any time soon. It's just a virus and you can control it if*

> *you want to. You mustn't let it control you because there are doctors that give us ARV's for free' (male, 18yrs)*

Many adolescents, who were accessing pediatric healthcare clinics regularly, saw these environments as particularly helpful in their lives:

> *'For me like, what works for me is to go to the clinic, get your meds and all that, you meet people there and sometimes it makes me feel that I'm not alone and all that. So ja, it didn't only happen to me, so ja' (male, 18yrs)*

They also relied on the pediatric clinic staff they had come to know and trust over time:

> *'…well it' convenient number one [coming to one place regularly for support] and the people here they have a good attitude and have a mind of a kid which is very good. They know what a kid who is HIV is thinking, they're very supportive…they know what a kid has to go through to fight this kind of thing' (male, 17yrs)*

Interestingly, all participants had a strong desire to support and help others, especially young people struggling with their own HIV disease.

> *'I picture myself helping people who are HIV positive, encouraging them with their treatment, advising them not to give up with life, not to think that it's the end of the world, you know' (female, 18yrs)*

Much of the help suggested tended to be around mentorship and factual information sharing regarding HIV infection, treatment and care, suggesting that many young people do not have accurate information about HIV disease or are deliberately told lies about their health.

> *Interviewer: So you feel it is your responsibility to educate other HIV positive teenagers?*
>
> *Interviewee: Yes, so they can get proper information*

> *Interviewer: Why? Why you?*
>
> *Interviewee: I don't know, maybe it's because I know what it is like and I would love to tell them, so that they can know...not hear it from one who is telling them lies (female, 19yrs)*

Being able to share their knowledge and expertise regarding HIV would likely be of benefit to peers experiencing similar realities and challenges.

> *'I would like to talk to other HIV positive teenagers about what it is like to live with HIV if they would like to listen and would like to be helped with getting information about HIV. We can fight this. We are lucky to have medication and together we can do more and give back to the community. We are not a bunch of losers' (male, 18yrs)*

The following quote indicates that many vertically infected children and adolescents may not know how they contracted HIV and need to understand vertical transmission as well as the prevention of mother to child transmission (PMTCT) prevention interventions.

> *'I will teach them how did they get HIV from…If they never slept with anyone, so it happens maybe they got it from the mother' (female, 19yrs)*

In terms of messages for other HIV positive and adolescents, this group had recommendations that are in line with national and international guidelines, suggesting that they may have internalized what they have been taught at the clinic and through support groups etc. including accepting one's status…:

> *'...accept your status and if you know how to work with it, you can have a good life...tell them it's all in the mind, you just have to change the way you think about taking treatment and it will work for you' (male, 18yrs)*
>
> *...disclosing one's status:*

> *'it's not a good thing to hide the virus to the people you live with, so it's better to tell them' (male, 17yrs)*

...and adhering to treatment:

> *'I will tell them 'drink your medication', don't be scared. Don't let other people break your heart, no matter what, never mind what people say about your status, your life is yours, it's not other people. Go to the clinic and fetch your medication' (female, 18yrs)*

These recommendations were framed by challenging stigma around HIV where myths and negative beliefs still appear to be present amongst young people.

> *'I will tell them that people who have HIV they are also normal people that can do what the people who don't have HIV do...being HIV it's a very normal thing, you are not a loser. And people who don't have HIV they can learn from people who have HIV a lot of things' (male, 18yrs)*

One participant alluded to the fact that stigma can be driven by lack of information, something he felt compelled to challenge:

> *'The one message I'd like to say to them, as South Africans, let us prove other countries wrong by taking our medication, starting to get very very low percentages of AIDS killing people in South Africa. I'd like to tell them that HIV is not a death sentence' (male, 16yrs)*

Discussion

The aim of this study was to identify characteritics of resilience in a group of perinatally infected HIV positive adolescents attending clinics in Johannesburg for their HIV care and treatment. Features of resilience in this group were underscored by beliefs and character traits that enabled their ability to manage their adversity, as well as social behaviours that created the agency necessary for success. This study identified that stigma, both community stigma and self-stigma, are significant challenges that HIV positive adolescents are dealing with. Many studies that identify stigma as a challenge, also identify social support as protective against the risks associated with stigma (Betancourt et al 2013). Opportunities to increase social support or even just the perception of social support (Cluver et al 2009) can enhance resilience in young people.

This study testifies to participant's creativity and demonstrates their active role in negotiating access to care, strategically navigating through the social supports available to them, including that of the healthcare sector. Counter to narratives of tragedy and doom, for orphans in particular, this study supports others that have identified tactical agency employed by young people in conditions of heightened vulnerability (Vale & Thabeng, 2015). Young people's agency and ability to steer through support networks is a key pathway to resilience (Skovdal & Daniel, 2012) and should be encouraged and reinforced, particularly in HIV positive adolescents.

The resilience characteristics highlighted among this adolescent sample are underlined by the capacity for self-reflection. Self-reflection is widely regarded as marking an unfolding developmental competence fully emerging in adolescence (Barkai & Rappaport, 2011). Interestingly, stressful life events tend to promote self-reflection in resilient people, representing an adaptive psychosocial capacity preferentially engaged as a means to overcome adversity (Thorne et al, 2004). Self-reflection is highly indicative of resilience. Thus supportive adults, including healthcare providers who ask young patients about their meaningful life experiences (such as bereavement) may guide patients to insight and reflection which could bolster resilience.

Theories of resilience posit that individual resilience occurs when there is an opportunity structure (an environment that facilitates access to resources) and willingness by those who control resources to provide what individuals need in ways that are congruent with their values (Ungar, 2013). As such, these data suggest that the healthcare environment could benefit from being sufficiently youth friendly with professionals willing to serve the needs of the adolescents who attend for care and treatment (Tylee et al, 2007; Pettitt et al, 2013). In addition, efforts to increase the perception of facilities as valuable resources for youth would improve access to services and could increase youth resilience in currently untapped ways. Participants in this study highlighted the fact that they had engaged in healthcare for many years — perinatally infected youth typically access treatment throughout their development and come to know their providers well. Intrinsically, this environment and those who work in it, can be seen as protective. The healthcare sector could foster an increased agency in its young patients, with consequent positive impacts on treatment adherence and retention in care; supporting empowered patients with hope for the future. This will be critical to the self-management of HIV disease when the infected adolescents are transitioned into HIV adult care centers.

Messages of perseverance and hope were consistent with strong encouragement for continued and consistent adherence to medication and treatment. Adherence is a known challenge in adolescent care (Cluver et al, 2015; Lowenthal et al, 2014; Agwu & Fairlie, 2013). Adolescents though have potential influence over their peers (Mavhu et al, 2013); acceptance and friendship are frequently moderators to adversity (Criss et al, 2002). As such, programmes that work with HIV positive adolescents may benefit from peer messaging at clinic level in the form of peer led support groups, peer treatment navigators/counsellors for young people (supported carefully and supervised by skilled facilitators), and inclusion of young HIV positive adolescents in the multidisciplinary team or on the clinic community advisory board etc. This inclusion improves HIV outcomes among adolescents (Van der Heijden & Swartz, 2010; Pettitt et al, 2014; Mupambireyi et al, 2014) and most participants in this study were open and invested in supporting other HIV positive youth.

The participants shared being confronted by pervasive negative beliefs about HIV, perpetuating stigma, which they countered with phrases such as “HIV is not the end of the world”, “you are not going to die soon”, and “HIV is not a death sentence”. Sensitization regarding HIV within adolescent communities may need improved efforts towards stigma reduction, with more accurate messaging regarding HIV disease and treatment, and especially, precise information about prevention methods such as PMTCT. Many young people, especially those perinatally infected, are dealing with personal losses of those who died of HIV (many of these deaths personally witnessed) which may lead to inaccurate and pervasive negative beliefs around the disease. In addition, it is likely that at the time of diagnosis for these adolescents, they were likely considered terminal (Small et al, 2014). These beliefs could translate to a fear of death at one’s own disclosure signifying the need for a keen understanding of death as well as HIV treatment so that negative beliefs can be managed as they surface developmentally (Wood et al, 2006; Daniel et al, 2007).

Negative beliefs are compounded by a ‘culture of silence’ surrounding death which serves to reinforce stigma; the antidote to this would be honest conversations with young people regarding HIV related death. Resilience must be framed within a personal struggle with bereavement that conceptually impacts on one’s own understanding of HIV disease and its management. These participants felt that only with accurate and factual information on both death (developmental understanding of death and accurate information regarding the death of primary caregivers) as well as HIV (vertical transmission, the benefits of treatment and the importance of adherence) can HIV positive adolescents be resilient in the face of their circumstances.

There is little doubt that HIV leads to experiences of anxiety and depression in children and adolescents, and a ‘pathologizing’ focus may serve an important purpose in highlighting the hardship experienced by children and adolescents leading to policies and programming to serve these needs. But it is crucial that such a focus does not overshadow the plurality of experiences of HIV infected and affected children and adolescents and the ability of some to deal successfully with significant hardship (Skovdal, 2012). It is critical to note too that attention should be paid to the potential hidden costs of resilience, i.e. some young people pay a price for resilient functioning where resilience in one developmental phase or in one domain of functioning may exact concurrent or deferred tolls in another or mask distress (Theron, 2012). This is somewhat evident in the findings predominantly around sexual relationships where disclosure and decisions to be sexually active can be particularly difficult and in some cases foreclosed upon in this developmental period. Being able to navigate sexual relationships intentionally and without fear will be an important feature of future sexual reproductive health and relationship intimacy for these young people. Resilience is nonetheless evident, and gives clues to understanding agency, promoting health in ways that can serve young people positively.

There is no single path to resilience and although the participants of this study demonstrated resilience at the time of interview, studies do suggest that adolescents have varying levels of resilience at various times during their lives (Howard & Dryden, 1999). Adolescents who seem resilient in one set of circumstances may suffer when other difficulties arise. This suggests that it is the interaction and accumulation of individual and environmental risk factors that contributes to both risk and resilience (Killian, 2004). If the healthcare environment can be seen and used as a resource to HIV positive adolescents, sustaining the positive effects of resilience lies within its area of influence and health care providers could be pivotal agents of resilience in their treatment and care of young people living with HIV. For perinatally infected HIV positive adolescents who endure many changes in their lives, their healthcare providers are often consistent and reliable resources — professionals with significant potential to foster resilience. Programmes that actively include some of the characteristics of resilience described in this study may powerfully impact their patients.

The findings from the study are limited in several ways. Firstly, the adolescents were purposively recruited from clinics based on their responses to a questionnaire and the view of the counsellor administering the tool, thus the sample is skewed and may overrepresent resilience among a population that may, more typically, face major barriers to resilience and mental health. Secondly, there was no comparison group of adolescents who were not coping and thus potential significant differences in what made some adolescents more resilient than others could not be assessed. Thirdly, this was a clinic-based sample in an urban environment and it is likely that participants may not reflect the broader adolescent population – futher research is needed with rural adolescents and those not accessing healthcare. Fourthly, there is currently is no precise test to determine perinatal infection, especially in resource poor settings where accurate clinical records are a challenge to obtain, so symptoms, time of first hospitalization and timing of ART initiation are used as guides (Ferrand et al, 2009). As a result, some adolescents assumed to be perinatally infected in this study may not have been. Lastly, it was not the intention of this study to analyse the concept of resilience but merely to describe resilient characteristics found in this particular population.

Conclusion

This study highlights how adolescents infected with HIV manage a range of risk factors and appear to have characteristics of resilience that enhance their ability to meet the challenges in their lives. Perinatally infected HIV positive adolescents are best-placed to define the outcome of resilience and their voices are underscored in this paper. Noting how adolescents cope can indicate elements of an effective response. Facilitating resilience in public health programming could have positive effects on mitigating risk for a vulnerable yet engaged population.

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CHAPTER 8

Results - Revealing the impact of loss: Exploring mental health through the use of drawing/writing with HIV positive adolescents in Johannesburg

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Introduction

Due to dramatic improvements in access to antiretroviral treatment (ART), children born with perinatal HIV infection are growing into adolescence in large numbers, especially in low and middle income countries (LMICs) (Ferrand et al, 2009; Idele et al, 2014). Approximately 2.1 million adolescents in LMICs were living with HIV in 2012, and of the nearly 3.2 million children under the age of 15 years infected with HIV globally, 90% are living in sub-Saharan Africa (WHO, 2013; UNAIDS, 2014). The HIV pandemic has increasingly brought attention to the unmet mental health needs of children and adolescents (Breuer et al, 2011), highlighting the comorbidity of HIV and mental health problems especially among those perinatally infected (Mellins & Malee, 2013; Lowenthal et al, 2014; Sherr et al, 2014; Stein et al, 2014). These children and adolescents tend to experience enduring adversity. Multiple losses and bereavement, numerous sickness and hospitalisation, poor school attendance, increased poverty and exposure to violence, stigma and discrimination, disclosure challenges, as well as low levels of physical and psychosocial support furthers their risk for developing mental health problems (Mavhu et al, 2013; Bernays et al, 2014; Lowenthal et al, 2014).

One of the key risks for poor mental health, especially among orphans (many of whom are perinatally infected), is bereavement (Cluver et al, 2012; Willis et al, 2014). Research indicates that many bereaved children and adolescents will show resilience in adjusting to loss (Skovdal & Daniel, 2012); however, certain factors may influence their ability to grieve (Currier et al, 2007). How children comprehend and understand the reality and complexity of death depends on many factors, including the child’s level of cognitive development, the nature of his/her relationship with the person who died, the specific manner of the death (for example, sudden or stigmatised death), resilience, quality of subsequent care and social support (Webb, 2003; Wood et al, 2006). After a major death, a child’s immediate social environment either facilitates or inhibits his/her ability to engage in adaptive grief processes and achieve key developmental tasks (Li et al, 2008; Kaplow et al, 2012).

Cross-cultural research on natural grieving processes suggests that most humans need to recognise their grief and be able to express it directly in order to resolve their loss (Li et al, 2008). This can be formidable in contexts, such as South Africa, where there is stigma around death, pronounced for children and adolescents (Wood et al, 2006). Locally it is typical for adults to notify a child about the death of a loved one by whispering in their ear while they are sleeping and speaking about the dead is discouraged (van der Heijden & Swartz, 2010; Daniel et al, 2007). Oftentimes, although intended to be protective, children and adolescents are excluded from rituals, such as funerals, that could potentially aid in their grieving and legitimise their role in participating in community practices (Daniel et al, 2007).

Profound and multiple losses, often unrecognised and unmourned can lead to complications in the ability to grieve. Doka (1989) defined the concept of ‘disenfranchised grief’ as the grief that persons experience when they incur a loss that is not or cannot be openly acknowledged, publicly mourned or socially supported (Crenshaw, 2005). Not only does the child/adolescent not receive recognition, support or facilitation of their grief, but also there is no social sanction for feeling a loss in the first place. Research suggests that if the ability to grieve is not successfully engaged with, individuals may suffer *complicated grief* which includes (1) a sense of disbelief regarding the death; (2) anger and bitterness over the death; (3) recurrent pangs of painful emotions with intense yearning and longing for the deceased; and (4) preoccupation with thoughts of the loved one, often including distressing intrusive thoughts related to the death (Shear et al, 2005). This has long term impacts on mental health.

Contextually, it appears that adults are ill-equipped to identify and manage children’s and adolescent’s grief positively (Wood et al, 2006). Utilizing unconventional means of understanding mental health in HIV positive patients, such as drawing and writing, may be of particular benefit (Campbell et al, 2010; Skovdal et al, 2009; Willis et al, 2014; LeRoux-Rutledge et al, 2015). Unfortunately, many perinatally infected children and adolescents haven’t been afforded the opportunity to grieve significant losses or express their feelings about those they have lost (Willis et al, 2014; Wood et al, 2006). As management of mental health, including bereavement, has positive gains on HIV care and treatment (Patel et al, 2008; Kagee et al, 2013) it seems prudent to address this in adolescent patients in the healthcare system. Professionals in this system often come to know their perinatally infected patients well; these patients typically access treatment throughout their development thus providers are well placed to identify and address mental health concerns in patients. This study aimed to understand how mental health was reflected in drawings/writing and explored loss through these methods that were facilitated by lay counsellors.

Theoretical Framework

Relationships with healthcare providers

John Bowlby's attachment theory and Winnicott's notion of holding are meaningful theoretical contributions to understanding why healthcare providers' relationships with HIV positive paediatric patients are significant.

Bowlby (1969) believed to grow up mentally healthy, the infant and young child needed to experience a warm, intimate and continuous relationship with the mother (or permanent mother substitute) in which both found satisfaction and enjoyment. The disruption of this relationship through loss has significant adverse effects on the developing child/adolescent (Bretherton, 1996) with a need for repair and adequate replacement. The quality of children's attachment relationships before and after the loss of their parent(s) might likely be important in predicting concurrent and future social and emotional health (Li et al, 2008).

Ill health in the patient is likely to activate the attachment system because of distress and perceived vulnerability. Healthcare providers such as doctors, nurses and lay counsellors are likely to be placed in significant positions of influence in terms of engaging with attachment patterns of patients and facilitating self-regulation, especially those with long standing relationships with patients (Thompson & Ciechanowski, 2003).

Donald Winnicott's concept of holding is used here to denote not only the actual physical holding of the infant but also the total environmental provision of this (Winnicott, 1960). In reality, healthcare providers are in positions of offering patients a 'secure base' through a holding and containing relationship, with physical facilities reincarnated as 'brick mothers' (Rey, 1994). The attachment to healthcare providers established over time is conducive to containing the emotional aspects of patients, especially issues related to bereavement, where trust and safety are already established. Creativity in the context of the provider relationship is enormously valuable in nurturing emotional development and mitigating mental health risk.

Non verbal ways of communication – the power and potential of image making

The prospect of telling adults painful personal information can be difficult for children and adolescents. Likewise the idea of asking children and adolescents about these difficult experiences, can be daunting for adults. Regardless, the expression of painful experience is necessary for processing, making meaning, understanding, coping, integrating and ultimately mastering difficult events in one's life (Malchiodi, 2005).

Non-verbal means of working with children and adolescents have been proven to be effective for the treatment of bereavement and post-traumatic stress disorder (PTSD) (Webb, 2003; Goodman, 2005; Goodman et al, 2009; van der Kolk, 2007). These methods facilitate recall of memories, enabling them to be processed and for the artist to have control over this process (Buk, 2009). The creative product serves as a container for the affect, aiding in emotional regulation (Goodman et al, 2009). Creating art uses both sensory and emotional stimuli, thus making the artistic process a beneficial vehicle to access and integrate memories (Lusebrink, 2004). The act of creating offers the opportunity to externalise the imagery associated with painful experience. Words and meaning can be attached to these remnants now in tangible form; they can be organised and managed to create coherent narratives and ultimately to integrate the experience and move on from it (Schouten et al, 2015).

Image making in the research process

Research that utilises non-verbal methods, such as drawings, are also increasingly recognised as particularly ethical as they offer research subjects active participation in the research process, authenticating their voice through their engagement, offering more developmentally appropriate means of accessing data, diminishing stress in the child/adolescent-adult interaction and providing a more comfortable method of engagement than language (Clacherty & Donald, 2007; Coad, 2007; D'Amico et al, 2016; Driessnack, 2005; Berman, 2016). Non-verbal methods thus offer children/adolescents and adults an easier platform for communication.

Methods

Participants and procedures

This study examined the use of drawings completed by perinatally infected adolescents accessing public health care in Johannesburg. These drawings were facilitated by counsellors, known to the adolescents in the clinic, as a means of engaging in the experience of loss. This qualitative study used data from a larger quantitative study assessing mental health (depression, anxiety, post traumatic stress disorder (PTSD) and suicidality) using standardised scales (n=343). Adolescents between 13 and 19 years volunteered to participate in a 90 minute questionnaire administered on tablet computers, known to improve reporting of stigmatised behaviours (Jaspan et al., 2007; Toska, 2015), and interspersed with drawing tasks. The 'research counsellors' routinely provided direct services to the adolescents as counsellors, were trained in pediatric HIV and advanced counselling, and participated in the research, engaging in principles of ethical research with minors (Clacherty & Donald, 2007). Research counsellors had been trained previously in art based methods of counselling by a registered art therapist (approximately 50 hours) and received an additional 5 day training for this study, with an emphasis on distress protocol management. They also received weekly debriefing and supervision from a registered therapist throughout the course of data collection. Participants were recruited from clinics; three were hospital based; one was a community health centre and one a primary healthcare clinic. Most adolescents were on treatment for HIV (92% of sample) and had been attending clinics for many years. Most participants were found to be infected at birth and had all lived with HIV for as long as they remembered. However, a small number may have been infected through blood transfusion or rape in early childhood, and 1% (4 participants) were known to be horizontally infected.

For the current study, drawings of the most symptomatic and the least symptomatic participants on overall mental health scores were retrieved for comparison after analysing the mental health scores of the entire sample (n=343). This led to 26 responses to the drawing task: 'draw a picture of someone close to you who died' being selected for analysis. Seven of these were written accounts and 19 were drawn images. Some participants chose to write instead of draw. This instruction was given about midway in the questionnaire when rapport had been established, conversations around life histories and mental health were completed, and less emotionally loaded drawing tasks such as ‘draw where you sleep at home’ had been completed. The participants were offered a variety of drawing tools: pencils, coloured pencils, felt tip pens, pens and paper to employ for this task.

These drawings/written accounts were then assessed through 3 focus group discussions (FGDs) with professionals working with adolescents in the public health sector (art therapists, psychologists, social worker, counsellors). For each FGD, all drawings and written accounts were exhibited on the walls of the room for easy access to the visual material. The first focus group was conducted with four registered art therapists to reflect on the drawings/written accounts selected. These therapists worked with disenfranchised children/adolescents in urban community settings using art as the basis for therapeutic engagement. The second focus group was conducted with two psychologists and a social worker who worked with the population being studied in primary healthcare environments to similarly reflect on the drawings selected. The last focus group was conducted with six research counsellors and a study coordinator undertaking the data collection for this research study.

All data collected were identified by a unique participant number and kept in confidential files and tablet computers. Confidentiality was maintained unless participants reported abuse and requested assistance or were at risk of significant harm. Participants were given a pocket sized card with referrals for services in their neighbourhood including counselling, legal and crisis resources. Upon completion of the interview, participants received reimbursement for travel; a snack; and a gift voucher for R50 ($4) at a clothing retailer for each interview they attended. These items were endorsed and recommended by the adolescent community advisory board (CAB) instituted for this research.

Data analysis

Mental health was measured using standardized scales utilized previously with children in South Africa (Cluver et al, 2012). Depression was measured with the 10-item Child Depression Inventory Short Form (Kovacs, 1992), highly correlated with the full scale (r 0.89; Kovacs, 1992). Anxiety was measured using an abbreviated version of the 28-item Revised Children’s Manifest Anxiety Scale (Reynolds & Paget, 1983), which has been validated for use in South Africa (Boyes & Cluver, 2012).

Posttraumatic stress symptoms were measured using the Child PTSD Checklist (Amaya-Jackson, 1995). This comprises 28 DSM-IV-derived items, and has been validated in South Africa (Boyes et al, 2012). Suicidal behavior was measured with the MINI International Psychiatric Interview for children and adolescents suicide scale (Sheehan et al, 2004). This scale is well validated, showing strong internal consistency and test-retest reliability (Lecrubier et al, 1997). Data were analysed using Statistica v13 on the quantitative sample (n=343). Descriptive and bivariate analysis identified the most symptomatic (20 respondents that met the criteria for being symptomatic for depression and anxiety, and had the highest PTSD scores) and least symptomatic (20 respondents that did not meet the criteria for being symptomatic for depression and anxiety, and had the lowest PTSD scores) participants for overall mental health scores. From this group n=26 participants were identified for further analysis.

The 3 focus group discussions were recorded and transcribed verbatim. All identifying characteristics were coded or removed. Data were interrogated building an analytical framework of broad codes by creating a ‘start list’ of possible themes and building upon the research questions. Each broad code, or wide thematic basket of ideas, was applied to each transcript and ‘fine codes’ were developed using an inductive approach deriving meaning from the data itself rather than imposing pre-formed ideas (Creswell, 2014). To ensure intercoder reliability, fine codes were developed by three researchers competent in qualitative data analysis for each transcript, identifying sub-themes emerging from the data. Results were critiqued to guarantee research findings. Drawings/written accounts presented in this paper were selected by the same three researchers to ensure themes were properly represented through the imagery identified and examined.

Ethics consideration

The South African National Health Act states that ‘for health research with minors (<18 year olds), consent from a legal parent or guardian for research with children must be obtained’ (Section 71, 2012). This sample was speculated to possibly not have “legal” guardians from whom to obtain consent. As such, the medical research ethics committee of the University of the Witwatersrand advised approaching the court for permission to enroll participants in the study by obtaining a court order which was granted and led to full ethics clearance and permission to interview volunteers without parental or guardian consent (M130258). Permission was also granted from

Gauteng Provincial Department of Health, Johannesburg District Department of Health, and the research committees of facilities. The adolescents gave verbal assent and written consent to participate in the research, they gave written consent to use imagery produced, and all participation was sought on the basis of good clinical practice guidelines (Verma, 2013).

Results

Table 15. Descriptive information on most symptomatic and least symptomatic HIV positive adolescents

	Gender	Age	Loss depicted in drawing/ written description	Age when loss occurred	Current caregiver	Age when mother died	Drawing/ writing	Number losses experienced /who died	No. moves	Age started ARV treatment	Age of disclosure	Who disclosed status
Lease symptomatic	Female	15yrs	Mother	3yrs	Elder sister	3yrs	Drawing	2 – mother, uncle, (father unknown)	2	10yrs	14yrs	Elder sister
	Male	18yrs	Uncle	8yrs	Bio mother	-	Drawing	1 – uncle (both bio parents alive)	3	17yrs	17yrs	Bio mother
	Male	16yrs	Grandmother	10yrs	Children's home	3yrs	Drawing	3 – mother, father, grandmother	2	8yrs	10yrs	Grandmother
	Male	16yrs	Grandfather	Unknown	Bio mother	-	Drawing	3 – father, grandfather, grandmother	-	11yrs	11yrs	Bio mother
	Male	15yrs	Sister	12yrs	Elder sister	4yrs	Drawing	2 – mother, sister, (father unknown)	3	13yrs	14yrs	Sister
	Female	16yrs	Mother	5yrs	Grandmother	5yrs	Writing	2 – mother, uncle, (father unknown)	3	5yrs	5yrs	Family member
	Female	13yrs	Uncle	10yrs	Grandmother	3yrs	Drawing	2 – mother, uncle, (father unknown)	2	9yrs	-	-
	Male	15yrs	Mother	4yrs	Grandmother	4yrs	Drawing	2 – mother, uncle, (father unknown)	3	12yrs	12ys	Grandmother
	Male	13yrs	Father	8yrs	Maternal aunt	3yrs	Drawing	4 – mother, father, grandmother, uncle	3	7yrs	-	-
	Female	15yrs	Mother	3yrs	Grandmother	3yrs	Drawing	2 – mother, uncle, (father unknown)	2	10yrs	14yrs	Grandmother
	Male	14yrs	Father	5yrs	Aunt	7yrs	Writing	2 – mother, father	3	8yrs	12yrs	Family member
Most symptomatic	Female	17yrs	Mother	6yrs	Grandmother	6yrs	Writing	1 – mother (father unknown)	2	7yrs	-	-
	Female	13yrs	Mother	8yrs	Grandmother	8yrs	Drawing	4 – mother, father, sibling	3	12yrs	12yrs	Doctor
	Male	15yrs	Father	7yrs	Bio mother	-	Drawing	1 - father	3	8yrs	14yrs	Bio mother
	Female	13yrs	Father	10yrs	Bio mother	-	Writing	1 - father	4	5yrs	13yrs	Bio mother
	Male	15yrs	Aunt	9yrs	Bio mother	-	Drawing	1 – aunt, (father unknown)	3	12yrs	14yrs	Counsellor

	Female	14yrs	Mother	6yrs	Aunt	6yrs	Writing	4 – mother, father, grandmother, sibling	4	13yrs	13yrs	Counsellor
	Female	14yrs	Uncle	7yrs	Bio mother	-	Drawing	3 – uncle, grandmother, grandfather	1	10yrs	10yrs	Bio mother
	Female	16yrs	Mother	5yrs	Aunt	5yrs	Drawing	1 – mother, (father unknown)	5	8yrs	9yrs	Aunt
	Male	13yrs	Mother	8yrs	Grandmother	8yrs	Drawing	2 – mother, father	3	11yrs	11yrs	Brother
	Female	16yrs	Mother	5yrs	Grandmother	5yrs	Writing	2 – mother, father	2	9yrs	9yrs	Grandmother
	Male	19yrs	Mother	12yrs	Cousin	12yrs	Writing	3 – mother, father, grandmother	5	10yrs	10yrs	Counsellor
	Female	19yrs	Mother	11yrs	Aunt	11yrs	Drawing	3 – mother, grandfather, grandmother, (father unknown)	4	11yrs	12yrs	Social worker
	Male	13yr	Mother	4yrs	Children's home	4yrs	Drawing	4 – mother, father, grandmother, grandfather	4	11yrs	11yrs	Counsellor
	Female	17yrs	Mother	5yrs	Grandmother	5yrs	Drawing	3 – mother, father, brother	4	9yrs	11yrs	Grandmother
	Male	18yrs	Mother	6yrs	Aunt	6yrs	Drawing	2 – mother, father	3	14yrs	14yrs	Counsellor

Table 15 represents data from the 26 participants examined. Of all 26 drawings/written accounts reviewed, 11 were from the group with the least overall mental health problem symptoms (7males, 4 females; age range 13-18yrs with mean age 15yrs) and 15 from the group with most overall mental health problem symptoms (6 males, 9 females; age range 13-19yrs with mean age 15yrs). Of all the drawings/written accounts depicting the dead, the majority was of mothers (56%); only 6 participants in this sample still had a mother who was alive (23%). The median age for losing one's mother was 5yrs (range 3yrs-12yrs), so this significant loss tended to occur early in development. Only one participant was not orphaned (incidentally in the 'healthier' group), all others were either single or double orphans, and if fathers were not deceased, the majority were unknown to the participants. Many participants were living with grandmothers (35%), and two were in children's homes. Twelve participants (42%) had their HIV status disclosed to them when they started antiretroviral treatment, the remainder being disclosed to some time after treatment initiation. Three participants had not been disclosed to but knew they were taking antiretroviral treatment and what it was for. All participants in the least symptomatic group had been disclosed to by a family member, whilst 7 participants (50%) in the most symptomatic group had been disclosed to by a health professional. Participants had relocated, on average, at least 3 times in their lives, typically to different provinces or countries. They had also experienced on average between 2-3 significant losses in their lives.

Contextual deprivation and impoverishment

As indicated in table 15, multiple loss and bereavement was pervasive in this sample. Resultantly there was inconsistency in care and unpredictability of primary attachment figures through development with significant moving disruption over time.

My sister was sick for something like 3 months. She was in and out of hospital. The third time she was admitted, she passed on after 3weeks of admission.

Figure 11. 'Lungi', 15 year old male, least symptomatic group

'My sister was sick for something like three months. She was in and out of hospital. The third time she was admitted, she passed on after 3 weeks of admission.'

Early loss of mothers leads to major disruptions in care and, typically, additional loss. This drawing depicts the loss of a sibling. This participant lost his mother at age 4 which led to a move from Johannesburg to Kwazulu Natal to live with a paternal grandmother. That grandmother died when the participant was 8 years old, which led to a move back to a different area in Johannesburg, to live with his biological sisters. One sister died when the participant was 12 years old - the picture represented is of her (the loss having occurred 3 years earlier). In this drawing it is clear that the participant had a relationship with this person – she is anonymously named ‘Lungi’, there are details representing the figure and consideration has been taken with the particulars of her shirt and facial features. The hands are missing from the figure. Interestingly, after this significant loss, the participant was hospitalized the following year and started antiretroviral treatment then, i.e. his physical health deteriorated after this significant loss. When he was 14 years old (the following year), his caregiver, his older remaining sister, disclosed his HIV status to him. The participant identified that in this same year he experienced a traumatic event, a neighbor he was close to was shot and died in the street, an event he witnessed and was impacted by. This participant at 15 years old was repeating grade 8 (usually grade 8 learners are 13-14 years old).

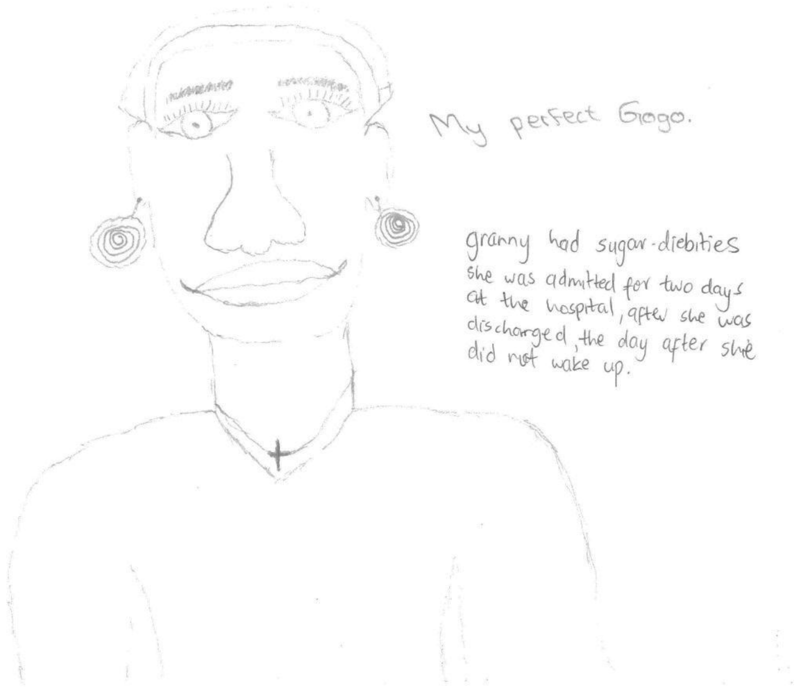


Figure 12. ‘My perfect gogo’, 16 year old male, least symptomatic group

‘Granny had sugar diabetes. She was admitted for two days at the hospital, after she was discharged, the day after she did not wake up.’

Similarly, this participant lost his mother at age 3, his father at age 5. This led to a move to another province and he began living with his grandmother. He became ill with shingles at age 8 and was hospitalised at this time, leading to a diagnosis of HIV and initiation of antiretroviral therapy. When he was 10 years old his grandmother disclosed his status to him and unfortunately, that same year she died (the loss occurring 6 years previously). The image depicted is of her and it is clear the participant had a close relationship with her, the figure being referenced as ‘my perfect gogo [grandmother]’ revealing possession and positive feeling. He fills the page with this image and adorns her with jewelry. It seems clear that the person is missed and beloved. This participant was moved to a children’s home and reported that at 11 years he started to accept his HIV status, understanding that ‘if I take my meds I can live more’.

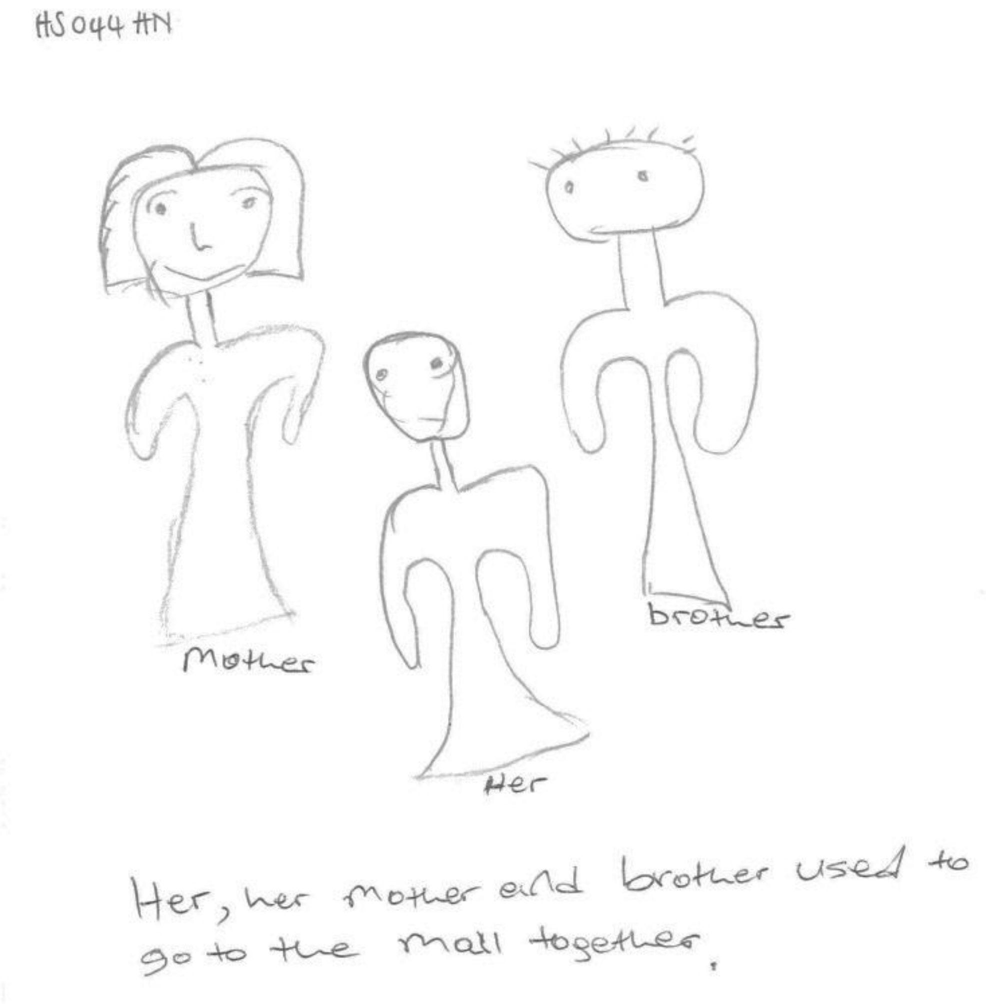
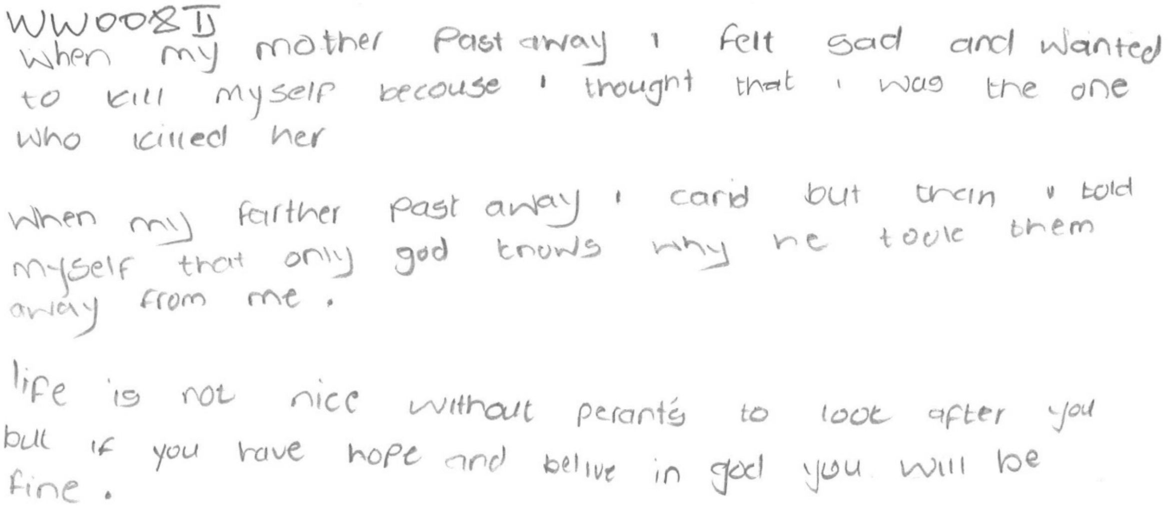


Figure 13. 17 year old female, most symptomatic group

‘Her, her mother and brother used to go to the mall together.’

Losses of biological parents in early childhood often led to outcomes of poor access to birth certificates and legal documents. This 17 year old participant lost her mother at age 5. It is unclear when she lost her brother, but it is assumed to be around the same time. She got critically ill after the death of her mother and at age 6 she was hospitalised for a few months. She had been living with her father, but after this event moved to live with her grandmother in another province. She started attending school at age 7, but schooling was interrupted by illness and she was again hospitalised at age 8. She was initiated on antiretroviral therapy by age 9. Her father died the following year. At age 11, the participant's aunt came to fetch her and her sister and took them to her deceased father's house that the aunt was now renting. Her aunt and grandmother were trying to get birth certificates for the children who didn't have them through social workers, also an attempt to obtain foster care grants. This was unsuccessful. At age 16 years, the participant was again hospitalised for illness. The image depicted is of her, her mother and brother. The figures are floating on the left side of the page; dismembered without hands and fingers or feet. The losses had occurred at least 12 years earlier but they do not seem integrated or resolved. The memory appears fragmented and the imagery ghost-like and not grounded.

Emotional deprivation and impoverishment



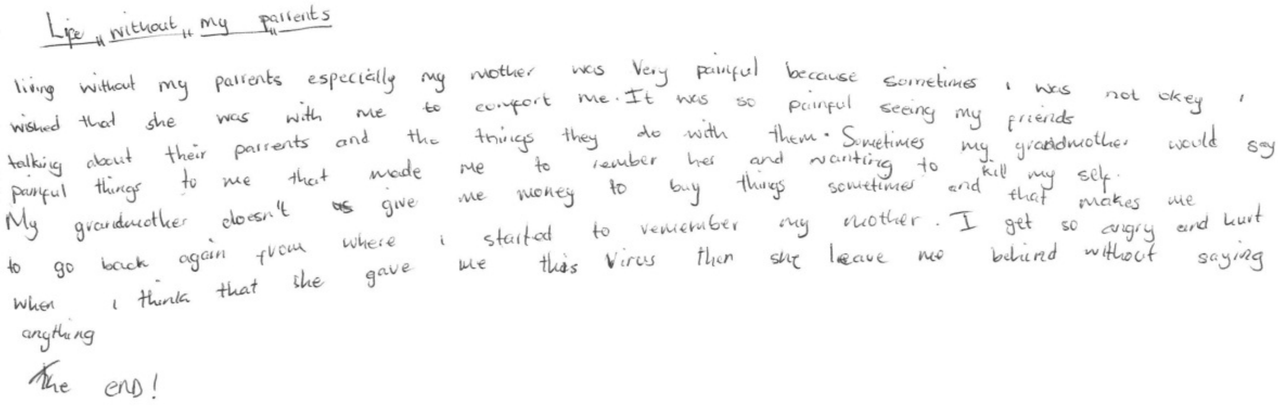
WW008TJ
when my mother Past away I felt sad and wanted
to kill myself becouse I thought that I was the one
who killed her

when my farther past away I carid but thein I told
myself that only god knows why he tooke them
away from me.

life is not nice without perants to look after you
but if you have hope and belive in god you will be
fine.

Figure 14. Written account, 14 year old male, most symptomatic group

'When my mother past away I felt sad and wanted to kill myself because I thought that I was the one who killed her. When my father past away I [cried] but then I told myself that only God knows why he took them away from me. Life is not nice without parents to look after you, but if you have hope and believe in God you will be fine.'



Life without my parrents

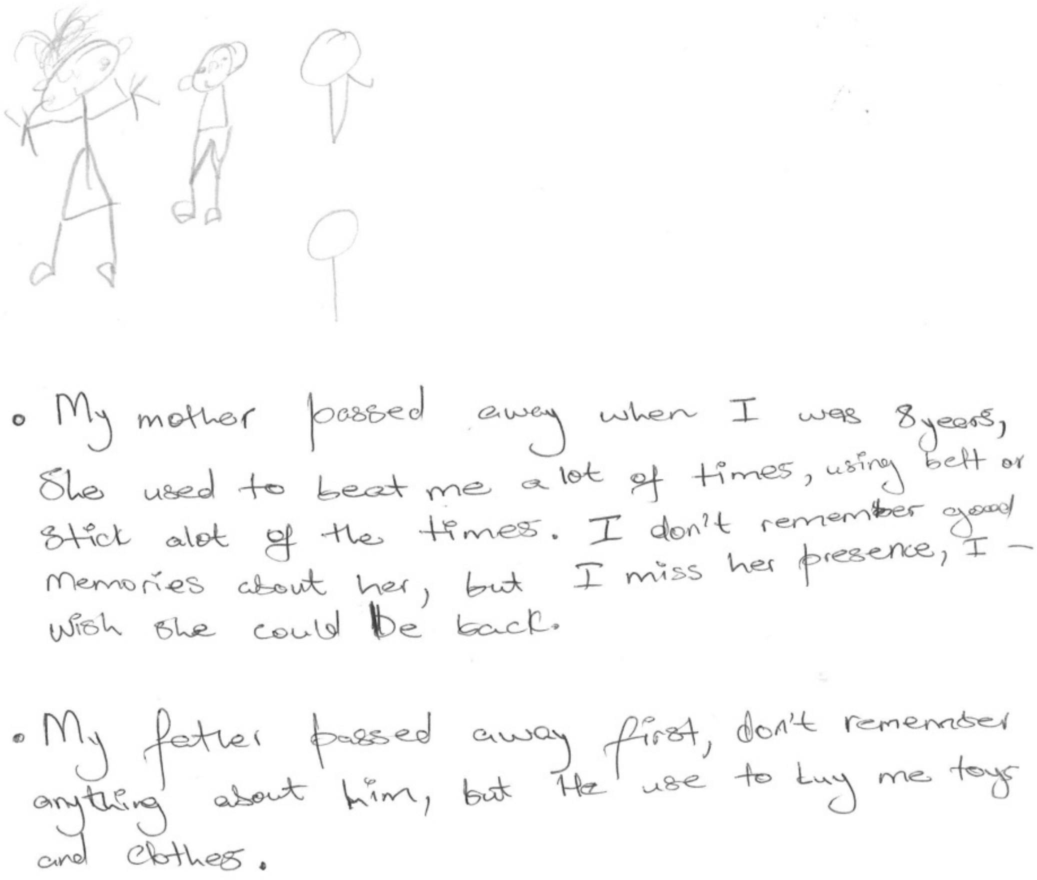
living without my parrents especially my mother was Very painful because sometimes i was not okey i
wished that she was with me to comfort me. It was so painful seeing my friends
talking about their parrents and the things they do with them. Sometimes my grandmother would say
painful things to me that made me to rember her and wanting to kill my self.
My grandmother doesn't ~~us~~ give me money to buy things sometimes and that makes me
to go back again from where i started to remember my mother. I get so angry and hurt
when i think that she gave me this Virus then she leave me behind without saying
anything

The end!

Figure 15. 'Life without my parents.' Written account, 16 year old female, most symptomatic group

'Living without my parents especially my mother was very painful because sometimes I was not okay. I wished that she was with me to comfort me. It was so painful seeing my friends talking about their parents and all the things they do with them. Sometimes my grandmother would say painful things to me that made me to remember her and wanting to kill myself. My grandmother doesn't give me money to buy things sometimes and that makes me to go back again from where I started to remember my mother. I get so angry and hurt when I think that she gave me this virus then she leave[s] me behind without saying anything. The end.'

Poor mental health as a result of bereavement and poor understanding of death is evident in these written accounts. Both participants were in the most symptomatic group. Both were double orphans having lost their parents at an early age (fig. 4 participant lost mother at age 6 years, father at age 9 years and currently living with an aunt; fig. 5 participant lost father at age 4 years, mother at age 5 years and currently living with grandmother). What is of note in these written accounts is how difficult life is without one's parents and both participants refer to having felt suicidal at times. The fig. 4 participant refers to feeling suicidal at the time of her mother's death (age 6 years) as she thought '*I was the one who killed her*'. This statement is also highly indicative of young children's cognition and ability to understand death at an early age. It is only by approximately age 8 years that children have acquired a mature understanding of death; namely that it is irreversible, final, inevitable and universal and an understanding of how it is caused (Goodman, 2005). As a result of young children's omnipotence, they often interpret death with their own meaning, feeling they were the cause of the event (Webb, 2003). One wonders if these cognitions of this participant were ever challenged or death ever understood through development. The fig. 5 participant also highlights levels of anger at the loss of her mother who gave her HIV and ‘*left me behind without saying anything’*. The mother died when the participant was 5 years old, and the grandmother disclosed the child’s HIV status to her when she was 6 years old. Ten years later, this participant is still angry about her mother’s betrayal of both lack of disclosure and death.



- My mother passed away when I was 8years, She used to beat me a lot of times, using belt or stick alot of the times. I don't remember good Memories about her, but I miss her presence, I – wish she could be back.
- My fatler passed away first, don't remember anything about him, but He use to buy me toys and clothes.

Figure 16. 13 year old male, most symptomatic group

‘My mother passed away when I was 8 years [old]. She used to beat me a lot of times, using [a] belt or stick a lot of the time. I don’t remember good memories about her, but I miss her presence. I wish she could be back. My father passed away first. [I] don’t remember anything about him but he use[d] to buy me toys and clothes.’

Developmental delays seemed evident in some drawings represented. Figure 6 is drawn by a 13 year old male who lost both his parents after long illnesses; father at age 6 years and mother at age 8 years. He started primary school at age 10 years after moving around for much of his early childhood and being hospitalised at age 4 years for 2 years. His imagery is child-like, disorganised, limited to the top left corner of the page and highly stylised. The research counsellor wrote the narrative of the drawing from the participant and it appears the mother beat this child when he was in her care. There seems little support was available through development and the family and education system let this participant down in terms of getting him appropriate access to timely education. This participant was currently in the care of his grandmother, was initiated on antiretroviral therapy at age 11 years and disclosed to that same year by his brother.

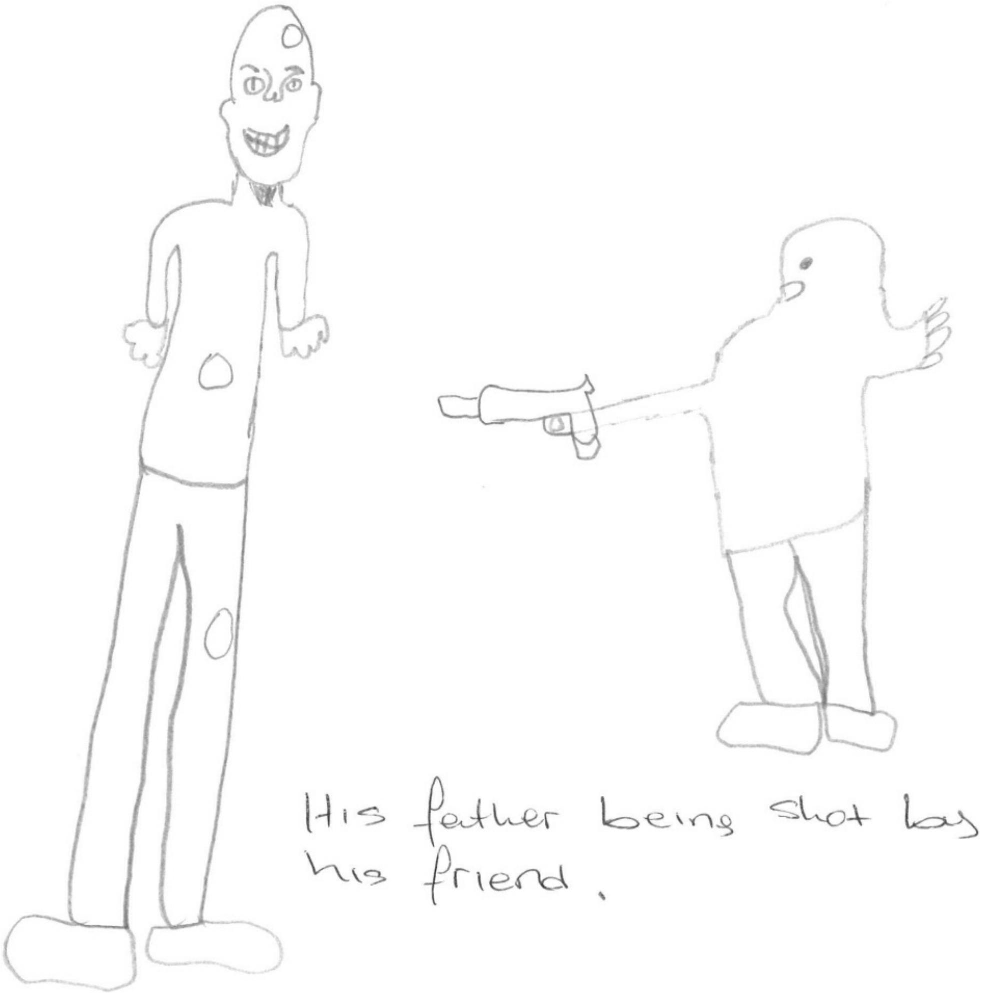
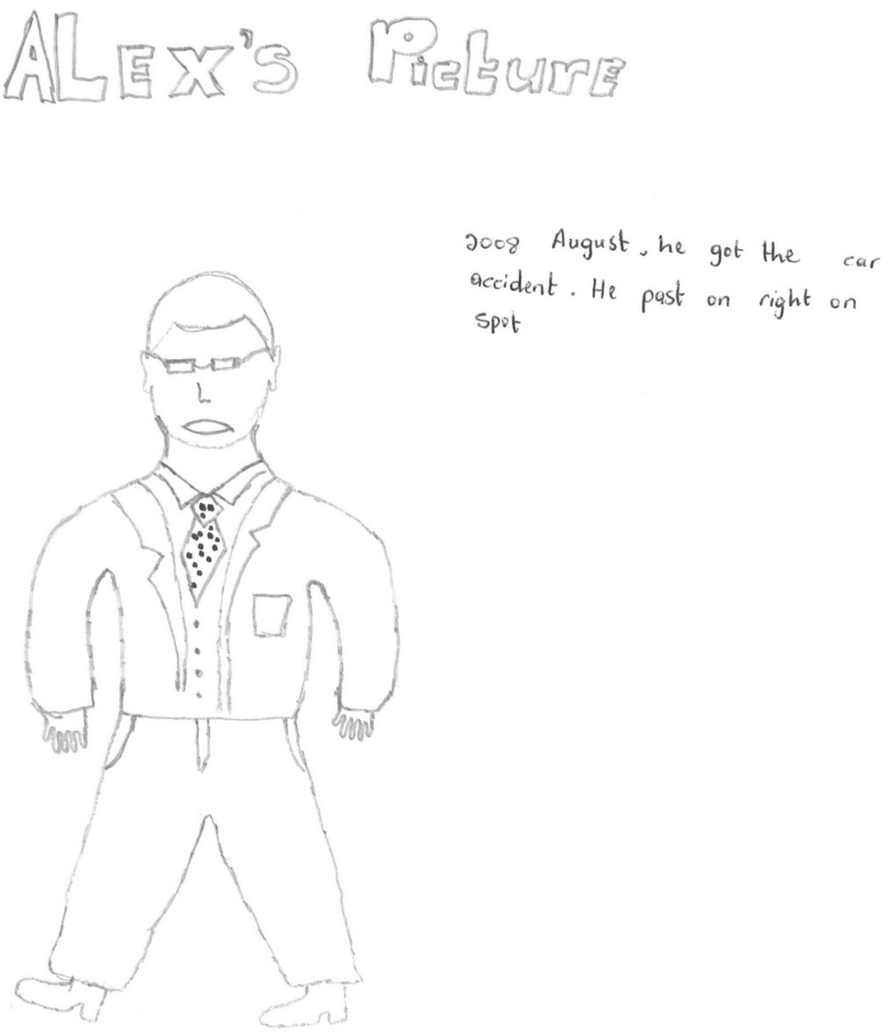


Figure 17. 'His father being shot by his friend', 15 year old male, most symptomatic group

Death seemed unresolved in many drawings, especially of participants in the most symptomatic group. This image depicts the death of the participant's father who was shot when the participant was 7 years old (8 years earlier). The participant became very ill the following year and was started on ARVs at age 8. The image is haunting - the deceased smirking with short arms and very long legs, three circles on the torso indicating where the bullets were fired, the perpetrator disfigured and dysmorphic, both images floating on the page. This participant also experienced multiple moves in his life, had numerous caregivers, attended many schools and had a history of fighting with peers. At age 12 years the police were called to the school as he attacked a teacher but he wasn't arrested. The title was written by the research counsellor.

Figure 18. 18 year old male, most symptomatic group

Similarly, figure 8 depicts the death of the participant's mother who died 12 years earlier. This participant also started school late, at 8 years and at 18 years was still attending school. He witnessed his mother's death at home after a long illness at age 6 years. The image is eerie with the female image vertical and the male horizontal. Both images are without hands, fingers or feet and seem suspended on the page. The eyes are vacant and there appear very few details on the figures presented. The writing is that of the research counsellor.



2008 August, he got the car accident. He past on right on spot

Figure 19. 'Alex's picture', 18 year old male, least symptomatic group

By way of comparison, figure 9 is a drawing by a male of the same age. This participant is the only one in the sample who was not orphaned. His parents were both still alive, both HIV positive and both adherent to treatment. The participant is a late progressor, discovering his HIV status when he attended a hospital for a circumcision at age 17 years and then initiated on antiretroviral therapy. His parents disclosed their status to him when he was 14 years old after he questioned them about the medication they were taking. The image depicts his deceased uncle, whom he was close to and who died in a car accident when he was 8 years old. The image is detailed; the participant used pencil and a marker for the dots on the tie of the image. The figure has hands and feet and even glasses. The image is entitled 'Alex's picture' which depicts ownership and a level of positive self-esteem.

Missed opportunities

Particularly for the most symptomatic group, mental health challenges had been evident for many years in most participants but were seemingly unrecognized by caregivers and not addressed in terms of access to care, leading to negative consequences in adolescence. As evidenced in other images, the issue of families not enrolling their children for timely early education is one system failure (as referenced in fig. 6). So too is the role of social services in obtaining identity documents to facilitate social welfare access (as referenced in fig. 3). Figure 10 below highlights a positive intervention on the part of social services. This participant's mother died when she was 3 years old and she moved provinces to live with her elder sister. The uncle appears to have taken ownership of the participant's mother's home and the participant used to visit the uncle in this home for the holidays. At age 14 years, the uncle wanted to sell the house and not give any inheritance to the mother's children. With the help of social workers, these sisters were able to receive their inheritance. The image depicted is of an integrated and adorned mother. Pencil as well as coloured marker was used to decorate and give detail to this figure.

I donot remember much because I was very young. Mom was very sick and she was ~~ab~~ admitted at the hospital in Mpumalanga and she passed on.

Figure 20. 'Thandayi Sithole', 15 year old female, least symptomatic group (synonym used)

'I don't remember much because I was very young. Mom was very sick and she was admitted at the hospital in Mpumalanga and she passed on.'

Discussion

The objective of this study was to use a drawing task with perinatally infected HIV positive adolescents who were bereaved to identify the impact of loss on their current mental health. Bereavement is pervasive in this population, often unidentified or unprocessed, and there are scant ways identified to manage loss in the public health system. This study reveals that loss can be engaged with through drawing and written accounts facilitated by lay counsellors to uncover areas of emotional difficulty in patients that require attention. In addition, drawings and written accounts may provide vital and obvious clues in identifying those at risk for mental health problems in adolescent patients.

Through focus group discussions with professionals engaged in care with HIV positive adolescents, the drawings of the participants in this study highlight contextual deprivation, including high exposure to multiple and consistent loss of significant members of their families. Losses led to relocation and loss of familiarity of context, inconsistency in caregivers and primary attachment figures and disruptions in schooling. There seems to be little support or value of these experiences in the lives of participants with little control over the events or preparation for them. The drawings also underscore emotional deprivation and impoverishment, including unresolved complicated grieving impacting on mental health functioning, exacerbating suicidality, emotional and developmental delays, poor self esteem and indications of HIV related stigma. Lastly, the drawings emphasise missed opportunities of families, education, social services and health systems in identifying early education opportunities for orphans, encountering difficulties in access to unclaimed birth documentation and legal standing and failing to address the mental health concerns for those most at risk and on treatment.

Participants in the most symptomatic group seemed to depict losses of mothers more than the other group. These losses had occurred many years before, often during key developmental stages of life, and their imagery appeared more fragmented, dislocated, ungrounded, ghost-like, idealised and stylised perhaps indicating a lack of integration of the event in their lives. Their grief appeared to be present but lacked resolution and was highly defended in its presentation.

The ability to symbolise and utilise imagination for some participants appeared to be difficult. This can be particularly true of children who have been traumatised to the point of psychological numbing (Malchiodi, 1998) and could highlight emotional defensiveness. These limitations were more evident in the most symptomatic group. Other children may have feared failure without any guidelines or assistance, or may have felt like they may ‘do it wrong’ in the presence of an adult watching them (although these barriers to engagement were addressed through continuous training and supervision of the research counsellors). Children’s drawing behavior tends to develop along with their cognitive skills (such as thinking, problem-solving and remembering) and emotional development (Kortesluoma et al, 2008). As such, the drawings, especially of the most symptomatic group indicated potential emotional and cognitive delays, these findings consistent with research indicating neurocognitive developmental delays evident in perinatally infected HIV positive adolescents (Lowenthal et al, 2014; Sherr et al, 2014).

A striking finding was that after the death of these significant figures in the lives of the participants, frequently their physical health deteriorated, often leading to prolonged hospitalisation and the advent of an HIV diagnosis alongside treatment initiation. It appears the psychological event of the death of a primary caregiver is a trigger to HIV treatment and uptake of healthcare services. Healthcare providers could thus valuably engage in conversations about bereavement and loss with their patients, especially if they find child or adolescent patients struggling with adherence to treatment or hospitalised for major illness.

The participants in this study had been accessing healthcare for many years, not only for themselves, but through family members who had been hospitalised for extended periods of time too. Healthcare providers had been working with them throughout their development. It could be argued that a valuable personal connection may be established through this consistency; patients have access to someone significant in their lives amidst much other change in their personal contexts. These provider relationships are essential to both physical and emotional care especially of HIV positive patients (Hatcher & Bonell, 2016). Utilising non-verbal ways of expressing life experiences and being witnessed through a supportive relationship would seem to strengthen understanding of patients. Therefore, art making and writing in this relational dynamic, which intrinsically facilitates communication and creates a containing space, presents a potentially valuable means of approaching mental health in adolescent patients.

Silence around death and bereavement may not help adolescents deal with loss optimally (Daniel et al, 2007). Hence, breaching cultural silence may be seen as a protective factor enhancing adolescent resilience (Daniel et al, 2007; Woollett et al, 2016). For participants in this study, painful memories and loss were not forgotten. Documenting and remembering significant people in their lives whom they had lost was a critical element of their life story. It is advisable that communities, including the healthcare community, consider how to allow adolescents to engage with and talk about their losses, even in cultural contexts where they are not normally included in rituals or conversations about death (Wood et al, 2006; Mannarino & Cohen, 2011). Not addressing these serious issues may curtail adolescents' opportunities to discuss, learn, understand, and accept their own illness as well as manage their disease (Bernays et al, 2014). The healthcare environment could be actively utilised as a coping-enabling social environment for adolescent patients, increasing opportunities for resilience, and enhancing participation as a strategy to cope with hardship (Skovdal & Daniel, 2012).

It is important that a pathological focus does not overshadow the plurality of experience and the ability of some to manage significant hardship (Skovdal & Daniel, 2012). Participants in the least symptomatic group seemed resilient in the face of adversity showing creativity both in their artwork and in their ability to navigate social supports available to them. Many had close relationships with their primary caregivers (sisters, grandmothers etc.) and although they lost these figures at some point, the loss was relatively more recent, indicating that there had been a close relationship over a number of years. There also appeared to be more support for these participants, perhaps helping them in their grieving and leading to more positive mental health outcomes. Their drawings appear more integrated and more detailed compared to the most symptomatic group.

Addressing mental health care in children and adolescents, has potential to improve HIV treatment and prevention; however, with poor resources of specialised mental health providers to facilitate care, the emotional needs of patients are largely untreated. Psychologists and psychiatrists are in short supply with 0.28 psychiatrists and 0.32 psychologists per 100,000 population working in the public health sector (Lund et al, 2010). It seems prudent that task-sharing, whereby non-mental health specialists provide mental health services under supervision of specialists, may be the most feasible way to deliver inexpensive, effective mental health services in primary care (Saraceno et al, 2007). There is growing evidence that lay counsellors are able to provide skillful and effective task-sharing interventions locally (Petersen et al, 2014; Padmanathan & De Silva, 2016; Mendenhall et al, 2014). Increased skills in the use of non-verbal methods of working that are easily transferred may be particularly useful. Creativity in patient care and in research has the potential to impact participants in meaningful ways, giving participants the opportunity to become active in their healthcare, permitting them to use imagination in productive and corrective ways. In this study, it seemed that through the facilitated conversations about the images, participants were able to articulate and verbalise some of their stories. Lay counsellors facilitated this process well.

The drawings in this sample reflect little experience in using art materials, a finding represented in other studies in South Africa, highlighting environments of limited material resources (Clacherty & Donald, 2007). Very little use of colour was evidenced and most participants chose to either write in pen or pencil or draw in pencil alone. Although this was the second drawing task in the questionnaire and research counsellors were versed in helping participants become comfortable with materials, it appears that materials were used tentatively. It is recommended that before engaging in using art materials with this population, participants be given time to explore materials and discover their potential.

It was not the intention to analyse the drawings represented in this study in a mechanistic, intellectualised approach to pictorial analysis. The drawings were processed with the research counsellors and participants gave voice in this containing relationship to their imagery and narratives. An intuitive response, which may be regarded as unreliable and subjective, was undertaken through participants in the focus group discussions. All participants had a keen aesthetic sensitivity, strong affinity and empathy for the visual images and it is believed they were able to perceive and experience the aesthetic dynamics inherent in each image. However, it may be possible that a different group would perceive alternative findings.

This limitation must be interpreted in light of others in this study. There was no control group and no comparator for visual imagery of this population, thus claims and conclusions based on these drawings are merely speculative and warrant further investigation. Participants were conveniently sampled and recruited from primary healthcare facilities in an urban setting so findings may not be generalisable to adolescents in other contexts. Drawings were requested in a quantitative questionnaire and were not overtly introduced as therapeutic per se. There may have been compliance or permission seeking on the part of participants leading to curbed expression in their drawings. The study relied on self-report that may have led to social desirability bias. There is currently no precise test to determine perinatal infection, especially in resource poor settings where accurate clinical records are a challenge to obtain, so symptoms, time of first hospitalization and timing of ART initiation are used as guides (Ferrand et al, 2009). Resultantly, some adolescents assumed to be perinatally infected in this study may not have been. Notwithstanding these limitations, our findings have several important clinical and research implications, and they highlight a potentially valuable means of interaction with patients that is largely underutilized in the health system.

Conclusion

It is only in recent years that adolescents have been afforded the opportunity of living a full and long life as a result of intensive scale up of antiretroviral therapy and treatment initiation. The push for survival has been in the biomedical effectiveness of managing HIV disease, but this is no longer sufficient given the impact of multiple losses and bereavement typically experienced by perinatally infected HIV positive adolescents and the longstanding effects of these events. Healthcare is not just about prolonging lives, there is need to support all parts of health, as this is the true burden of care. In contrast to policy and programming for ART, there has been relatively little commitment to the need for effective therapeutic interventions that can aid HIV positive adolescents in managing the emotional and developmental challenges in their lives. Screening for common mental health problems, particularly bereavement, would be of enormous benefit to patients at high risk, including adolescents in healthcare contexts. Including more adolescent friendly ways of working, such as utilising the arts and creativity may offer a means of mitigating the detrimental impact of bereavement associated with this population. The use of these methods by healthcare professionals could be especially valuable.

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CHAPTER 9

Discussion – using the evidence to understand the mental health of HIV positive adolescents retained in care and improve mental health services for them

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Introduction

The aim of the study that this PhD thesis is founded on is to strengthen the evidence base for improving the delivery of mental healthcare services to HIV positive adolescents in care in South Africa. Adolescents are an increasingly growing and vulnerable population and healthcare environments will have an intensifying burden to treat and manage this population in the coming decades. Much more can be done to strengthen systems of care and attend to patients who present with a diversity of need, including significant mental health issues and complex social problems.

The increasing numbers of HIV-infected adolescents entering adult care in the next 5-10 years could put a strain on already limited resources. Infants surviving and initiating ART in the mid-2000s are now transitioning into adolescence. Additionally, 25–30% of perinatally infected children are slow progressors who can survive undiagnosed and untreated well into adolescence (Ferrand et al, 2009; Marston et al, 2011). As this wave of perinatally HIV-infected adolescents mature, combined with the high number of new infections amoung older adolescents, a large number of adolescents will transfer from paediatric or adolescent based clinics to adult services (Ikard et al, 2005). There is little to nothing in place in terms of policy or practice to assist with transitioning this population into adult HIV care systems. These already overwhelmed institutions in South Africa are poorly prepared for the increased patient population. In addition, adolescents have different needs from patients currently in care at adult services and have lower viral suppression and retention rates (Zanoni et al, 2016). With many chronic illnesses, this transition is often linked with lapses in adherence and poor clinical results (Cervia, 2013; Fish et al, 2014; Patton et al, 2016). Revolving healthcare professionals, lack of youth-friendly care, inflexible scheduling and decreased adult caregiver involvement have marred this transition process (Tylee et al, 2007; Lowenthal et al, 2015; Dahourou et al, 2017).

Furthermore, although efforts have been made to improve mental healthcare services both in South Africa and internationally, gaps are still noted in the literature.

In this thesis I have addressed some of these gaps in five broad focus areas: (1) challenges of undertaking research with adolescents in South Africa (Chapter 4); (2) mental health problems in HIV positive adolescents accessing treatment (Chapter 5), (3) how bereavement and poor disclosure impact on understanding HIV disease in this population (Chapter 6), (4) resilience in HIV positive adolescents (Chapter 7), and (5) how lay counsellors can utilize drawing in engaging adolescents regarding loss and mental health concerns (Chapter 8).

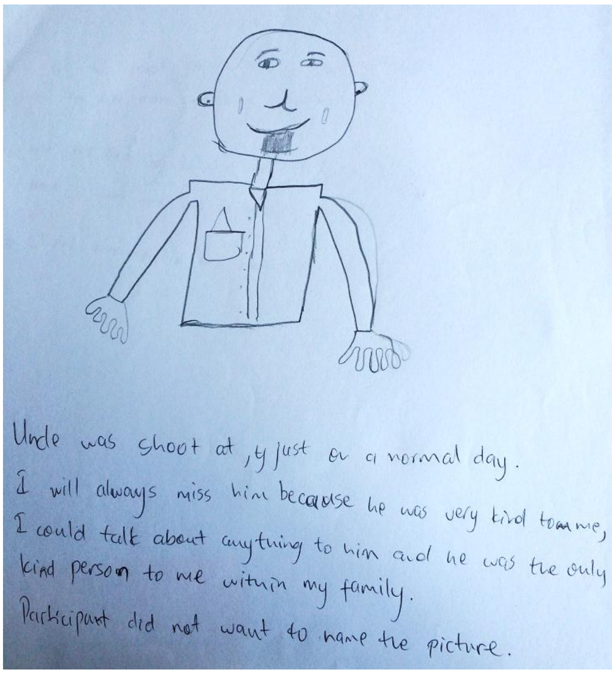
In this chapter I summarize how the main findings of this thesis contribute to the current evidence on the mental health of HIV positive adolescents engaged in care, reflecting on the implications these findings have for mental healthcare services in South Africa. Overall limitations of all the publications are then presented before ending with recommendations for future research and a final conclusion on the thesis.

Summary of findings

Findings from our study underscore the need to improve efforts to identify and reduce mental health problems in adolescents accessing public healthcare for HIV treatment. We found that approximately a third (27%) of the HIV positive adolescents were symptomatic for any of these mental health disorders: depression, anxiety, PTSD, suicidality. Our study found that being HIV positive may be a critical predictor of mental health problems in adolescence. This is a similar finding in comparison to US and European studies; however in these other global contexts, mental health problems are usually treated and the paediatric HIV epidemic is near eradication (Mellins & Malee, 2013). In LMICs like South Africa, staggering numbers of children have been or will be infected with HIV and with increasing access to ART, they will reach adolescence and young adulthood, requiring proven mental health treatment and prevention programmes. Our sample was ‘non-clinical’, i.e. they were not accessing healthcare for mental health, but rather HIV care and treatment. However, it was clear from our study that it is critically important to assess comorbid mental health problems of youth accessing HIV treatment and care services. Our study recommends that policy and public health practice integrate HIV and mental healthcare for young people, with HIV being a facilitative nexus to mental healthcare.

Global suicide rates have risen by 60% in the past 50 years, although reliable data are lack from SSA (Cluver et al, 2015). Suicidality and suicidal ideation was high in our sample (24% with 5% screened out at the start). This is not surprising as suicide is a major risk factor in adolescence both nationally and internationally. South African suicide rates range from 11.5 per 100 000 to 25 per 100 000 of the population; and on average 9.5% of non-natural deaths in young people are due to suicide (Schlebusch, 2012). However, it is troubling that most of the adolescents in our sample had not been asked about suicide before from anyone, least of all from a healthcare provider. Screening in such a high risk group seems necessary and a missed opportunity in linking them to appropriate care.

Experience with violence in adolescence is widespread and related to increased risk of depressive disorders and suicide attempts, poor educational attainment, and increased risk of perpetrating or experiencing intimate partner violence in future relationships (Devries et al, 2015). The experience of violence, both directly and indirectly, at school, in the home and community was high in our sample and had similarly significant implications for mental health. Exposure to violence was strongly related to PTSD, but also to anxiety and depression to a lesser degree. Peer victimization in and outside of school was powerfully associated with poor mental health outcomes indicating the need to address violence not only at community, but also at school level and particularly amoungst adolescent peers. Findings suggest the need for increased stigma reduction at the adolescent level related to ill health, particularly HIV. Poor relationships with peers, feelings of lack of security, and negative life events may increase the risk of mental disorders in this population (Cheng et al, 2014). Unfortunately, although violence is an important risk factor for adverse mental health, and violence exposure is particularly high in South Africa (Seedat et al, 2009; Nothling et al, 2016), it is rarely screened for in young people who require adult and system protection.

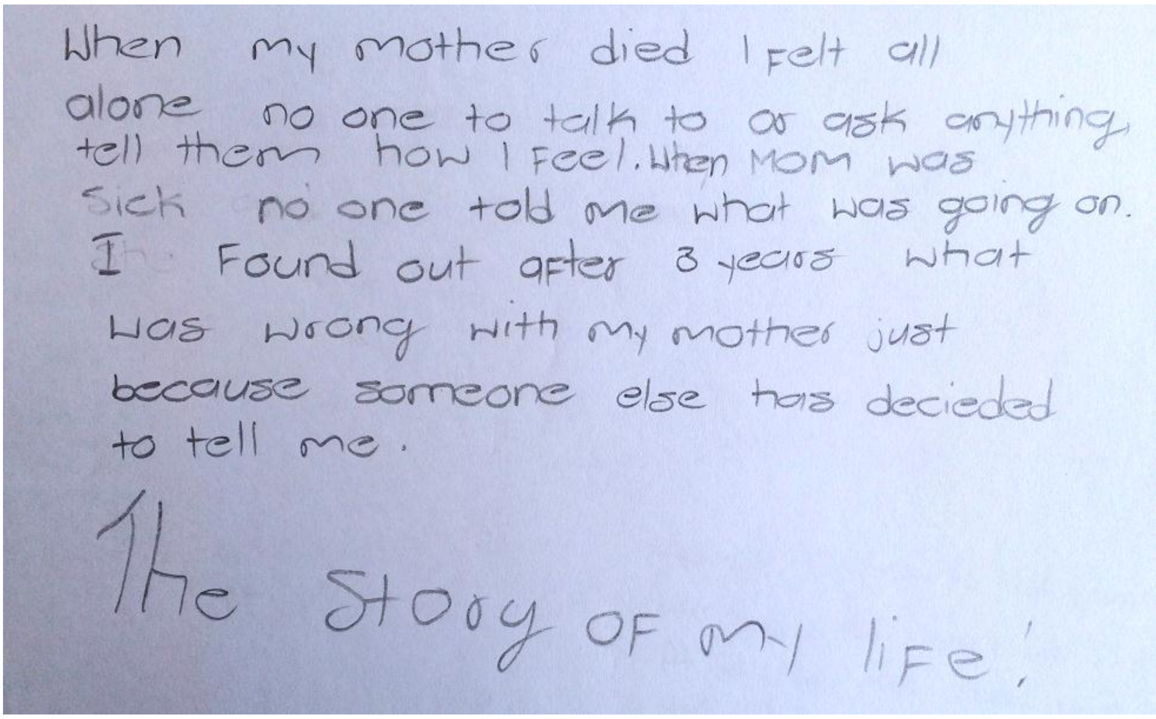


Uncle was shoot at, y just on a normal day.
I will always miss him because he was very kind to me,
I could talk about anything to him and he was the only
kind person to me within my family.
Participant did not want to name the picture.

Figure 21. Written account of community violence (Female, 14 years old at time of the interview in 2013).

'[My] uncle was shot at…just on a normal day. I will always miss him because he was very kind to me. I could talk about anything to him and he was the only kind person to me within my family.'

Although 78% of our sample reported having been disclosed to, just 50% knew how they became infected, and only 23% reported to disclosing their status to someone else. Adolescents need more reliable and comprehensive information regarding vertical transmission. They also need to be able to speak openly about their HIV disease and understand it. Indeed, chapter 7 clearly indicates that even with participants thought to be well informed about HIV they actually weren't. Our participants had both a lack of understanding of PMTCT and future reproductive health options, as well as unreliable comprehension of how they contracted HIV and pathways to vertical transmission. Increased rates of unprotected sex have been described by HIV positive adolescents and notably higher rates of virological failure amoungst HIV positive adolescents engaging in unprotected sex, indicating higher transmission risk to uninfected peers (Toska et al, 2016). Effective programming to reduce sexual risk behaviour for this vulnerable group is vital. In tandem, awareness of and knowledge about reproductive health, HIV transmission, and contraceptive methods is poor amoung HIV-infected adolescents and needs to be strengthened to avert secondary transmission, increase uptake of contraception, and promote safe pregnancies (Lowenthal et al, 2014). Evidence suggests that HIV positive adolescent females rarely discuss pregnancy intentions with family or providers suggesting a potential fear of being judged for wanting to conceive when living with HIV; indicating a need and opportunity for preconception counselling in this patient population (Echenique et al, 2016). Topics such as sexual and reproductive health are taboo and are not easily spoken about in families, thus healthcare environments are poised to fill this gap with factual and developmentally appropriate information (Vujovic et al, 2014). By reaching adolescents before they become sexually active, programmes that raise awareness of sexual and reproductive health matters can play a constructive role in preventing onward transmission (Vujovic et al, 2014). Furthermore, our study indicated that disclosure, both with regards to their HIV status as well as the cause of parental death, was a central theme that emerged to impact perinatally infected adolescents' understanding of their diagnosis as well as their mental health. Cultural silence around both death and disclosure, although intended to be protective to children and adolescents, has some unintended and dire consequences. The denial inherent in this silence and its formulation over time and through development leads to poor understanding of one's disease and reinforces stigma around HIV with consequent costs to mental health functioning (Daniel et al, 2007).



When my mother died I felt all
alone no one to talk to or ask anything,
tell them how I feel. When MOM was
Sick no one told me what was going on.
I Found out after 3 years what
was wrong with my mother just
because someone else has decieded
to tell me.

The Story OF my life!

Figure 22. 'The story of my life'. Written account death of mother (Female, 16 years old at time of the interview in 2013).

'When my mother died I felt all along, no one to talk to or ask anything…[or] tell them how I feel. When mom was sick no one told me what was going on. I found out after 3 years what was wrong with my mother just because someone else has decided to tell me.'

Unfortunately, lack of comprehension has calamitous consequences for adolescents especially when they age out of paediatric care and where assumptions may be made about their knowledge and understanding. Studies have found very high morbidity and mortality rates amoung adolescents who are transitioned out of paediatric care; reasons include lack of relationship with adult providers, inadequate detection of mental health concerns, lack of independence on the part of the adolescent (with poor understanding of medical histories), and often being ill prepared for self management of the HIV disease (Pearlstein et al, 2013; Fish et al, 2014; Hussen et al, 2015; Patton et al, 2016).

Early and full disclosure (i.e. disclosure as a process over time) is powerfully linked to improved adherence amoungst ART-initiated adolescents (Cluver et al, 2015; Vaz et al 2010). Adolescents who have been told their HIV status and understand their diagnosis are significantly less anxious than those who haven't and those that know their status for longer report higher intentions to self-disclose to potential sex partners (Santamaria et al, 2011). Disclosure may be a crucial tool in improving adolescent adherence and decreasing mortality and onwards transmission. Our study also suggests that disclosure is protective against mental health problems in adolescence; a compelling reason to support both families and healthcare providers to engage in comprehensive disclosure with youth in their care (Santamaria et al, 2011; Kidia et al, 2014; Cluver et al, 2015). Empowered young patients who know their status and have improved agency as a result of it (Kidia, 2014), may more easily be able to think about their future and dream into it. These elements were found to be protective against mental health problems.

Bereavements' impact on HIV positive adolescents

Almost 90% of this sample reported they did not feel they belonged in the family they were being raised in. Ninety percent shared that they did not get praise from those they live with, and 85% conveyed they did not get the same things as other children in the home. Given that these adolescents are being raised outside of their nuclear families, and live in environments characterized by high levels of migrancy and mobility, urban poverty, violence, and lack of family structure, these factors all intensify the difficulty of being infected. Emotional bonds to those taking care of them appear to be weak and unstable. Family based prevention interventions have valuable public health potential for advancing family functioning and mental health of HIV infected adolescents, including addressing emotional and behavioural problems that intensify risk of HIV reinfection and secondary transmission (Betancourt et al, 2014). In addition, adolescents who did not feel safe in their homes or communities presented higher mental health problems, indicating the need for increased social protection of this vulnerable population and recognition of this link to mental health challenges. Reducing family disadvantage (most notably through poverty alleviation mechanisms such as government provided cash transfers), abusive parenting (through positive parenting interventions) and mental health services for adolescents and caregivers (through improved access to treatment) is essential in improving adolescent health in South Africa (Meinck et al, 2016).

Notably, from chapter 6 and 8 it was apparent that this population was still grieving multiple and significant losses that had occurred many years prior and throughout their childhoods, and that their suffering was complicated. Orphans are significantly disadvantaged by social norms that exclude children and adolescents from the truth about death which in turn leaves the most vulnerable in the community to grieve clandestinely and unsupported (Wood et al, 2006; van der Heijden & Swartz, 2010). HIV related death is compounded by the stigma of the disease, leading to further silence and secrecy, and with potential increased internalized stigma on the part of the HIV positive adolescent. This is particularly the case in South Africa (van der Heijden & Swartz, 2010). Without detection and treatment of these exclusions, the consequent unresolved feelings can lead to more longstanding mental health problems that may become worsened in adolescence and present as currently unaddressed (Sherr & Mueller, 2009). In addition, it is likely that at the point of diagnosis for these adolescents, they were probably considered terminal (Small et al, 2014). These beliefs could translate to a fear of death at one’s own disclosure signifying the need for a keen understanding of death as well as HIV infection and treatment so that negative beliefs and misconstrued understandings can be managed as they surface developmentally (Wood et al, 2006; Daniel et al, 2007).

In HIV endemic areas such as South Africa, children and adolescents are exposed to the effects of HIV at the household and community level from an early age, including exposure to death and dying. It is only by approximately age 8 years that children have acquired a mature understanding of death; namely that it is irreversible, final, inevitable and universal and a reliable comprehension of how it is caused (Goodman, 2005). Most of the literature discussing children's cognitive understanding of death relies on Piaget's general theory of cognitive development and the 2-7 year old developmental phase (pre-operational stage) is characterised by magical thinking and egocentricity (Piaget, 1954). (It was during this developmental phase that most participants in our study lost their primary caregivers, namely their parents). The child believes that the world revolves around him/her and that events happen because of his or her good or bad behaviour (Webb, 2003). As a result of young children's omnipotence, they often interpret death with their own meaning, feeling they were the cause of the event (Webb, 2003). Young people may thus carry with them the idea that they caused the death of their loved one and this can only be dispelled when it is raised and discussed – for that to transpire, there needs to be an environment of openness regarding talking about death and how or why it occurs.

Parental and caregiver support to deal with parent-child communication about HIV and death is an important public health priority in the South African context (Rochat et al, 2016). There is often a mismatch between what caregivers believe children can understand, and what children actually understand (Gaab et al, 2013). Their willingness to communicate about HIV related illness and death may be influenced by cultural beliefs and practices, concerns about stigma, and a desire to protect children (Mdleleni-Bookholane et al, 2004; Van der Heijden & Swartz, 2010). This lack of communication is unhelpful, and can even be harmful for children (Gaab et al, 2013). Recent local research found that the period following disclosure is an opportune time to provide children with accurate, developmentally-appropriate information, which would be protective and inhibit the development of an incomplete or erroneous understanding of HIV, that may compromise children's longer-term adjustment to parental illness and death (Rochat et al, 2016).

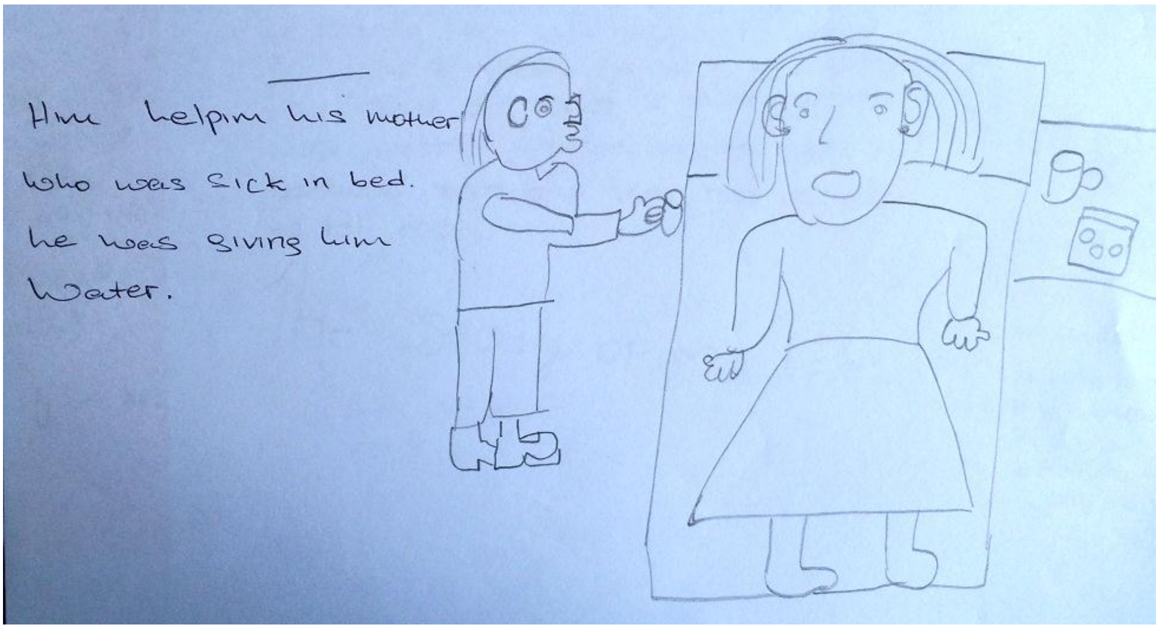


Figure 23. Drawing of taking care of sick, bedridden mother (Male, 15 years old at time of interview in 2014).

Penetrating cultural silence may be seen as a protective factor improving adolescent resilience (Daniel et al, 2007). For participants in our studies, sorrowful memories and loss were not forgotten even though they were not spoken about. Documenting and remembering significant people in their lives whom they had lost was an essential element of their life story. It is advisable that communities, including the healthcare community, consider how to allow adolescents to engage with and talk about their losses, even in cultural contexts where they are not normally included in rituals or conversations about death (Wood et al, 2006; Mannarino & Cohen, 2011). Not addressing these serious issues may limit adolescents' opportunities to discuss, learn, understand, and accept their own illness as well as manage their disease (Bernays et al, 2014). An adolescent's ability to cope is shaped by the extent to which they are able to engage with their community and negotiate assistance from it (Skovdal et al, 2009) thus enabling environments that include their participation lead to optimal coping. As such, the healthcare environment could be actively employed as a coping-enabling social environment for adolescent patients, increasing opportunities for resilience, and boosting participation as a strategy to cope with hardship (Skovdal & Daniel, 2012).

Implications for healthcare settings

There are some critical indicators of mental health risk that emerged from the studies that could be incorporated into practical screening for adolescents at primary healthcare level (with little training required). These include assessing if patients are hungry and whether they have been sick or hospitalized in the last year. Whether they are orphans and still yearning for their parents. A striking finding from chapter 5 was that after the death of significant figures in the lives of the participants, frequently their physical health declined rapidly, often leading to prolonged hospitalisation and the advent of an HIV diagnosis together with treatment initiation (typically these children did not know they were HIV positive and were not on ARVs prior to their bereavements). It appears the psychological event of the death of a primary caregiver is a trigger to HIV treatment and uptake of healthcare services. So, enquiring about recent caregiver or parental death may identify high risk adolescents. There was a high possibility that adolescents would be struggling with mental health concerns if they did not feel they controlled their future or if they did not have a dream for the future. These questions could easily be asked in patient care and could lead to referral for high risk patients. Also, consistent and continuous messaging around HIV and ART is needed to ensure care and treatment is optimal, especially for this high risk population. HIV care programmes must provide age-appropriate information on prevention of HIV transmission and family-planning/contraceptive services and present support regarding disclosure of HIV status to partners (Lowenthal et al, 2014).

Interventions to meet the mental health challenges of HIV infected young people are increasing in neighbouring African countries (Mavhu et al, 2013; Strasser & Gibbons, 2014) and locally (Bhana et al, 2014) where outcomes have largely been successful. The VUKA Family Program is a cartoon-based family intervention aimed at reducing risk behaviours in perinatally HIV infected youth in poverty-impacted areas and is based on an evidence-based family mental health and prevention programme for uninfected youth, Collaborative HIV and Adolescent Mental Health Program (CHAMP), that has been tested in multiple RCTs (Bhana et al, 2014). It is delivered in 6 sessions over 3 months by trained lay counsellors in KwaZulu Natal. Pilot data show that participants improved in mental health outcomes, and although the RCT is ongoing, baseline findings are similarly encouraging (Bhana et al, 2016). However, the disparities in risk factors for this population underscores the necessity for a unique life course approach (Cluver et al, 2012), appreciating that young people are a population in transition. Dynamic and adaptable interventions that aim to identify and address developing threats and opportunities are necessary (Mutumba et al, 2016).

There are substantial challenges to implementing mental health interventions at public healthcare level that need to be thoroughly addressed for the best possible impact. Screening for mental health can lead to increased access to treatment but it is necessary to invest in screening instruments with high specificity, validity and reliability; that are short and can be administered easily in multiple languages (Kagee et al, 2012). Lack of skilled mental health professionals available to intervene and the need to utilize and upskill lay counselors to meet the demand ethically with targeted training and consistent expert supervision (Patel et al, 2011; Petersen et al, 2011; Breuer et al, 2011; Ventevogel, 2014; Mendenhall et al, 2014) is now vital to public health systems. There is expanding proof that lay counsellors are able to provide skillful and effective task-sharing interventions locally (Petersen et al, 2014; Padmanathan & De Silva, 2016; Mendenhall et al, 2014). In addition, adolescents have potential influence over their peers (Mavhu et al, 2013); friendships with peers frequently moderate adversity (Criss et al, 2002), and HIV positive youth with other infected youth in their social networks report being able to accept their diagnosis more easily (Ramaiya et al, 2016). As such, programmes that work with HIV positive adolescents may benefit from peer messaging at clinic level in the form of peer led support groups, peer treatment navigators/counsellors for young people (supported carefully and supervised by skilled facilitators), and inclusion of young HIV positive adolescents in the multidisciplinary team or on the clinic community advisory board etc. This inclusion improves HIV outcomes amoung adolescents (Van der Heijden & Swartz, 2010; Pettitt et al, 2014; Mupambireyi et al, 2014) and most participants in our study were open and invested in supporting other HIV positive youth as described in chapter 7.

Local research indicates that perceived support both from peers (Cluver et al, 2009) and from caring adults (Cheng et al, 2014) has significant positive effects on adolescent mental health. Therefore, healthcare personnel are well placed to have a positive and perceptibly supportive impact on young people who access them regularly. Although the physical environment presents many challenges and risks for adolescents living with HIV, the health system could be utilized to counter these effects. In addition, support groups at facility level hold promise in curbing mental health problems in HIV positive adolescents; social support may help protect youth against the deleterious effects of stressors and promote more positive mental health outcomes (Mupambireyi et al, 2014; Cheng et al, 2014).

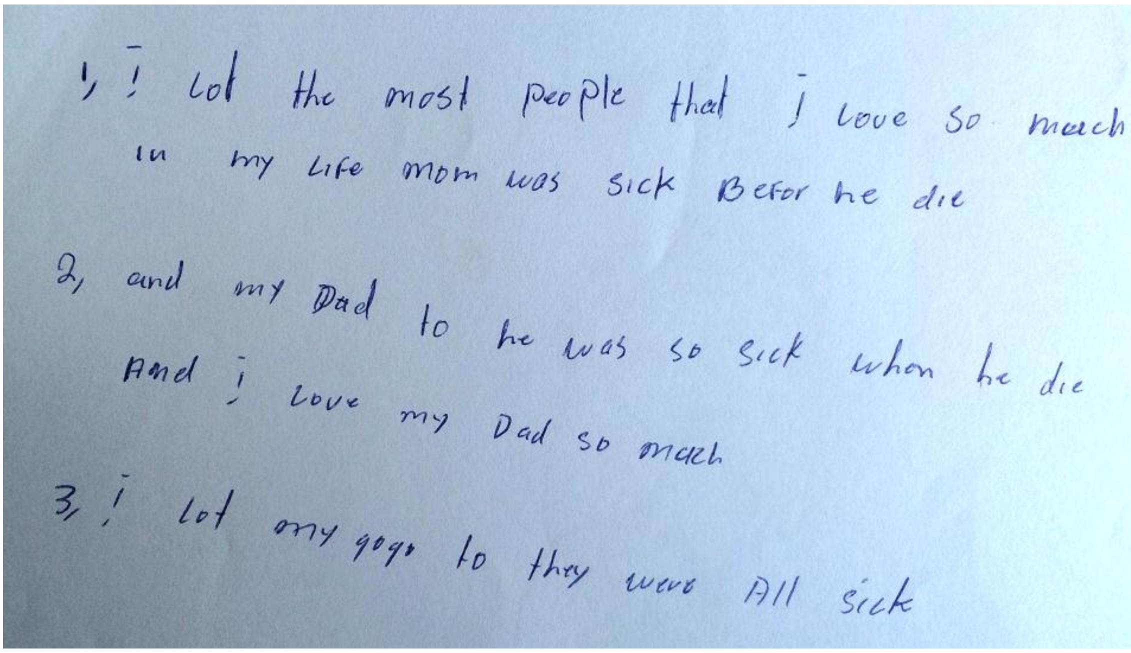
Chapter 8 highlights that bereavement, though pervasive in perintally infected HIV positive adolescents, is often unidentified or unprocessed, and that there are scant ways recognized to handle loss in public health systems. Our study showed that loss can be engaged with through drawing and written accounts facilitated by lay counsellors to uncover areas of emotional difficulty in patients that require attention. Similar findings were uncovered in Zimbabwe through digital storytelling with HIV positive adolescents (Willis et al 2014). In addition, drawings and written accounts may provide pertinent and conspicuous clues to identifying those at risk for mental health problems. Drawings of the participants in this study highlight contextual deprivation, including multiple and consistent loss of significant members of their families. Losses led to relocation and loss of familiarity of context, inconsistency in caregivers and primary attachment figures with interruptions in schooling. There appeared minimal support or value of these experiences in the lives of participants with poor control over the events or preparation for them. The drawings also accentuated emotional deprivation and impoverishment, including unresolved complicated grieving impacting on mental health functioning, exacerbating suicidality, emotional and developmental delays, poor self esteem and HIV related stigma. The drawings called attention to missed opportunities of families, education, social services and health systems in identifying early education opportunities for orphans, perpetuating difficulties in access to unclaimed birth documentation and legal standing and failing to tackle the mental health difficulties of adolescents.

The prospect of telling adults painful personal information is difficult for children and adolescents. Likewise the idea of asking children and adolescents about these difficult experiences can be daunting for adults. However, the expression of painful experience is necessary for processing, making meaning, understanding, coping, integrating and ultimately mastering difficult events in one's life (Malchiodi, 2005). Non-verbal therapy and counselling safely enables the expression of painful experiences through supportive relationship, and discovery through engaging with methods such as art making. This is largely because these ways of communication are latent to this population, are child and adolescent friendly, provide opportunities for self-expression, active participation, imagination and mind-body connections (Malchiodi, 2005). Art making allows children and adolescents to control the amount and content of information shared, while affording the chance to feel a sense of mastery over a situation where there is usually a sense of total loss of control (Clements et al, 2001; Willis et al, 2014). Adults can capitalise on this, finding that ‘therapeutic communication’ can be easier or more direct through the use of symbols or images rather than through the complexities of spoken language.

Non-verbal means of working with children and adolescents have been proven to be effective for the treatment of bereavement and post-traumatic stress disorder (PTSD) (Webb, 2003; Goodman, 2005; Goodman et al, 2009). Perinatally infected children and adolescents with a history of bereavement of their primary caregivers have shown significant symptoms of PTSD (Cluver, 2012). Research indicates the meaningful contribution of neuroscience to understanding the importance of the use of images and ‘action-oriented’ interventions in working with those who experience trauma, the precursor to PTSD (van der Kolk, 2007).

Trauma, the emotional response to a terrible event underscored by fear, helplessness or horror, demonstrates long-term effects. In particular, it interferes with declarative memory, or conscious recall of the event, whilst implicit memory, emotional reactions, and sensorimotor sensations connected to the experience stay intact (van der Kolk, 2007). Implicit memory bypasses language and thought (Talwar, 2007). The images and experiences are accumulated in incoherent, muddled and fragmented ways, often indescribable in words. Non-verbal methods provide a simplified means of communication when direct verbal access to trauma-related experiences are not possible or advisable. These methods facilitate recall of memories, enabling them to be processed and for the ‘artist’ to have control over this process (Buk, 2009). The creative product serves as a container for the affect, aiding in emotional regulation (Goodman et al, 2009). Creating art uses both sensory and emotional stimuli, thus rendering the artistic process a beneficial conduit to access and integrate memories (Lusebrink, 2004). The act of creating offers the opportunity to externalise the imagery associated with painful experience. Words and meaning can be attached to these remnants now in tangible form; they can be organised and managed to create coherent narratives and ultimately to integrate the experience and move on from it (Schouten et al, 2015).

Research that utilises non-verbal methods, such as drawings, are also increasingly recognised as particularly ethical as they offer research subjects active participation in the research process, authenticating their voice through their engagement, offering more developmentally appropriate means of accessing data, diminishing stress in the child/adolescent-adult interaction and providing a more comfortable method of engagement than language (Clacherty & Donald, 2007; Coad, 2007; D'Amico et al, 2016; Willis et al, 2014). Drawings also tend to facilitate communication, enhancing research outcomes, especially in healthcare settings in the pursuit of understanding children's experience of illness (Driessnack, 2005; Coad, 2007). Research indicates that these processes tend to be beneficial to participants as they serve as a form of reflection and offer the ability to express themselves (D'Amico et al, 2016). Furthermore, and critically, in the absence of sufficient therapeutic services to address trauma and loss, the need for a creative therapeutic approach to research, which is facilitative and relational, offers, simultaneously, enormous potential for societal and personal transformation (Berman, 2016). Psychology literature supports these findings. Evidence indicates that a large proportion of research participants, including those who have experienced major traumas or adversities (Kuyper et al, 2012; Edwards et al, 2009) or with recent traumatic experiences in their lives perceive talking about such issues in a research context as beneficial, not psychologically damaging (Griffin et al, 2003; Langhinrichsen-Rohling, 2006). Employing qualitative methods is particularly valuable as perceptions and experiences of risks and benefits in social science research is a subjective issue (Reynolds & Nelson, 2007), and qualitative methods are most suitable for exploring the meanings people attach to their lived experiences (Hennink et al, 2011).



1, I Lot the most people that I love so mach
in my Life mom was sick Befor he die

2, and my Dad to he was so sick when he die
And I Love my Dad so mach

3, I Lot my gogo to they were All sick

Figure 24. Written account of multiple loss on account of sickness (Male, 19 years old at time of interview in 2014).

'1. I lost the most people that I love so much in my life. Mom was sick before [s]he die. 2. And my dad to[o] he was so sick when he die. And I love my dad so much. 3. I lost my gogo [grandmother] to[o]. They were all sick'

The participants in this study had been accessing healthcare for many years, not only for themselves, but through family members who had been hospitalised for extended periods of time too. Healthcare providers had been working with them throughout their development. It could be argued that a valuable personal connection may be established through this consistency and in many cases, the healthcare provider may have been the only continuous adult in their lives; patients have access to someone significant in their lives amidst much other change in their personal contexts. These provider relationships are essential to both physical and emotional care especially of HIV positive patients (Hatcher & Bonell, 2016). Utilising non-verbal ways of expressing life experiences and being witnessed through a supportive relationship would seem to strengthen understanding of patients. Therefore, art making and writing in this relational dynamic, which intrinsically facilitates communication and creates a containing milieu, presents a potentially valuable and largely untapped means of approaching mental health in adolescent patients. In addition, in support of group based interventions at clinic level, this can also be employed in group therapy settings so peers have the assistance of one another, the clinic itself can be perceived as supportive, more patients' needs can be met and limited time can be protected of clinicians.

Increased skills in the use of non-verbal methods of working that are easily transferred may be particularly useful. Creativity in patient care and in research has the potential to impact participants in meaningful ways, giving participants the opportunity to become active in their healthcare, permitting them to use imagination in productive and corrective ways. In this study, it seemed through the facilitated conversations regarding the images, participants were able to articulate and give voice to some of their stories. Lay counsellors facilitated this process justly and effectively.

Resilience in HIV positive adolescents

It is imperative that a pathological emphasis does not dominate the diversity of experience of HIV positive adolescents and the ability of some to cope with significant adversity (Skovdal & Daniel, 2012). Participants in the least symptomatic group from chapter 8 seemed resilient in the face of adversity showing creativity both in their artwork and in their ability to navigate social supports available to them. Many had close relationships with their primary caregivers (sisters, grandmothers etc.) and although they lost these figures at some point, the loss was relatively more recent, indicating that there had been a close relationship over a number of years. There also appeared to be added support for these participants, perhaps helping them in their grieving with consequently enhanced mental health outcomes. Their drawings appear more integrated and detailed compared to the most symptomatic group.

Chapter 7 also testifies to participant's creativity and highlights their active role in negotiating access to care, strategically navigating through the social supports available to them, including that of the healthcare sector. Contrary to narratives of tragedy and misfortune, for orphans in particular, this study supports others that have identified tactical agency utilized by young people in conditions of intensified vulnerability, particularly in SSA (Vale & Thabeng, 2015). Young people's agency and ability to steer through support networks is a crucial pathway to resilience (Skovdal & Daniel, 2012) and should be nurtured and reinforced, particularly in HIV positive adolescents.

Qualities of resilience in this group featured beliefs and character traits that enabled their aptitude to manage their adversity, as well as social behaviours that created the agency required for success. This study (in accord with the quantitative study) identified that stigma, both community stigma and self-stigma, are significant challenges that HIV positive adolescents are dealing with. Most research that identifies stigma as a hardship, also identifies social support as protective against the risks connected to stigma (Betancourt et al 2013). Prospects to increase social support or merely the *perception* of social support (Cluver et al 2009) can enhance resilience in young people.

The resilience characteristics in the study are underscored by the capacity for self-reflection. Self-reflection is widely considered as marking an unfolding developmental capability fully arising in adolescence (Barkai & Rappaport, 2011). Interestingly, stressful life events tend to foster self-reflection in resilient individuals, signifying an adaptive psychosocial ability preferentially employed as a means to overcome adversity (Thorne et al, 2004). Self-reflection is highly indicative of resilience. Thus supportive adults, including healthcare providers, who enquire kindly about meaningful life experiences (such as bereavement) may direct patients to insight and reflection that might encourage resilience.

Evidence indicates that the healthcare environment could gain from being sufficiently youth friendly with healthcare providers willing to serve the needs of adolescents who seek services (Tylee et al, 2007; Pettitt et al, 2013). Recent findings on views of ‘good patients’ in resource-poor settings indicate that South African nurses consider ‘good patients’ as those who are friendly and calm most of the time, accept help without complaining and are extremely polite (Campbell et al, 2015). These notions affect patient-nurse relationships and may be particularly important in adolescent HIV care and treatment as constructive clinical experiences, particularly the development of good quality relationships has been found to enhance ART adherence and emotional wellbeing (Campbell et al, 2015; Hatcher & Bonell, 2016). In addition, efforts to intensify the perception of facilities as valuable resources for youth may expand access to services and improve youth resilience in currently untapped ways. If the healthcare environment can be seen and utilized as a resource to HIV positive adolescents, sustaining the beneficial consequences of resilience lies within its range of influence and health care providers could be vital enablers of resilience in their treatment and care of youth living with HIV. Programmes that deliberately include some of the characteristics of resilience described in this thesis may credibly influence their patients.

The recent endorsement of WHO consolidated guidelines for universal test and treat marks a paradigm shift in the delivery of HIV treatment: from who is eligible and when to start ART, to how to provide client-centered and enhanced quality care to all living with HIV. Differentiated care, an approach to HIV testing, care and treatment that differentiates client groups according to broad definitions, has been promoted to assist this new model of service delivery (Grimsrud et al, 2016). This form of care at its core is client-centered and rights based that simplifies and modifies HIV services across the cascade to both serve the needs of patients more efficiently and reduce unnecessary burdens on an already overstretched health system (Grimsrud et al, 2016). Concepts such as task-shifting, decentralization, community based care etc. become more focal within the differentiated care approach. Adolescents could be recognised as a group with specific needs that require a nuanced system response for optimal health. It is hoped that some of the findings from this thesis can inform policy and practice towards the realization of differentiated care's objectives.

Lastly, it should be noted that although this PhD set out to assess the association between modes of transmission (horizontal versus vertical) and mental health outcomes in the population being studied; a startling finding was that in a random cross-sectional study of this kind, only four adolescents (1% of n=343) who were accessing these five paediatric clinics, were known to be horizontally infected. This means that most adolescents currently accessing care are those that have typically been doing so since childhood and the newly infected adolescents acquiring HIV are not utilizing treatment at present.

Limitations

The limitations for each study have been described in Chapter 3 and in the separate chapters for the studies (Chapters 4 – 8) however there are some overall limitations that need to be considered.

Determining perinatal infection: Arguments in this thesis were made specifically with reference to adolescents who were perinatally infected. However, there is currently no precise test to determine perinatal infection, especially in resource limited settings where accurate clinical records are difficult to obtain, thus symptoms, time of first hospitalization and timing of ART initiation are used as guides (Ferrand et al, 2009). These indicators were sourced from clinical records as well as staff at clinics and participants but it is possible that some adolescents assumed to be perinatally infected in this thesis may not have been.

Lack of validated scales: Although all standardised instruments utilized in this research had been previously used with the adolescent population in South Africa, no standardised psychological scales for this age group have been validated locally (Flisher, 2007). For this reason, continuous scores were used, excluding clinical cut-off scores that have been established in high income contexts. As such we used a conservative method to establish the likelihood that participants who were at risk were categorized appropriately: a symptomatic group was identified as adolescents who experienced >50% of the symptoms on any of the depression, anxiety or PTSD scales, and answered yes to any of the five suicidality questions. These methods, although imperfect, have been used in Africa to measure symptomatology with scales validated in other contexts. Although our scoring method identified a lower threshold than cut-off scoring, it was more likely to capture those participants possibly at risk, which was our aim.

No control group: None of the studies had a control group as part of the design and resultantly comparisons regarding the variables of interest could not be easily made or tested. For instance, there was no comparison group of HIV negative adolescents for this study to assess the role of HIV in mental health problems. Whenever possible, we tried to compare to studies in South Africa and neighboring countries to provide a context for our findings.

Reliance on youth report: Ideally, multiple informants are used when assessing children/adolescent's psychological distress (Offord et al, 1996). There are a number of reasons why this was not possible in this study. The court order and ethical issues related to undertaking this research contextually granted permission to invite and recruit participants without caregiver consent. A major methodological consideration in reliance on youth self-report is the difficulty in obtaining dependable caregiver report for adolescents, particularly for orphaned adolescents. Options for them would include having no caregiver report or having reports from caregivers who may have been likely to further underestimate symptoms (Berg-Nielsen et al., 2003). Thus, the use of caregiver report would likely have introduced a systematic bias of poorer reporting for some of the most vulnerable participants in the sample.

This systematic bias would have also applied to obtaining teacher report for adolescents. Teacher report has been used in other studies of youth mental health (Suldo & Shaffer, 2008). However, township schools are characterised by large class sizes and very little teacher time to complete questionnaires. There may also have been difficulties in accessing teacher report for these students on account of their HIV status and problems with disclosure and adolescent rights to privacy.

It is recognised that a reliance on youth self-report of symptoms is not ideal in determining mental health problems (Smit et al, 2006). This study used tablet computers in an attempt to improve the reporting of sensitive issues such as mental health deliberately to mitigate this limitation.

Limitations of the quantitative study: Any quantitative study, using structured or semi-structured measurement tools, risks the omission of variables that have not been hypothesized or included in the study design. In this study, there were two main areas that risk omission. Firstly, not all mental health outcomes were measured. Disorders such as schizophrenia were excluded due to late onset in adolescence and disorders in the hyperactivity and attention deficit spectrum were not included. Greater focus was given to disorders that have been recognized as more common in this population following international and local evidence (Lowenthal et al., 2014; Gadow et al, 2012; Cluver et al, 2007, 2009; Thom, 2009; Petersen et al, 2014). Therefore, it is possible that some relevant disorders were omitted in this study.

Secondly, this study risked omission of risk and protective factors that were not included in the questionnaire. Extensive efforts were made to include all relevant factors primarily from literature review, however, questionnaires had to be of a length suitable for adolescents to complete in busy clinics (Robertson et al., 1999), and thus limits on the number of items may have led to omission of pertinent issues. For example, individual-level factors such as IQ have been shown to influence adolescent resilience (Sherr et al, 2014; Li et al, 2015). However, IQ levels were not easily measurable in this study and were thus excluded.

Limitations of cross-cultural psychology: A broader and more conceptual, limitation of this study is the potential difficulties of using western psychological constructs and measurements in a different cultural context. This is part of much wider debates around the classification of mental illness per se, the tensions between western and non-western health systems, and post-colonial power relationships. This is particularly relevant in South Africa as psychological testing contextually cannot be divorced from the country's political, economic and social history where tests historically may have been used with bias and unfairness in certain populations (Laher & Cockcroft, 2014). The following discussion will touch only briefly on these contested and complex areas.

Claasen (1997) and Summerfield (2004) outline dangers of using Western psychological definitions in a non-Western context. They advocate, instead, the use of indigenous categories of dysfunction and distress. For children in particular, there is ongoing and unresolved debate around the use of Western categories of trauma and distress in particular (Dowdney et al., 2006), including the classification of post-traumatic stress disorder amoungst children and adolescents in the developing world (Summerfield, 2001; Dowdney et al., 2006). In South Africa, several difficulties have been highlighted in using Western psychological or psychiatric constructs (Mzimkulu & Simbayi, 2006). These include the individualistic approach of Western mental health, which may have limited relevance in the context of African notions of community or 'ubuntu'. Anthropological studies have highlighted the importance of beliefs around bewitchment in local understandings of HIV and AIDS (Stadler, 2003). Swartz (2002) reports potential confusion for Black and Coloured Africans in the medicalisation of mental health, which is often conceptualized rather in spiritual, supernatural or theological terms.

However, there are several arguments for the applicability of Western psychological measurements in a South African context. Firstly, as practitioners, our aim is a reduction in children/adolescent's suffering. With such an objective, questions of indigenous versus western culture become less important. They are replaced instead by questions of whether children and adolescents are experiencing emotional difficulties, and how those difficulties can be reduced most optimally (Dyregrov et al, 2002). With caution, and with sensitivity towards cross-cultural differences, it is possible to measure the extent of adverse child and adolescent reactions (Laher & Cockcroft, 2014).

Secondly, South African society is not able to clearly be compartmentalized into ‘African’ and ‘Western’. Life in urban Johannesburg townships is a complex interplay of cultures. Influences include the legacy of apartheid health services, multiple African cultures, migrant influences from neighbouring African countries, American media, traditional beliefs around health, and government messages around health, HIV and AIDS. Thus categorisation of urban Black Africans as distinct from Western culture would not accurately represent the more multifaceted reality.

Recognition of power as researcher: As an older, white female researcher, it was obvious that I held a position of relative power compared to participants. I was keenly aware of helping participants feel at ease with the research process, ensuring they understood the informed consent and their option to stop at any time. We started the interview with a joint drawing game to ensure a comfortable and relaxed atmosphere had been established and all adolescents willingly participated, seemingly enjoying themselves. While this positionality could not be completely eliminated, the rich narratives presented by most participants suggests comfort in sharing their stories through the research process. Many participants ended the interview thanking me for listening to them divulge their story and share their opinion. Only one participant became distressed at telling his story and this was managed by the researcher (who is also a trained and registered child/adolescent therapist). This participant was followed up to ensure he was safe.

Directions for future research

Additional research questions arose from the findings of this thesis, its limitations and the suggested implications regarding mental healthcare. There is need for research on a larger scale on the mental health status of perinatally infected HIV positive adolescents across South Africa. Particularly those accessing healthcare as this group is likely to be present for the foreseeable future and with increased understanding of their mental health needs, more nuanced and effective interventions could be devised at public healthcare level. In addition, explicating the changes in adolescent mental health across adolescent development and associated risk factors is critical to understanding the etiology of mental health problems for this population and could inform the development of evidence based mental health services. To this end, when developing rigorous evaluations of interventions, it is important to test effects not only in the short-term but over a number of years too.

Large scale, meticulous research that compares the mental health of perinatally infected, behaviourally infected, HIV-exposed but uninfected and uninfected adolescents would yield important findings on the burden of HIV to mental health consequences. This kind of quantitative research would also shed light on other outcomes of increasing significance in adolescents, such as individual, family and contextual variables and pathways that increase or limit risk to mental health problems and HIV infection and transmission. Given the close relationship of HIV to mental health problems and the high prevalence of HIV in South Africa, mental health should be made a funding priority and more resources made available to address its impact.

The lack of screening and diagnostic instruments validated for use in the South African context is a significant limitation to extending mental health work to where the need is most critical. Instruments that are effective, time sensitive and can be easily administered in busy healthcare environments need to be normed and validated for local populations of adolescents to ensure easier access to appropriate care. In tandem with this development, is a need for reliable and competent training of staff in the ability to use mental health screening tools and diagnostic assessments aptly.

Findings underscore the necessity to reduce or eliminate exposure to traumatic events, and reducing risks to traumatic experiences in adolescents is likely to have a positive impact on HIV infection and transmission through multiple pathways. Adolescents suffering multiple and enduring adversity, who have low levels of psychological and social resources need to be targeted for long term interventions to help ensure they live in safe, caring and stable family environments with opportunities to remain in school and participate in community life. The scale-up of community and structural level interventions, as well as a focus on trauma-informed models of care for adolescents in South Africa is critical for addressing the HIV epidemic and ensuring protection of a vulnerable population of minors (Closson et al, 2016).

Adolescence is a time for transformation of the adolescent-caregiver relationship as adolescents establish relationships with peers and significant others outside the family, they encounter a myriad of challenges that could impact their wellbeing and also expand their repertoire of coping skills and resources (Mutumba et al, 2016). In the context of family disruption and HIV, it is likely that the quality of relationships with caregivers is critical to their development. Interventions that focus on the caregiver/adolescent relationship are likely to lead to improved coping in this patient population. This is also probable with provider/adolescent relationships and should be investigated further at healthcare level.

In South Africa, dedicated healthcare services for young people are the exception rather than the rule, and little or no provision has been made for the special needs of this age group. Without appropriately tailored services, adolescents are likely to fall through the cracks of paediatric or adult-orientated HIV care. There is an urgent need to develop and rapidly implement policies and programmes aimed at early diagnosis and improvement of care provided to the expanding numbers of adolescents who are growing up with HIV. A model that integrates HIV clinical care with sexual and reproductive health and mental health services is likely to help prepare young adults for an independent and productive future and reduce the effect of the epidemic at community and society level.

Research is required on delivering mental health services at healthcare level and the effects of improved mental health on HIV care and treatment, such as adherence, enhanced sexual and reproductive health, retention in care and increased disclosure etc. Without improved understanding of how to achieve adherence and continuous access to potent ARVs, LMICs are at risk of running out of options for perinatally infected HIV positive adolescents transitioning to adulthood. It is possible that improved mental health will have positive effects on adherence and retention in care with this population.

Service providers need to integrate innovative, dynamic counselling approaches that appeal to the interests and capacities of adolescents. As such, the effectiveness on non-verbal therapies, such as drawing, writing, drama, digital storytelling and photovoice interventions that address mental health and psychosocial issues in this population needs to be rigorously tested and controlled for. These should also be upscaled to lay counsellors who appear to be well placed to utilize and deliver these methods with careful assessment of effectiveness. It is imperative that culturally appropriate adolescent-centered interventions are developed that engage youth in a therapeutic process, acknowledge their life experiences and help them cope with their situations so that can move forward with their lives.

The literature on HIV continues to be largely heedless of adolescent's resilience and agency and the fact that many children and adolescents are trained at an early age in a variety of life skills to prepare them for life's inevitable struggles. More research is required on adolescent resilience and how the healthcare environment can maximize from this to improve HIV health outcomes in this population. Methodologically, research should prescribe to principles of adolescent participation where youth are consulted and their perspectives carefully considered through the process. This may be through skillful qualitative research or through utilizing non-verbal methods that are known to be child/adolescent friendly and may give way to projecting and amplifying the voices of adolescents on issues that affect them most (such as beliefs about adherence, beliefs about death and bereavement, questions about sex and violence, fears regarding their futures, sexual and reproductive health concerns etc.).

To this end, changes need to be made to the National Health Act governing research with children and adolescents, so that their voices can be heard and their interests actively advocated for on the basis of empirical findings. Specific issues remain necessary to address at policy level and include informed consent, confidentiality and autonomy in a group with evolving capacities and with whom research is likely to continue to be fundamental to successful public health outcomes for the country.

Conclusion

While access to medical treatment is clearly vital to health, the social and ecological context shapes the health and developmental wellbeing of adolescents growing up with HIV. These other dimensions of health drive physical ill health and should be recognized and understood to enable improved quality of care at the provider and facility level. In many ways, health is socially determined and to improve health of adolescents, the conditions of daily life (i.e. the conditions in which adolescents live and grow) must be targeted. With enriched understanding of these social determinants, a more effective response may mitigate long term risk and enhance individual, family and community functioning. Resilience is both a function of characteristics of the individual adolescent and the relationships (both in and outside of the healthcare facility) that support the adolescent, as well as the quality of that adolescent's environment that provides the resources necessary for positive development despite adversity. Thus, there is need for a broader vision of HIV care, one that goes beyond clinical virus detection, suppression and management. Recognition of mental health challenges in HIV positive adolescents is crucial to effective HIV care and treatment and providers need to be sufficiently sensitized to this reality. Opportunities for innovative therapeutic intervention exist and should be scaled up to assess effectiveness. Mental health problems exist and should be a critical component of overall healthcare planning for youth. Integrating mental healthcare into HIV treatment, particularly in key populations such as adolescents, is highly recommended.

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APPENDICES

Appendix A. Court Order

Appendix B. Ethics Clearance Certificates

May 2013
July 2013

Appendix C. Research committees ethics clearances

1. Chris Hani Baragwanath Hospital research committee approval
2. Charlotte Maxeke Academic Hospital research committee approval
3. Gauteng DoH Provincial research committee approval

Appendix D. Questionnaire

Appendix E. Informed Consent

1. Informed consent - CAB participation
2. Informed consent - study participation
3. Informed consent - permission to record

Appendix F. Distress protocol

Appendix G. SOP distress management

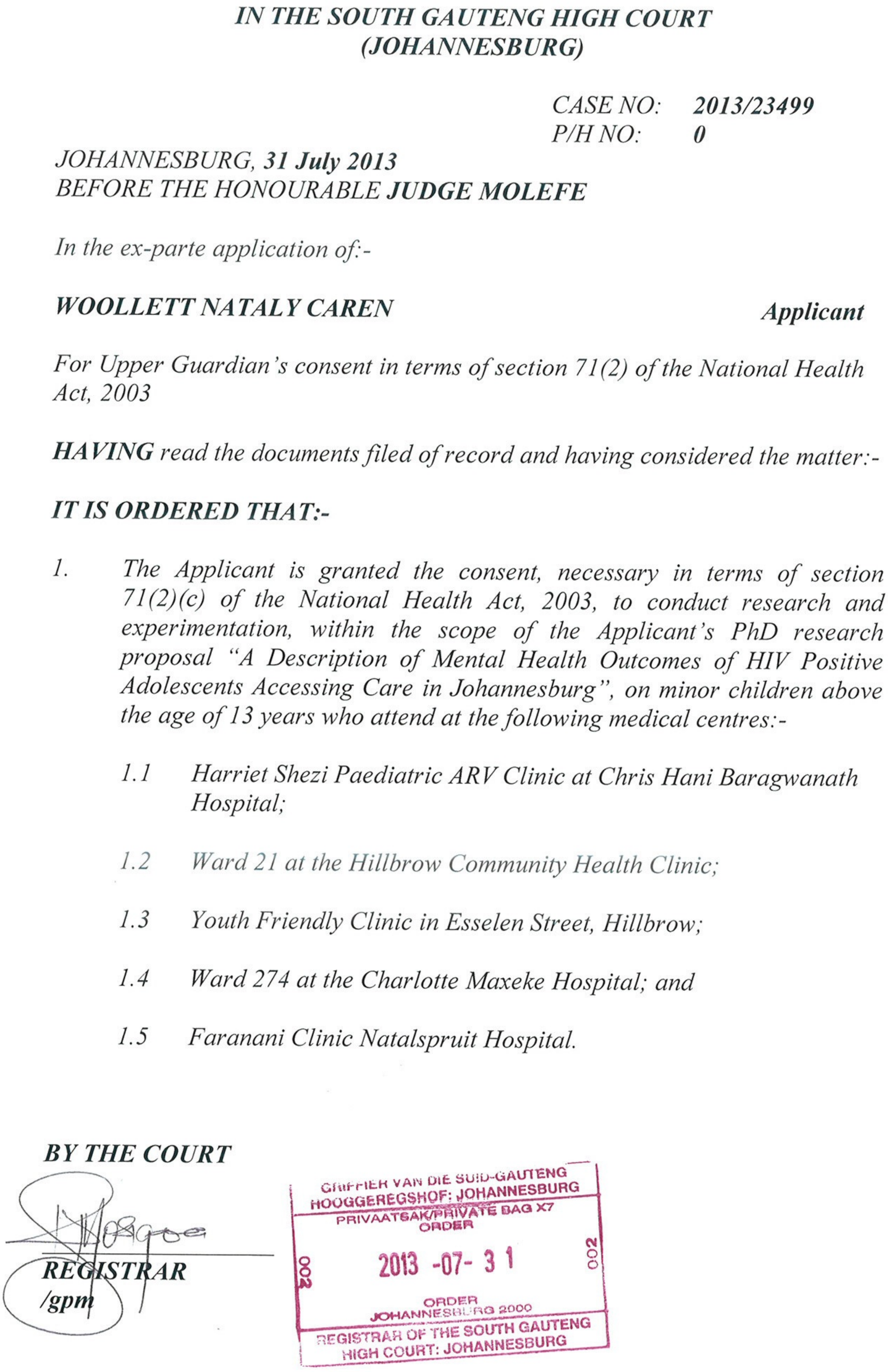
Appendix H. SOP Process

Appendix I. In-depth interview guide

Appendix J. Declaration by co-authors

Appendix K. Turn-it-in-report

Appendix A. Court Order



IN THE SOUTH GAUTENG HIGH COURT
(JOHANNESBURG)

CASE NO: **2013/23499**
P/H NO: **0**

JOHANNESBURG, **31 July 2013**
BEFORE THE HONOURABLE **JUDGE MOLEFE**

In the ex-parte application of:-

WOOLLETT NATALY CAREN ***Applicant***

For Upper Guardian's consent in terms of section 71(2) of the National Health Act, 2003

HAVING *read the documents filed of record and having considered the matter:-*

IT IS ORDERED THAT:-

1. The Applicant is granted the consent, necessary in terms of section 71(2)(c) of the National Health Act, 2003, to conduct research and experimentation, within the scope of the Applicant's PhD research proposal "A Description of Mental Health Outcomes of HIV Positive Adolescents Accessing Care in Johannesburg", on minor children above the age of 13 years who attend at the following medical centres:-

1.1 Harriet Shezi Paediatric ARV Clinic at Chris Hani Baragwanath Hospital;

1.2 Ward 21 at the Hillbrow Community Health Clinic;

1.3 Youth Friendly Clinic in Esselen Street, Hillbrow;

1.4 Ward 274 at the Charlotte Maxeke Hospital; and

1.5 Faranani Clinic Natalspruit Hospital.

BY THE COURT

REGISTRAR
/gpm

GRIFFIER VAN DIE SUID-GAUTENG
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REGISTRAR OF THE SOUTH GAUTENG
HIGH COURT: JOHANNESBURG

Appendix B. Ethics Clearance Certificates

1. May 2013

UNIVERSITY OF THE WITWATERSRAND JOHANNESBURG

R14/49 Ms Nataly Woollett

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M130258

NAME: **(Principal Investigator)**	Ms Nataly Woollett
DEPARTMENT:	Wits Reproductive Health & HIV Institute Hillbrow Health Precinct
PROJECT TITLE: `	A Description of the Mental health Outcomes of HIV Positive Adolescents Accessing Care` in Johannesurg
DATE CONSIDERED:	22/02/2013
DECISION:	Approval limited to:
CONDITIONS:	Adults 18years and older; minors 13-17 years who have legal (biological) guardians or have Legal (foster) guardians
SUPERVISOR:	Heena Brahmhatt
APPROVED BY:	____________________ Professor PE Cleaton-Jones, Chairperson, HREC (Medical)

DATE OF APPROVAL: 15/05/2013

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

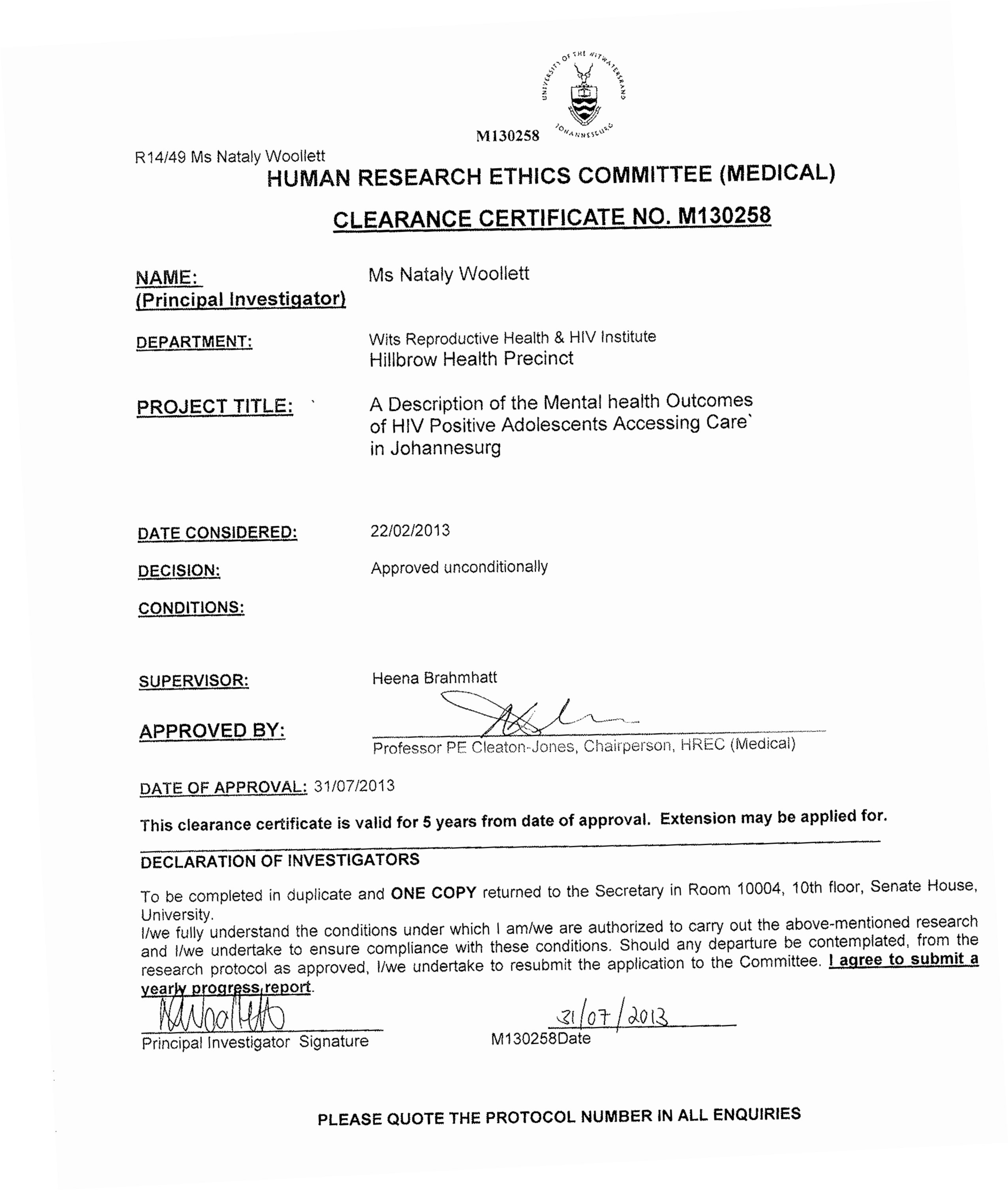
DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Secretary in Room 10004, 10th floor, Senate House, University.
I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report**.

____________________ ____________________
Principal Investigator Signature Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

2. July 2013



UNIVERSITY OF THE WITWATERSRAND JOHANNESBURG

M130258

R14/49 Ms Nataly Woollett

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M130258

NAME: **(Principal Investigator)**	Ms Nataly Woollett
DEPARTMENT:	Wits Reproductive Health & HIV Institute Hillbrow Health Precinct
PROJECT TITLE: `	A Description of the Mental health Outcomes of HIV Positive Adolescents Accessing Care` in Johannesurg
DATE CONSIDERED:	22/02/2013
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Heena Brahmhatt
APPROVED BY:	Professor PE Cleaton-Jones, Chairperson, HREC (Medical)
DATE OF APPROVAL:	31/07/2013

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Secretary in Room 10004, 10th floor, Senate House, University.

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report**.

Principal Investigator Signature

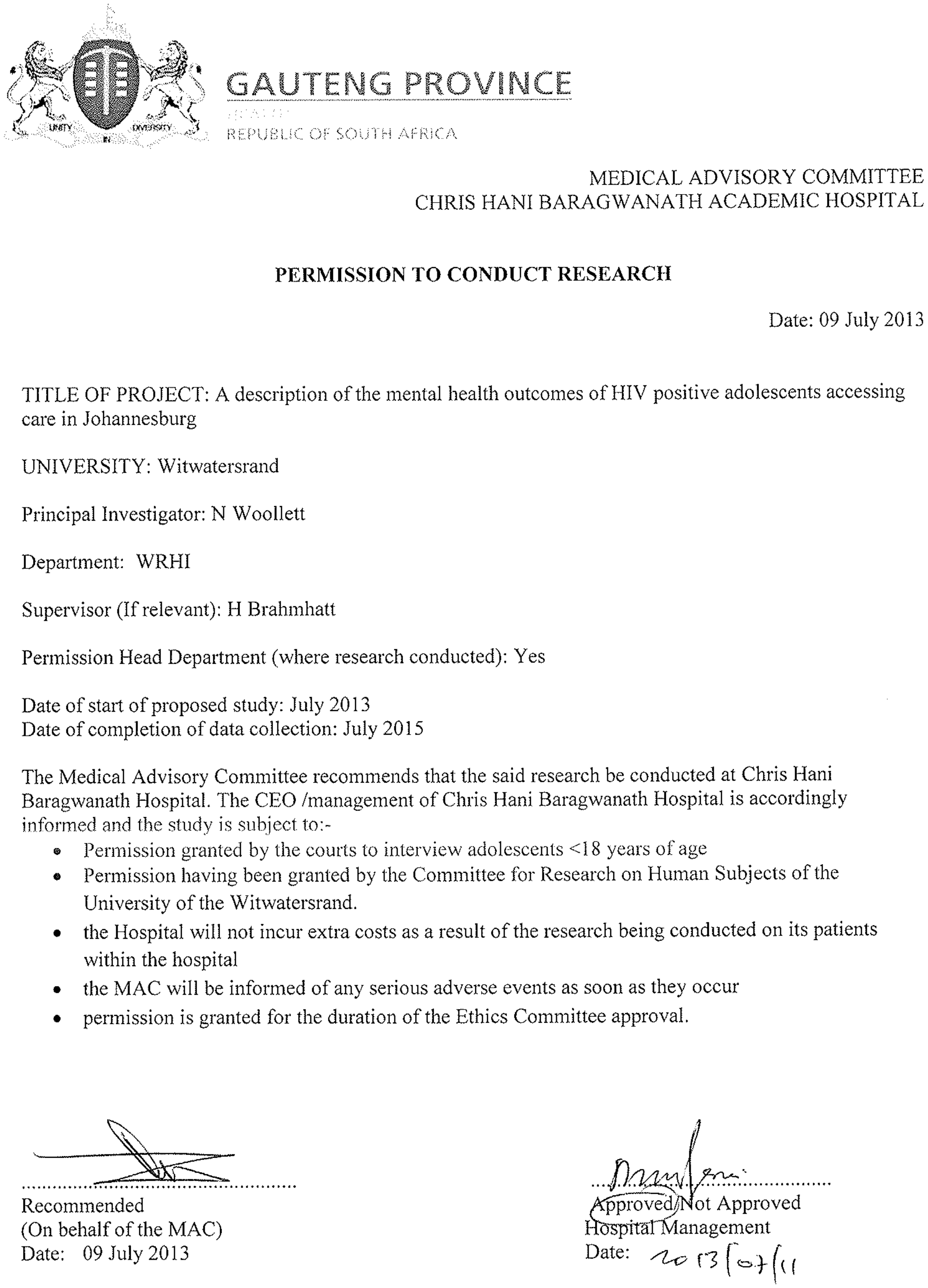
31/07/2013

M130258Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix C. Research committees ethics clearances

1. Chris Hani Baragwanath Hospital research committee approval



GAUTENG PROVINCE
REPUBLIC OF SOUTH AFRICA

MEDICAL ADVISORY COMMITTEE
CHRIS HANI BARAGWANATH ACADEMIC HOSPITAL

PERMISSION TO CONDUCT RESEARCH

Date: 09 July 2013

TITLE OF PROJECT: A description of the mental health outcomes of HIV positive adolescents accessing care in Johannesburg

UNIVERSITY: Witwatersrand

Principal Investigator: N Woollett

Department: WRHI

Supervisor (If relevant): H Brahmhatt

Permission Head Department (where research conducted): Yes

Date of start of proposed study: July 2013
Date of completion of data collection: July 2015

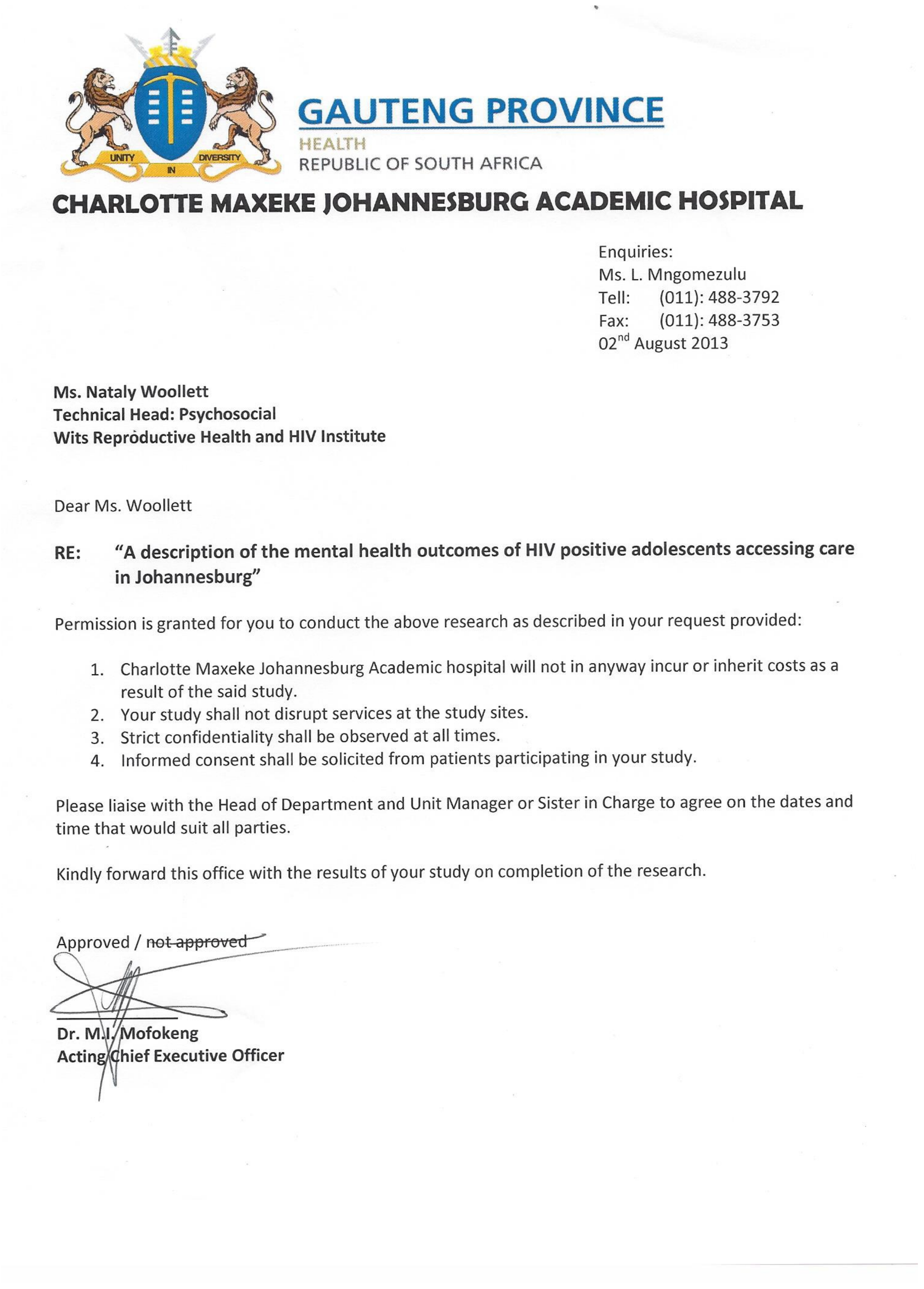
The Medical Advisory Committee recommends that the said research be conducted at Chris Hani Baragwanath Hospital. The CEO /management of Chris Hani Baragwanath Hospital is accordingly informed and the study is subject to:-

- Permission granted by the courts to interview adolescents <18 years of age
- Permission having been granted by the Committee for Research on Human Subjects of the University of the Witwatersrand.
- the Hospital will not incur extra costs as a result of the research being conducted on its patients within the hospital
- the MAC will be informed of any serious adverse events as soon as they occur
- permission is granted for the duration of the Ethics Committee approval.

....
Recommended
(On behalf of the MAC)
Date: 09 July 2013

....
[✓ Approved]/Not Approved
Hospital Management
Date: 2013/07/11

2. Charlotte Maxeke Academic Hospital research committee approval



GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

CHARLOTTE MAXEKE JOHANNESBURG ACADEMIC HOSPITAL

Enquiries:
Ms. L. Mngomezulu
Tell: (011): 488-3792
Fax: (011): 488-3753

02nd August 2013

Ms. Nataly Woollett
Technical Head: Psychosocial
Wits Reproductive Health and HIV Institute

Dear Ms. Woollett

RE: "A description of the mental health outcomes of HIV positive adolescents accessing care in Johannesburg"

Permission is granted for you to conduct the above research as described in your request provided:

1. Charlotte Maxeke Johannesburg Academic hospital will not in anyway incur or inherit costs as a result of the said study.
2. Your study shall not disrupt services at the study sites.
3. Strict confidentiality shall be observed at all times.
4. Informed consent shall be solicited from patients participating in your study.

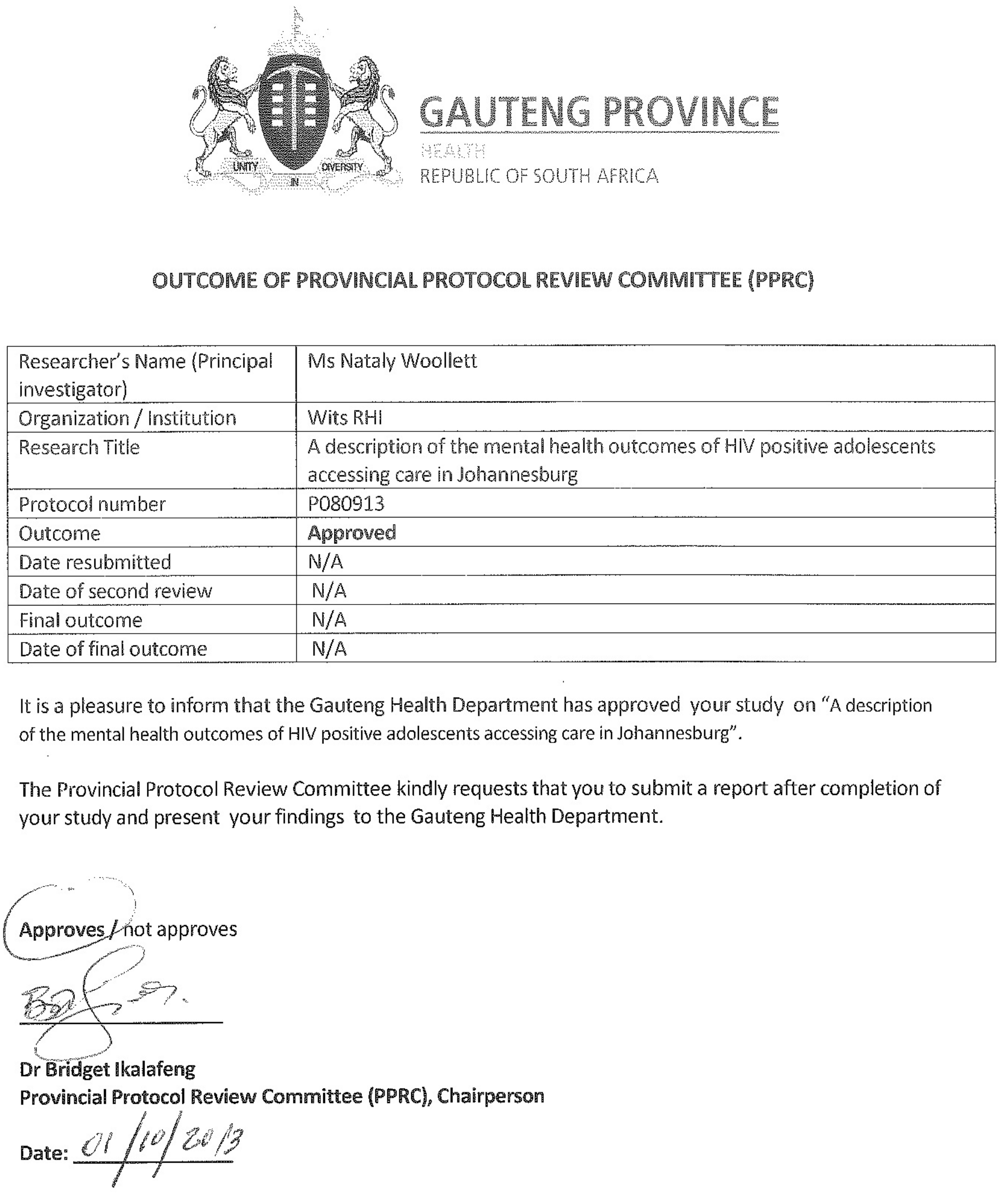
Please liaise with the Head of Department and Unit Manager or Sister in Charge to agree on the dates and time that would suit all parties.

Kindly forward this office with the results of your study on completion of the research.

Approved / ~~not approved~~

Dr. M.I. Mofokeng
Acting Chief Executive Officer

3. Gauteng DoH Provincial research committee approval



GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

OUTCOME OF PROVINCIAL PROTOCOL REVIEW COMMITTEE (PPRC)

Researcher's Name (Principal investigator)	Ms Nataly Woollett
Organization / Institution	Wits RHI
Research Title	A description of the mental health outcomes of HIV positive adolescents accessing care in Johannesburg
Protocol number	P080913
Outcome	**Approved**
Date resubmitted	N/A
Date of second review	N/A
Final outcome	N/A
Date of final outcome	N/A

It is a pleasure to inform that the Gauteng Health Department has approved your study on "A description of the mental health outcomes of HIV positive adolescents accessing care in Johannesburg".

The Provincial Protocol Review Committee kindly requests that you to submit a report after completion of your study and present your findings to the Gauteng Health Department.

[✓ **Approves**] / not approves

Dr Bridget Ikalafeng
Provincial Protocol Review Committee (PPRC), Chairperson

Date: 01/10/2013

Appendix D. Questionnaire

Abbreviations for the forms

Socio Demorgraphic	**SD**
Screening form	**SF**
Drawing task 1 (living situation)	**LS (DT1)**
Depression screen (Children's Depression Inventory)	**DS**
Suicide screen (Mini International Psychiatric Interview for Children and Adolescents)	**SS**
Anxiety screen (Children's Manifest Anxiety Scale)	**AS**
Sexual reproductive health	**SH**
Drawing task 2 (timeline)	**TL (DT2)**
Bullying (Social and Health Assessment Peer Victimization Scale)	**PV**
Exposure to violence	**EV**
PTSD screen (Children's PTSD Checklist)	**PT**
Alcohol abuse screen (National survey of HIV and risk behaviour amongst young South Africans)	**AA**
HIV information	**HI**
Qualitative questioning	**QQ**
Coping resources	**CR**
Research team data collection	**RT**

Screening form

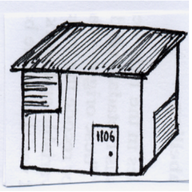
1. Questionnaire number ☐
2. Clinic attending ☐
3. Grade ☐
4. Date ☐
5. Interviewer ☐
6. Adolescent consent received ☐
7. Age ☐
8. Gender ☐
9. What is the main language you speak at home? ☐

Socio-demographics

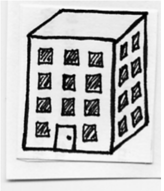
my home and...

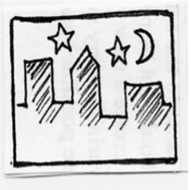
1. please select the one which is most like your home

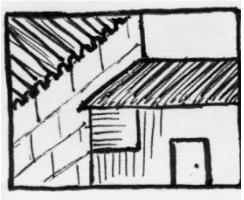

a) hut made of traditional materials



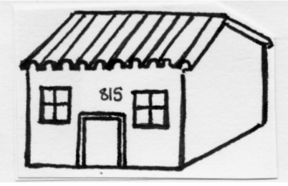
b) shack on it's own plot


c) block of flats

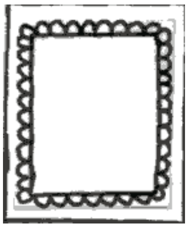

d) living on the street


e) shack in a back yard

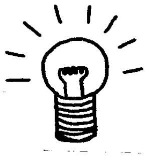

f) children's home or shelter for kids



g) house made of brick or concrete


h) other
______

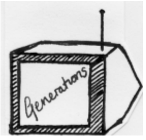
2. please select the things which you have in your home (in working order)

a) 
electricity

c) 
bath or shower

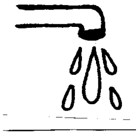
e) 
fridge

g) 
phone/cellphone

b) 

TV

d) 
Radio

f) 
Water from a tap

h) 
computer

YOU AND YOUR HOME…

3. do you help look after younger children in your home? ☐

4. have you ever helped to look after sick people in your home? ☐

5. do you feel that you belong with the people who you live with? ☐

6. does someone at home praise you when you have done something well? ☐

7. does anyone who lives with you have a job? ☐

8. do you get the same food/clothes/school fees/ school equipment as other children you live with? ☐

9. how many days did you go to bed hungry this week? ☐

10. (a) Do you have brothers and sisters who do not live with you? ☐

(b) Please can you tell me their names and ages? ☐ ☐ ☐ ☐

11. a) Are you attending school? ☐

b 1) If yes, what is your attendance like? ☐

1 = very good
2 = miss some days
3 = poor

b 2) If missing school, why?

12. Highest grade passed ☐

Drawing task 1 (living situation)

people who i live with

For interviewers guiding questions…

1) **How many rooms are there in your home? Kitchen? Bathroom? Other rooms?**

2) **Who sleeps in each room? Draw and write their relationship to you, and their age**

(for adolescents living in shelters/children's homes/on the street, just draw own room/ where they sleep)

Depression screen (Children's Depression Inventory)

what i think and feel...

This part of the questionnaire looks at sadness and other difficulties which many peo experience at some point in their lives. This questionnaire is arranged in groups of 3 statements. Please listen to each group carefully. Then pick out ONLY ONE statemen from each group which best describes the way you have been feeling during the *last* *2 weeks*

1) a) I am sad once in a while ☐
b) I am sad many times
c) I am sad all the time

2) a) I feel like crying every day ☐
b) I feel like crying many days
c) I feel like crying once in a while

3) a) Nothing will ever work out for me ☐
b) I am not sure if things will work out for me
c) Things will work out for me OK

4) a) Things bother me all the time ☐
b) Things bother me many times
c) Things bother me once in a while

5) a) I do most things OK ☐
b) I do many things wrong
c) I do everything wrong

6) a) I look OK ☐
b) There are some bad things about my looks
c) I look ugly

7) a) I hate myself ☐
b) I do not like myself
c) I like myself

8) a) I do not feel alone ☐
b) I feel alone many times
c) I feel alone all the time

9) a) I do not think about killing myself ☐
b) I think about killing myself but I would not do it
c) I want to kill myself

10)	a) I have plenty of friends	
	b) I have some friends but wish I had more	
	c) I don’t have any friends	
11)	a) Nobody really loves me	
	b) I am not sure if anybody loves me	
	c) I am sure that somebody loves me	

Suicide screen (Mini International Psychiatric Interview for Children and Adolescents)

1) In the past month, did you:

a) Wish you were dead? ☐

b) Want to hurt yourself? ☐

c) Think about killing yourself? ☐

d) Think of a way to kill yourself? ☐

e) Try to kill yourself? ☐

(distress protocol to be used as needed)

Anxiety screen (Children's Manifest Anxiety Scale)

what i think and feel...

1 = Yes **2 = No**

1. I worry a lot of the time ☐

2. I worry about what my carers will say to me ☐

3. I feel that others do not like the way I do things ☐

4. It is hard for me to get to sleep at night ☐

5. I worry about what other people think about me ☐

6. I feel alone even when there are people with me ☐

7. I worry about what is going to happen ☐

8. Other children are happier than I am ☐

9. I have bad dreams ☐

10. I wake up scared some of the time ☐

11. I worry when I go to bed at night ☐

12. I am nervous ☐

13. A lot of people are against me ☐

14. I often worry about something bad happening to me ☐

Sexual reproductive health

LET'S TALK ABOUT SEX

1 = Yes **2 = No**

1. Do you know what sex is? ☐
(skip to next page if 'no' after probing)

2. Have you ever had sex before? ☐
(by sex we mean when you have wanted to or when you have been forced or coerced)

3. How old were you the first time you had sex? ☐

Sometimes we have sex because we choose to and sometimes we are forced.

4. Have you ever been forced to have sex? ☐

5. Was the first time you had sex forced? ☐

6. If you did have sex in the last year, how many times did you use a condom? ☐
  a) Always
  b) More than half the time
  c) Less than half the time
  d) Never

1 = Yes **2 = No**

7. Have you ever had sex when you were drunk? ☐

8. Did you ever have sex with someone who was more than 5years old than you? ☐

9. Have you ever had sex with someone in exchange for something like:

a) Food ☐
b) Airtime ☐
c) School uniform ☐
d) Better marks at school ☐
e) Money ☐
f) Place to stay ☐
g) Something else ☐

10. Have you ever had sex with someone when you didn't want to because they hurt you, or you were afraid that they were going to hurt you if you didn't? ☐

11. Have you ever been pregnant or got someone else pregnant? ☐

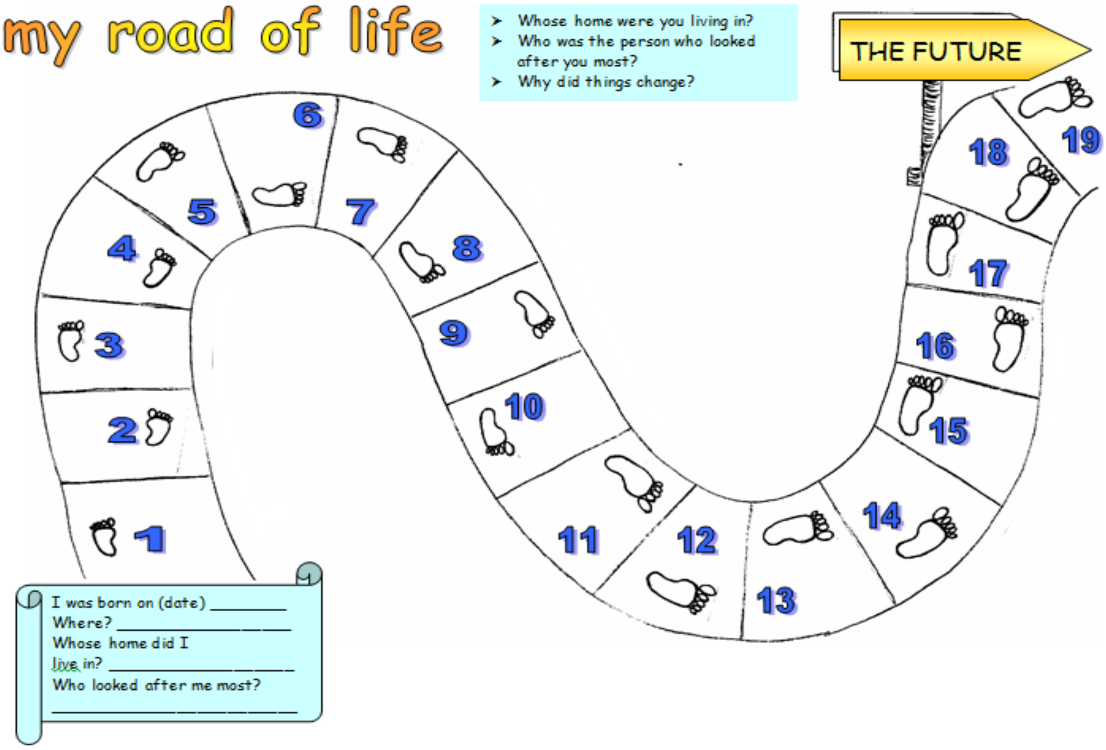
12. Did you ever have a termination of pregnancy (abortion)? ☐

13. If yes, how old were you? ☐

14. Do you use contraception (condom, IUD, injection, pill)? ☐

15. Would you like family planning services? ☐

Drawing task 2 (timeline)



- Whose home were you living in?
- Who was the person who looked after you most?
- Why did things change?

I was born on (date) ________
Where? ______________
Whose home did I live in? ________________
Who looked after me most?
____

Bullying
(Social and Health Assessment Peer Victimization Scale)

Friends and other adolescents…

Other adolescents can be great. They can also be really mean to each other.
For each question, please say whether you think it is 'not true', 'sometimes true' or 'certainly true'. Think about it as how things have been for you in the last *6 months*.
It would help if you answered all the questions even if you are not certain or if it seems silly!

1 = Not true for me **2 = Somewhat true for me** **3 = Certainly true for me**

1. I am usually on my own. I generally play alone or keep to myself ☐

2. I have one good friend or more ☐

3. Other people my age generally like me ☐

4. Other children or young people pick on me ☐

5. I get on better with adults than with people my age ☐

Now we want to know about this past year. During this year other adolescents…

1 = Not at all **2 =Once** **3 = 2-3 times** **4 = 4 or more times**

6. Called me names or swore at me ☐

7. Tried to get me into trouble with my friends ☐

8. Took something without permission or stole things from me ☐

9. Made fun of me for some reason ☐

10. Made me uncomfortable by standing too close or touching me ☐

11. Punched, kicked or beat me up ☐

12. Hurt me physically in some way ☐

13. Tried to break or damaged something of mine ☐

14. Refused to talk to me or made other people not talk to me ☐

15. Did this happen mainly: ☐
   a) in school
   b) outside school
   c) both

16. When you have a problem, who do you talk to?

Exposure to violence

stuff that's been difficult for me...

Many adolescents face difficulties in South Africa and have had challenging experiences. Could you tell us whether these things have also happened to you?

1. This year, how many times have you had things stolen?

2. a) Have you been unwell/sick this year?

b) with what?

3. There are inappropriate ways to touch a person. Has anyone ever touched you in a way that made you feel uncomfortable?

4. Has anyone ever made you do anything with your private parts or their private parts that you did not want to do?

5. Sometimes parents/caregivers shout at adolescents a lot. How many times in an ordinary week do you get shouted at in your home?

6. a) Have you ever been hit or attacked

a 1) outside of your house/in your community or at school?
a 2) with what?

b 1) at home?
b 2) with what?

7. a) Have you seen someone being shot

7. b) Have you seen someone being stabbed

Sometimes adults shout at each other and sometimes there is fighting in the home.

8. a) This last week , how many days were there arguments with adults shouting in your home?

b) What are the arguments normally about?

c) Do you feel safe at home?

d) Has anything happened that we have not asked about that upset you?

e) How many days this week did you **not** have enough food?

Sometimes our parents or family members have been very sick or have died. Sometimes people are unkind to adolescents because of this.

9. a) Have you ever been teased because of people in your family being sick?

1 = not at all
2 = sometimes
3 = often

9. b) Have you ever been treated badly because of people in your family being sick?

10. a) Has anyone close to you died?

b) Could you tell me who they were?

c) Could you tell me when?

d) What happened? **(Provide participant with paper as they can write, or draw them) (Photo to be taken after)**

Sometimes it helps to talk to someone about our feelings when a person close to us has died.

11. a) Did you or do you talk to anyone about this?

11. b) Who?

12. What support have you received in your life when life has been hard for you?

PTSD screen (Children's PTSD Checklist)

how do you feel about . . . ?

Many adolescents go through things that are very upsetting or frightening, we would like to know about them and how you felt about it. They might have happened recently or they might have happened a long time ago, but still upset you. Can you tell us what was the most upsetting or frightening thing that has happened to you?

Now for each question, could you tick one box to show whether you have felt this way 'not at all', 'some of the time', most of the time' or 'all the time' **in this past month**:

1 = not **3 = most**
2 = some **4 = all**

1. Do you get nightmares or bad dreams about what happened? ☐

1 = not **3 = most**
2 = some **4 = all**

2. Do you get upset when you think about what happened? ☐

1 = not **3 = most**
2 = some **4 = all**

3. When something reminds you of what happened, do you get tense or upset? ☐

1 = not **3 = most**
2 = some **4 = all**

4. Do you go over and over what happened in your mind? ☐

1 = not **3 = most**
2 = some **4 = all**

5. Do you think about (or see pictures in your head of) what happened even when you don’t want to?

1 = not **3 = most**
2 = some **4 = all**

6. Do you worry that it might happen again?

1 = not **3 = most**
2 = some **4 = all**

7. Do you try not to think about what happened?

1 = not **3 = most**
2 = some **4 = all**

8. Do you try to stay away from things that remind you of what happened?

1 = not **3 = most**
2 = some **4 = all**

9. Do you have trouble remembering important parts of what happened?

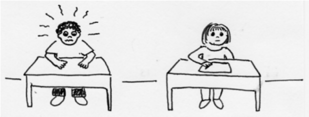
1 = not **3 = most**
2 = some **4 = all**

10. Do you act out things or repeat things like what happened?

1 = not **3 = most**
2 = some **4 = all**

11. Do you feel like it’s happening all over again even when it’s not?

1 = not **3 = most**
2 = some **4 = all**



12. Do you feel it’s hard to have any feelings any more, like you feel numb?

1 = not **3 = most**
2 = some **4 = all**

13. Do you make yourself very busy and do things so you won’t think about what happened?

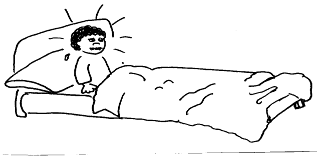
1 = not **3 = most**
2 = some **4 = all**

14. Do you get physically upset when something reminds you of what happened – like getting sweaty, shaking, your heart pounding, getting short of breath, or stomach aches? ☐

1 = not **3 = most**
2 = some **4 = all**

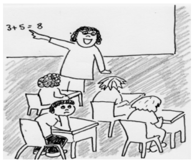
15. Do you have trouble falling asleep or staying asleep? ☐

1 = not **3 = most**
2 = some **4 = all**



16. Is it hard for you to pay attention – like listening to your teacher, or doing your work – because you can't concentrate well? ☐

1 = not **3 = most**
2 = some **4 = all**



17. Do you feel you need to stay 'on guard', like something could happen and you need to be ready? ☐

1 = not **3 = most**
2 = some **4 = all**

18. Do you get jumpy or startle easily? ☐

1 = not **3 = most**
2 = some **4 = all**

19. Do you get annoyed (grouchy) or irritable (kind of angry) really easily? ☐

1 = not **3 = most**
2 = some **4 = all**

20. Do you get angry or upset at people for no reason? ☐

1 = not **3 = most**
2 = some **4 = all**

21. Do you get so angry at people you hit or hurt someone? ☐

1 = not **3 = most**
2 = some **4 = all**

22. Do you ever think you won’t grow up and be what you want to be?

1 = not **3 = most**
2 = some **4 = all**

23. Do you feel it’s hard to have fun doing things?

1 = not **3 = most**
2 = some **4 = all**

24. Do you ever feel it’s hard to feel happy?

1 = not **3 = most**
2 = some **4 = all**

25. Do you feel alone even when other people are around?

1 = not **3 = most**
2 = some **4 = all**

26. Do you feel bad or guilty – like what happened was your fault?

1 = not **3 = most**
2 = some **4 = all**

27. Do you wet your pants or bed by accident?

1 = not **3 = most**
2 = some **4 = all**

28. Do you feel like you are ‘tuned out’ or in a ‘daydream’ so you can go away in your mind and not think?

1 = not **3 = most**
2 = some **4 = all**

29. When you get very upset, how do you calm down?

Alcohol abuse screen

1. In the past month how often did you drink alcohol? ☐

a) Never
b) Every day
c) Several times per week
d) Once a week
e) Once a month

1 = Yes 2 = No

2. Have you been drunk in the past month? ☐

(*distress protocol to be used as needed)*

3. Do your parents or caregivers drink too much alcohol in your opinion? ☐

4. Is there a safe place in the community for young people to hang out? ☐

HIV information

1. Do you know why you are coming to this clinic? ☐

2. It is really important to know about our health. Would you be interested in knowing your HIV status? ☐

NOTE: If adolescent answers 'no', please skip this section

3. How old were you when you found out you were HIV positive? ☐

4. How did you find out you were HIV positive? ☐

5. a) Do you know how you became HIV positive? How? ☐

b) If YES, how ☐

6. Are you taking ARVs? ☐

7. If 'yes', how old were you when you began antiretroviral treatment (ART)? ☐

8. In the last week did you take your treatment every day? ☐

9. How do you remember to take your treatment? ☐

10. What makes it difficult to take ARVs regularly? ☐

11. What support do you need to maintain ART? ☐

12. Have you ever had TB? ☐

13. a) Have you ever been hospitalised for being sick? ☐

b) If Yes, what were you hospitalised for?

c) If Yes, how long were you hospitalised for?

14. a) Have you disclosed your status to anyone before?

b) If so, what happened?

15. a) Do you think it is a good idea for children and adolescents to know their HIV status?
b) Why?

16. a) Do you find other adolescents have a good understanding of HIV care and treatment?
b) what make you say this? Please explain…

c) what would help adolescents improve their understanding of HIV care and treatment?

17. Do you know other adolescents who are HIV positive?

18. Do clinic staff treat you well?

19. What do clinics need to be more inviting to adolescents?

20. What do you think about testing for HIV at school? Why? Please explain

Qualitative questioning

1. if you were president and had a million rand, what would you do for adolescents like you in South Africa?

2. if someone could do something for you for 67 minutes (like Mandela Day), what would it be?

3. a) Do you have a dream for yourself and your future? ☐

b) What is it?

CR

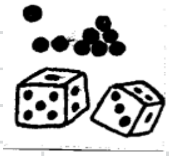
stuff i do in an ordinary week...

1. Please circle the ones you usually do:

a) playing an instrument

b) singing

c) playing a game like marbles or dice

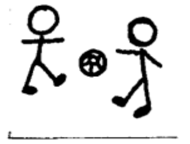


d) listening to music

e) seeing a counsellor

f) playing netball

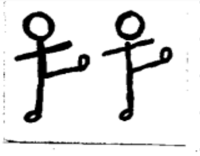
g) playing soccer



h) swimming

i) doing another sport (which one?)

j) dancing

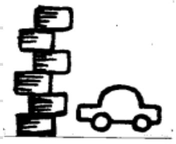


k) begging

l) socialsing with friends

m) using the computer

n) playing with toys



o) doing housework (how many hours a day)

p) job outside the home (how many hours a day?

q) going out with family

r) watching TV

s) playing games

t) reading

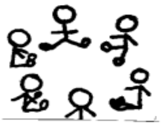
u) other things?

YOUTH CLUBS AND GROUPS

2. Do you go regularly to any youth groups?

a) music, theatre or dance

c) support group



b) sports

d) another kind of youth group

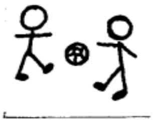
When you are feeling down or sad, do you do any of these things to cheer yourself up?

a) reading

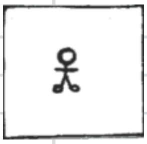
f) comfort from a friend

k) listening to music

b) sport



g) being alone



l) going to the library

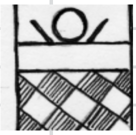
c) homework

h) seeing friends

m) writing or drawing your feelings down

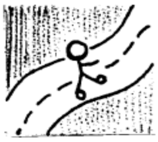
d) playing

i) going to bed



n) other things

e) going for a walk



j) TV

Research team data collection

1. Lastest CD4 count?

2. Latest viral load?

3. a) Orphan status
   1 = single
   2 = double
   3 = not an orphan

b 1) Cause of Parental death

b 2) If has surviving parent and not living with them, does adolescent **know** that person?
   1 = yes
   2 = no

b 3) If has surviving parent and not living with them, does adolescent have a **relationship** with them?
   1 = yes
   2 = no

4. Is the household receiving any grants?
   a) no grants ☐
   b) foster care grant ☐
   c) child support grant ☐
   d) pension ☐
   e) war veterans grant ☐
   f) disability grant ☐
   g) care dependancy grant ☐
   h) grant in aid ☐
   i) social relief of distress ☐
   k) child maintenance support (from father) ☐

5. Been disclosed to?
   1 = yes
   2 = no

6. Disclosed to others?
   1 = yes
   2 = no

7. On treatment? ☐
1 = yes
2 = no

8. Adherent to treatment? ☐
1 = yes
2 = no

9. Type of transmission: ☐
1 = perinatal (vertical)
2 = behavioural (horizontal)
3 = unknown

10. Need for family planning? ☐
1 = yes
2 = no

11. Is this participant appropriate for Nataly's in-depth interview? ☐
1 = yes
2 = no
(if yes, please ask permission to take details and add to log or to comments below)

12. Any comments:

Appendix E. Informed Consent

1. Informed consent - CAB participation

Information and Informed Consent: Adolescent Community Advisory Board (CAB)

Protocol Title:	A description of the mental health outcomes of HIV positive adolescents accessing care in Johannesburg
Principal Investigator:	Nataly Woollett

Introduction

We are conducting a study with young people to understand their health and their feelings about their lives. We know young people attend clinic visits and have views about their own mental health as well as their healthcare and the systems in place to achieve that. I would like to invite you to take part in informing this study as a member of the community advisory board advising this study. It is entirely up to you to decide whether you would like to take part or not and you can ask as many questions about this as you like.

What is a community advisory board (CAB)? A CAB is a group consisting of members who are able to advise on the content of a study or the issues that are related to the study. In other words, adolescents are the best members to advise adults on issues that adolescents face and what might be in their best interests. There are no right or wrong answers but your feedback about the study will be helpful and make it more relevant. We value your opinion.

Do I have to take part? Not at all. It is up to you to decide whether or not to take part. If you do not want to, this will not affect any help you may be getting from anyone. You will not get in any trouble if you do not want to take part. If you decide to take part, you are still free to stop at any time. You don’t have to give a reason.

What would I have to do? If you decide to take part, you will first sign a consent form (on the next page), and then join this board to discuss the study. You will be invited to participate on this board a number of occasions (probably 3 times) to give your advice and opinion on the study and to meet with the rest of the group.

Will what I say be kept confidential? Although the views shared on the board will be used outside the group, individual identifying information will be kept private. Members are asked to respect this privacy of other board members as well.

What will happen to the results of the study? The results of this study will be used to help the government and others make policies for young people to improve their health.

Reimbursement? Participation in the CAB is voluntary. You will be reimbursed for your time and travel costs at each meeting. A meal will also be provided.

Do you have any questions?

Informed Consent: Adolescent Community Advisory Committee (CAB)

Please answer these questions by ticking the box to the right.	**Tick**
1. I have read and understand the information sheet for this study and have had the chance to ask questions	
2. I understand that I have chosen to take part and that I should keep information discussed in this group confidential.	
3. I agree that any words I may say during the CAB meetings can be used, without giving my name, in the presentation of the study.	
4. I agree to be a community advisory board member for this study	

Name:	Signature:
Phone number:	Address:
Interviewer:	Date:

Thank you!

2. Informed consent - study participation

Permission for recording interview: adolescent

Protocol Title:	A description of the mental health outcomes of HIV positive adolescents accessing care in Johannesburg
Principal Investigator:	Nataly Woollett

***NOTE*: For eligible participants aged under 18, permission will be obtained from a parent or guardian first.**

Introduction
Thank you for completing the prior questionnaire. We have chosen a few adolescents to give some addition feedback in an in-depth interview. This means a researcher will ask you a few additional questions about your views and we would like to record these so we don't forget what was talked about. This discussion will take about 30 minutes to an hour to complete. There are no right or wrong answers, it is more a discussion between two people.

Do I have to take part? Not at all. It is up to you to decide whether or not to take part. If you do not want to, this will not affect any help you may be getting from anyone. You will not get in any trouble if you do not want to take part. If you decide to take part, you are still free to stop at any time. You don't have to give a reason. Again, this will not affect any help or support you are getting from anyone.

What would I have to do? We will ask your parent/caregiver to also give signed permission for you to take part in the research. If they do not give permission, even if you do, you will not be able to participate. If you decide to take part, you will first sign a consent form (on the next page), and then spend about an hour talking together with me. We will record our conversation so we can remember everything that was discussed.

What if the questions upset me? You can stop at any point, and you do not have to give a reason. You can also contact the research team at any point and say that you want your answers about certain questions to be destroyed, which we will do straight away. If you want to talk to someone about anything that has come up from this, you can tell one of the researchers or staff at the clinic.

Will what I say be kept confidential? Anything you share about yourself will be kept strictly confidential, and will not be told to anyone else. Any information about you would have your name and address changed so that you cannot be recognised from it. But during this study, it may become clear that you are suffering from serious difficulties. If so, the researcher will explain to you some possibilities for further help. If there is a safety issue, we may contact a welfare organisation for you. All this will be talked over with you first. After we have finished the research, the recording will be destroyed.

What will happen to the results of the research study? The results of this study will be used to help the government and others make policies for young people to improve their health.

Who is organising and reviewing the research? The research is being organised by Wits Reproductive Health and HIV Institute (WRHI), and the University of Witwatersrand. An ethics committee has approved the research. If you have any complaints about ethics, please contact the University of Witwatersrand Research Ethics Committee - telephone: (011) 717 7123/4.

Do you have any questions?

Informed Consent: Adolescent recording

Please answer these questions by ticking the box to the right.	**Tick**
1. I have read and understand the information sheet for this study and have had the chance to ask questions	
2. I understand that I have chosen to take part and that I am free to stop at any time, without giving any reason. This will not change any support or help I am getting	
3. I agree that this interview can be recorded	
4. I agree that any words I may say during the interview can be used, without giving my name, in the presentation of the research. I agree to take part in the study	

Name:	Signature:
Researcher:	Date:

Thank you!

3. Informed consent - permission to record

Information and Informed Consent: Adolescent

Protocol Title:	A description of the mental health outcomes of HIV positive adolescents accessing care in Johannesburg
Principal Investigator:	Nataly Woollett

Introduction
We are conducting a study with young people to understand their health and their feelings about their lives. We know young people attend clinic visits and have views about their own mental health as well as their healthcare and the systems in place to achieve that. I would like to invite you to take part in this study to learn your views and how you manage some stress adolescents have. It is entirely up to you to decide whether you would like to take part or not and you can ask as many questions about this as you like.

What is this study about? As mentioned above, this study is about young people, their health and their feelings about their lives. We are trying to figure out how healthcare systems can provide services that adolescents need and your feedback will be helpful.

Do I have to take part? Not at all. It is up to you to decide whether or not to take part. If you do not want to, this will not affect any help you may be getting from anyone. You will not get in any trouble if you do not want to take part. If you decide to take part, you are still free to stop or withdraw at any time. You don’t have to give a reason. Again, this will not affect any help or support you are getting from anyone.

What would I have to do? If you decide to take part, you will first sign a consent form (on the next page), and then spend about an hour talking with an interviewer.

What if the questions upset me? You can stop at any point, and you do not have to give a reason. You can also contact the research team at any point and say that you want your answers about certain questions to be destroyed, which we will do straight away. If you want to talk to someone about anything that has come up from this, you can tell one of the interviewers or staff at the clinic.

Will what I say be kept confidential? Anything you tell us about yourself will be kept strictly confidential, and will not be told to anyone else. Any information about you would have your name changed so that you cannot be recognised from it. But during this study, it may become clear that you are suffering from serious difficulties. If so, the interviewer will explain to you some possibilities for further help. If there is a safety issue, we may contact a welfare organisation for you. All this will be talked over with you first.

What will happen to the results of the research study? The results of this study will be used to help the government and others make policies for young people to improve their health.

Who is organising and reviewing the research? The research is being organised by Wits Reproductive Health and HIV Institute (Wits RHI), and the University of Witwatersrand. An ethics committee has approved the study. If you have any complaints about the study, please contact the University of Witwatersrand Research Ethics Committee - telephone: (011) 717 7123/4.

Reimbursement? Participation in the study is voluntary. You will be reimbursed for your time with voucher. You will also be provided with a snack during the interview.

Do you have any questions?

Informed Consent: Adolescent

Quiz:

1. We will use your name when we discuss the interview you participated in? True ☐alse ☐
2. If you do not want to participate, you will be treated differently at the clinic? True ☐ False ☐
3. Even if you agree to participate, you can withdraw at any time without giving a reason? True ☐ False ☐

Please answer these questions by ticking the box to the right.	**Tick**
1. I have read and understand the information sheet for this study and have had the chance to ask questions.	
2. I understand that I have chosen to take part and that I am free to stop at any time, without giving any reason. This will not change any support or help I am getting.	
3. I agree that any words I may say during the interview can be used, without giving my name, in the presentation of the study.	
4. I agree to take part in the study.	

Name:	Signature:
Interviewer:	Date:

Thank you!

Appendix F. Distress protocol

Distress Protocol

Protocol Title:	A description of the mental health outcomes of HIV positive adolescents accessing care in Johannesburg
Principal Investigator:	Nataly Woollett

- All interviews will be held in private to ensure confidentiality.
- All identifying information will be known only to the research team (principal investigator, research assistants and psychosocial team in case of emergency). All data will be locked in a secure office and with password protected computers.
- If the participant displays signs of significant emotional or psychosocial distress, the interview will be stopped. With the permission of the participant, a counselor will be requested to enter the interview room and counsel and debrief the participant. In addition,
- If adolescents answer ‘no’ to knowing their status (page 2 of the questionnaire), i.e. they report that they have not been disclosed to or are attending clinics for HIV treatment but do not know they are HIV positive, the interviewer will skip all HIV related questions on the following page (page 3) and start the interview with the demographic questions (page 4).
- There is a screening for suicidality (page 6). All interviewers will be trained in managing this aspect of the questionnaire and referral to a specialist on site will be made immediately if there is any suicidal ideation. Part of the research team comprises psychologists, social workers and therapists who are capable of managing any crisis situations:
    - Nataly Woollett HPSCA AT0001023
    - Kirsten Thomson SACSSP 1018869
    - Shenaaz Pahad HPCSA PS0118427
- There are questions that assess participants’ feelings of safety, both personal safety and safety at home. Again, interviewers will be trained in assessing levels of risk and if needed, will report abuse or suspicion of abuse to Childline, DSD or SAPS according to mandated reporting laws (Children’s Act, Section 110, 2010).
- There are questions about forced sex (pg. 9) and inappropriate touching (pg. 11). Again, in accordance with mandated reporting laws, interviewers will intervene and report as necessary. If participants are in any current danger, appropriate interventions will be initiated. All research team members will be thoroughly trained in these aspects of crisis management and legal requirements.
- An adolescent advisory board will be instituted to provide oversight on the study, input on ethics issues and will aid in dissemination of research findings.

Harriet Shezi children’s clinic

- Participant’s requiring ongoing psychological care will be referred to the counseling psychologist at Harriet Shezi for one-on-one counseling sessions. If the counseling psychologist determines that psychiatric or more expert psychological support is required the participant will be referred to the relevant services at Chris Hani Baragwanath hospital, utilizing the standard referral mechanisms in place at the clinic.
- Participants will be referred to the Nthabiseng rape crisis centre which is situated next door to the Shezi clinic for issues relating to trauma, violence and rape
- Participants will also be provided with the number for Childline (08000 55 555) and/or Lifeline (011 728 1347).

Essellen Street clinic/Shandukani HCHC

- Young people requiring counselling will be advised to contact the Family Life Centre in Johannesburg (011 788 4784/5, 011 833 2057 or 082-231-0370) who are able to offer counselling services specific to young people or alternatively to the Centre for the Study of Violence and Reconciliation (CSVR) located on the 4th Floor, Braamfontein Centre, 23 Jorissen Street, Johannesburg and can be contacted on 011 403 5650.
- Participants will be referred to the medico-legal clinic at Hillbrow Community Health Center for issues relating to trauma, violence and rape.
- Participants will also be provided with the number for Childline (08000 55 555) and/or Lifeline (011 728 1347).

Appendix G. SOP distress management

Managing distress in Survey Participants	
Subject	The process and documentation of managing and reporting psychological distress in survey participants 18 years or older
Responsible Staff	All clinical, regulatory and field staff

Introduction

The structured interviews contain questions about previous experience of distressing or traumatic events such as intimate partner violence, rape, neglect, physical abuse etc. These can potentially cause distress in research participants through the process of recalling and re-living traumatic events. Furthermore, after answering questions about these events, participants may wish to seek psychological services. This SOP describes the processes for containing and referring participants who experience distress during the interviews or who disclose traumatic experiences for which they wish to access ongoing psychological support.

Training of research staff

All study staff who conduct patient interviews will be trained by a social researcher experienced in qualitative interviewing on how to conduct interviews and discuss sensitive issues. Study staff will also be trained in the early identification and immediate management of emotional and psychological distress by a qualified psychologist or counseling psychologist.

Managing emotional and/or psychological distress during the interiew

If the participant displays signs of significant emotional or psychosocial distress, the interview will be stopped. With the permission of the participant, a counselor will be requested to enter the interview room and counsel and debrief the participant. If the participant expresses any suicidal ideation, the counselor will request a clinician at the site to assess the participant for further management.

Referral for ongoing care

Harriet Shezi children's clinic

- Participant's requiring ongoing psychological care will be referred to the counseling psychologist at Harriet Shezi for one-on-one counseling sessions. If the counseling psychologist determines that psychiatric or more expert psychological support is required the participant will be referred to the relevant services at Chris Hani Baragwanath hospital, utilizing the standard referral mechanisms in place at the clinic.
- Participants will be referred to the Nthabiseng rape crisis centre which is situated next door to the Shezi clinic for issues relating to trauma and violence and rape
- Participants will also be provided with the number for Childline (08000 55 555) and/or Lifeline (011 728 1347). –

Esselen Street clinic

- Young people requiring counselling will be advised to contact the Family Life Centre in Johannesburg (011 788 4784/5, 011 833 2057 or 082-231-0370) who are able to offer counselling services specific to young people or alternatively to the mental health community clinic of their choice (See table below).
- For issues relating to trauma and violence, young people will be referred to the Centre for the Study of Violence and Reconciliation (CSVR). They are located on the 4th Floor, Braamfontein Centre, 23 Jorissen Street, Johannesburg and can be contacted on 011 403 5650 which is close to the Esselen Street clinic.
- Participants will also be provided with the number for Childline (08000 55 555) and/or Lifeline (011 728 1347).

LIST OF COMMUNITY MENTAL HEALTH CLINICS

JOHANNESBURG METRO AREA

CLINICS	ADDRESS	TELEPHONE	REPEAT CLINICS
Brixton	77 Ingelby Rd Crosby	(011) 837-7449	A. Patel (Mon-Fri)
Chiawelo	17 Rihlampfu St Chiawelo	(011) 984-8336	S.Dlalisa| K. Manthoko| C.Seguba (sessional) (Tues-Thurs)
Discoverers	Discoverers Hospital, Corner Goldman &Mitchell Street	(011) 674-1200	T.Manana | R. Singo Mon-(Wednesday)
Dobsonville	34 Elias Motsoaledi Road, Soweto	(011) 988-1820	J.Mavundla | C. Diyane|Z Melato (sessional) (Mon, Wed, Thursday)
East bank	Corner Impala & Springbok Rd	(011) 443-7828	K.Moagi|P.Mhlambi (Mon- Fri)
Eldorado Park	21Ascot Road, Ext 8, Eldorado Park	(011) 342- 1164	V.Nyembe| L. Mthethwa (Mon-Thurs)
Ennerdale Ext 9	Corner Katz &Smith Walk ,Ext9, Ennerdale	0730069508, 0828575972	M.Latedisa | R. Kantoro (Mon-Wed)
Hillbrow	Hillbrow Community Health Centre, Corner Smith and Klein Street	(011) 694-3755	E.Gatlane| E. Mabaso (Mon-Fri)
Jeppe	34 Ford Str, Jeppestown	(011) 614- 7233	B. Ndlazi|J. Makgatho (Monday-Thurs)
Lenasia	95 Nirvana Drive,Lenasia	(011) 852-3823	N.Khumalo |G.Khan (Tues-Thurs)
Lenasia South	3 Cosmos Str, Lenasia South	(011) 213-9600/9631	T. Gamede (Mon-Thurs)
Lillian Ngoyi	Old Potch Rd Kwa-Xuma 1804	(011) 938-1556	W.Melato| L.Gova (Mon-Fri)
Meadowlands	Hekroodt Circle, Zone 2, Meadowlands	(011) 936-4613	S.Mnguni| R. Yumba (Mon-Thurs)
Mofolo	1412 Elias Motsoaledi Rd, Mofolo South	(011) 982 5542	N.Tsotetsi|M.Mnembe| K. Konyane (sessional) (Mon&Wed)
Orange Farm	Bristlecone Nursery	(011) 850-0094 0761125362	D. Kunene| S. Mahoa |M. Kunene(Mon-Thurs)
Orlando	Corner Rathebe & Mooki Str, Orlando East	(011) 935-1163	G.Stemar|N.Mabuya (Mon –Wed)
Pimville	3623 Amtagala Str Zone 3 Pimville	(011) 933-2503	T. Ramokonopi (Mon-Wed)
Riverlea	Health Center Colorado Drive	(011) 474-2881	D.Shomang (Wednesday)
South Rand	North road	(011) 435-3829	J. Orritt| R. Letsoalo Tues-Friday)
Westbury	Corner Du Plessis Str & Chrisma Rd	(011) 673-1002	D.Shomang (Thursdays)
Zola	Health Center, Bendile Street	(011) 934-1719	L Mdhluli\ S. Manzini\(Mon,Tues& Thurs)
Randburg	c\o Braamfischer &Selkirk	(011) 787-9393	V. Ncapayi | P. Tsotetsi (Monday-Thursday)
Bophelong	Stand 3699, Ivory Park	(011) 261-1212	P. Koenaite (Fridays)
Halfway House	18 Market street, Halfway house	(011) 805-3112	G. Maswanganyi (Mon- Friday)
Mpumelelo	Stand 13985 Ivory Park	(011) 203-3445\3439	G. Sithole (Fridays)
Rabie Ridge	Erf 1074, c\o Korhaan &Stilt Street, Rabie Ridge	(011) 310-1977	M. Lepuwane (Mon-Friday)

Child and Adolescent Mental Health Clinics

East bank	8th Avenue East Bank Alex	(011) 443-7828	Mon-Thurs	Wednesday
Mofolo	Roodepoort Rd, Mofolo South	(011) 982-5542	Thursdays (alternate)	Thursday
Chiawelo	Chris Hani&	(011) 984-8336	Thursdays	Thursday

	Rihlampfu street		(alternate)	
Zola	Health Center Bendale Rd	(011) 934-1719	Thursdays (alternate	Thursday
Orange Farm	Bristlecone Nursery	(011) 850-0094	Wed	Wednesday

Version #	2
Date	*07/07/2011*
Effective Date	
SOP History	V 1 09/05/2011 – initial draft *Note: Previous versions are archived electronically.*
Training Date and Method	Unless otherwise specified: 1. All new or revised SOPs are presented at the next staff meeting. Those not present at the meeting are responsible for reviewing the meeting minutes. 2. The SOP becomes effective the day after the training. 3. All staff are responsible for reviewing all SOPs yearly. 4. New employees are responsible for job specific SOPs within 30 days of hire and all SOPs within 90 days of hire.

Approvals

I have reviewed and approve this SOP for implementation

Dr Harry Moultrie **Investigator of Record**	**Signature**	**Date**

Appendix H. SOP Process

Process standard operating procedure (SOP)

Protocol Title:	A description of the mental health outcomes of HIV positive adolescents accessing care in Johannesburg
Principal Investigator:	Nataly Woollett

Order	Process undertaken:	Tick
1	Check you have your research bag: Voucher, voucher invoice book, snack (chips and drink), resource cards, tissues, paper, drawing tools, sign, flip file with distress protocols, visual aids, logs, stickers, stress ball, informed consents (ICs), yellow folder and tablet	
2	Check that your tablet is charged and working	
3	Put stickers on ICs for the day	
4	Place ‘do not disturb’ sign on the door of the room you will be using	
5	Get room set up with 2 chairs and a table; make sure drawing tools and paper easy to access	
6	Invite research participant to join you in confidential space	
7	Complete informed consent *and give participant the front page to keep*	
8	Complete questionnaire on tablet: remember to put corresponding IC sticker info onto tablet	
9	Ensure you have completed questionnaire without mistakes before you save as complete	
10	Thank participant for completing questionnaire and ensure they are fine to leave	
11	Give participant voucher and snack	
12	Ask participant to sign for voucher and *give them 3rd triplicate copy (faintest copy)*; put IC sticker on 1st copy of the invoice you will give back to Nataly	
13	Give participant resource card and briefly explain it	
14	Is this participant a potential candidate for in-depth interview on resilience? If so, ask if they would be interested in a follow up interview with Nataly? If yes, please ask them for their contact details (which would only be used by Nataly) so Nataly can contact them for in-depth interview. Record their details (name and number) on the interviewer log form	
15	Thank the participant for their time and escort them back outside the room	
16	Put corresponding IC sticker on log form and complete entry	
17	Clip IC, drawings and invoice copies together with paper clip and put in yellow folder	
18	Invite next research participant to join you	
19	At end of the week give Nataly all the clipped documents in the yellow folder as well as the log form for that week; Ahmed will collect data from the tablet as well	

Thank you!!!!

Appendix I. In-depth interview guide

In-depth interview guide

Protocol Title:	A description of the mental health outcomes of HIV positive adolescents accessing care in Johannesburg
Principal Investigator:	Nataly Woollett

NOTE: This interview will be recorded, ensure consent given for recording

INTRODUCTION

Thank you for agreeing to talk with me today.

The questions I have don't have any right or wrong answers. I am interested in any experiences, stories, and ideas you'd like to share. Please feel free to share your honest thoughts and opinions. I would like to ask you to remember that what is said here today is confidential (which means that I can't talk to others about what we talk about and if I reference your opinion anywhere outside of our conversation your name would never be used).

Do you have any questions for me before we begin?

Great. Let's get started.

IN DEPTH INTERVIEW DISCUSSION GUIDE

Adolescents who are HIV positive and need to attend clinics for their health have lots of good ideas for healthcare providers on what they need from the healthcare system. Adolescents may require more help than just getting ARVs and I would like to ask you today for your opinion on these issues. Some HIV positive adolescents have had difficult experiences growing up; I would also like to ask you about these sorts of experiences too. Especially important is to get your perspective on what the risks are that would make adolescents feel bad and what the resilience (emotional strengthen) factors are for adolescents to be okay.

Risk factors

- In your opinion, what are some of the challenges faced by HIV positive adolescents?

- Do you think these challenges would be different if you were born with HIV or if you got infected later? Why?

- In your opinion, what kinds of mental health problems do HIV positive adolescents face? (A mental health problem is something like depression, trauma, alcohol abuse etc.)

- Do you think these mental health problems are different in HIV positive adolescents as opposed to HIV negative adolescents? How come?

- What do you think some of the challenges are for HIV positive adolescents to take care of themselves?

- Do you think HIV positive adolescents experience difficulties in their relationships with family members, friends and romantic partners? What are some of these difficulties?

- What do you think HIV positive adolescents need from others for life to turn out well?

- What behaviours normally show that people are having a hard time managing their feelings?

- What have been some of the more difficult things you have had to deal with in your life until now? (So far, what is the most difficult thing that you have had to cope with in your life?)

Resilience factors

- Are there people in your life you can go to when life gets tough? Who are these people and what do they offer you?

- What do HIV positive adolescents need from the healthcare system (by healthcare system I mean hospitals, clinics, or any health facility one goes to when sick)?

- How can the healthcare system be improved to help adolescents more?

- For adolescents who have a great deal of difficulty that they have managed (e.g. parent dies, get separated from siblings, get very sick, school is tough, people discriminate against them because of their status etc.) what helps them cope and come out of the situation okay?

- What sorts of things help you manage life and its stress?

- Who do you look up to and why?

- If you were president and had a million rand, what would you do for adolescents in your situation?

Is there anything else you would like to tell me about the topics we have discussed today?

If not, that is the end of our discussion. Do you have any questions for me?

Thank you for your time and participation, it is really appreciated!

Appendix J. Declaration by co-authors

Declaration: Student's contribution to articles and agreement of co-author(s)

I, Nataly Woollett, student number 9107306-D, declare that this thesis is my own work and that I contributed adequately towards research findings published in the articles stated below which are included in my thesis.

Nataly Woollett (candidate)   10th March, 2017

HBrahmbhatt

Dr. Heena Brahmbhatt (internal supervisor)   10th March, 2017

Agreement by co-authors: By signing this declaration, the co-authors listed below agree to the use of the article by the student as part of her thesis.

The candidate was first author of all 5 articles and both supervisors co-authored all 5 articles. Supervisors agree to the use of the manuscripts in this thesis:

HBrahmbhatt

Dr. Heena Brahmbhatt (internal supervisor)   10th March, 2017

Lucie Cluver

Dr. Lucie Cluver (external supervisor)   13th March, 2017

In addition all other co-authors of the 5 articles give permission to the use of the articles in this thesis as follows:

<u>Article 1</u> – **Woollett, N., Peter, J.R., Cluver, L. & Brahmbhatt, H. (2017). Enrolling HIV-positive adolescents in mental health research: a case study reflecting on legal and ethical complexities. South African Medical Journal, 107(8), 679-683**

John Peter

Adv. John Peter   16th March, 2017

<u>Article 2</u> – **Woollett, N., Cluver, L., Banderia, M., & Brahmbhatt, H. (2017). Identifying risks for mental health problems in HIV positive adolescents**

accessing HIV treatment in Johannesburg. Journal of Child and Adolescent Mental Health, 29(1), 11-26

MBandeira

Monica Bandeira 10th March, 2017

Article 3 – **Woollett, N., Black, V., Cluver, L., & Brahmbhatt, H. (2017). Reticence in disclosure of HIV infection and reasons for bereavement: impact on perinatally infected adolescents' mental health and understanding of HIV treatment and prevention in Johannesburg, South Africa. African Journal of AIDS Research, 16(2), 175-184**

Dr. Vivian Black 11th March, 2017

Article 4 – **Woollett, N., Cluver, L., Hatcher, A. M., & Brahmbhatt, H. (2016). "To be HIV positive is not the end of the world": Resilience among perinatally infected HIV positive adolescents in Johannesburg. Children and Youth Services Review, 70, 269-275**

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Article 5 – **Woollett, N., Brahmbhatt, H., Dodd, K., Booth, M., Berman, H., & Cluver, L. (2017). Revealing the impact of loss: Exploring mental health through the use of drawing/writing with HIV positive adolescents in Johannesburg. Children and Youth Services Review, 77, 197-207**

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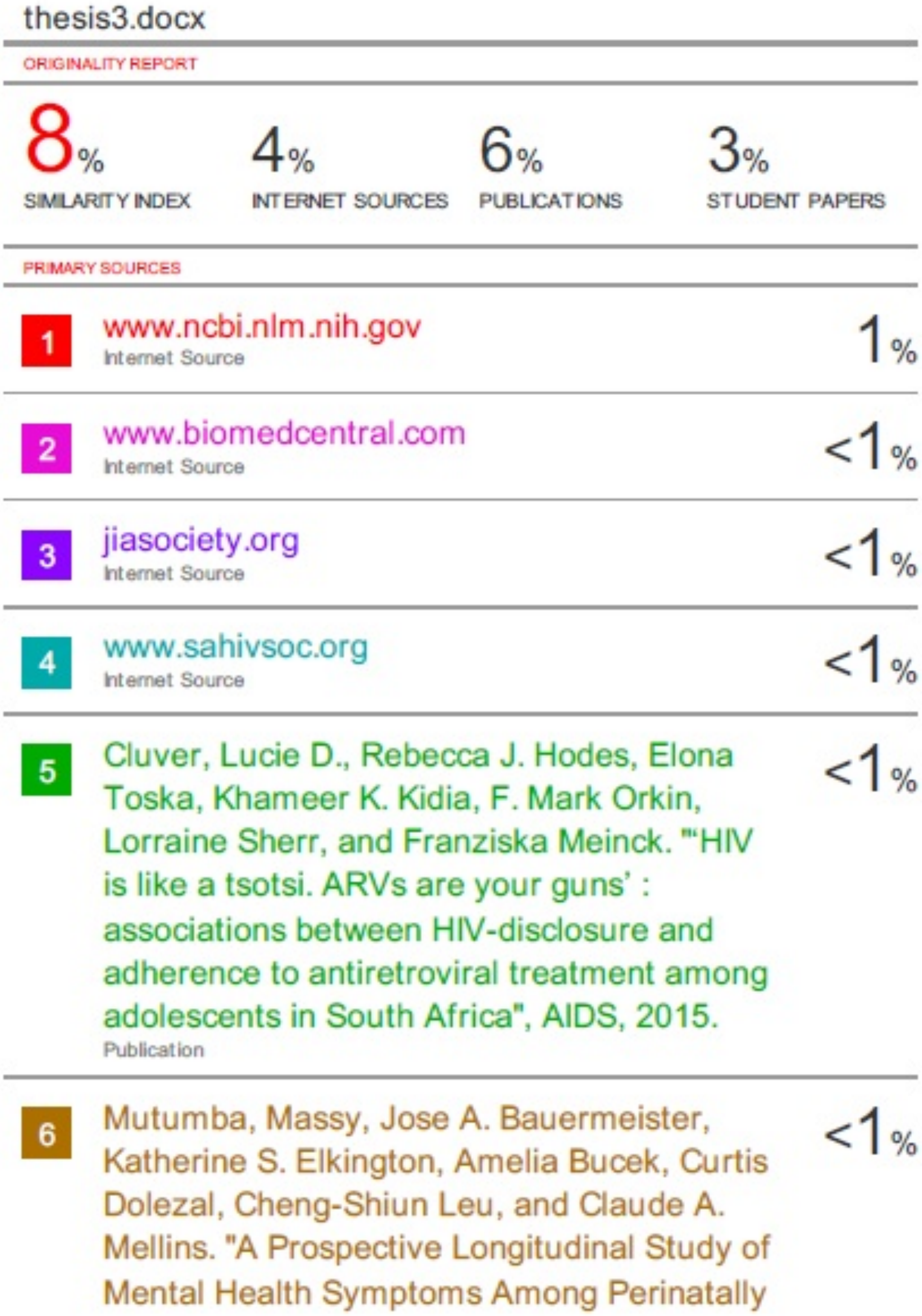

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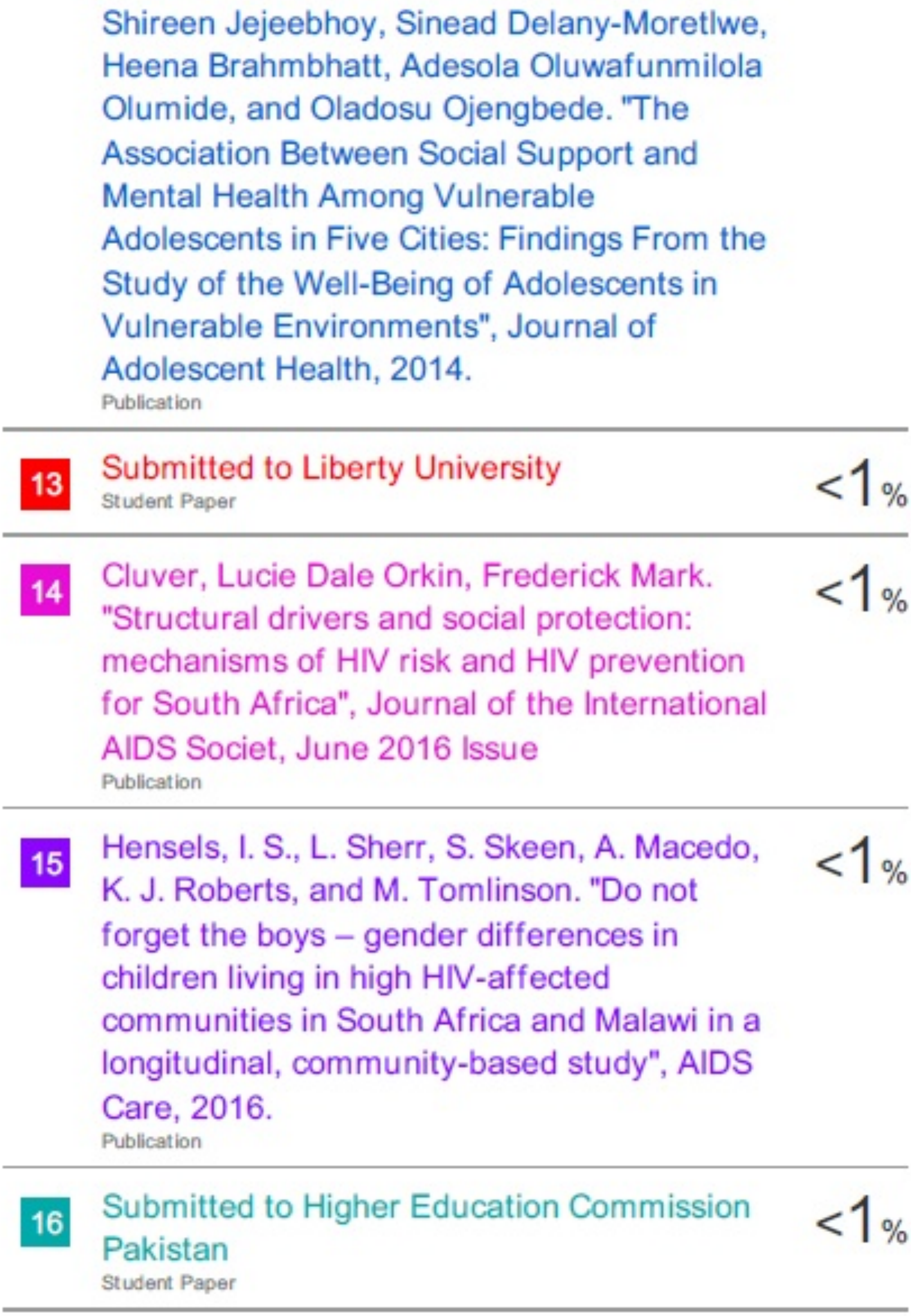

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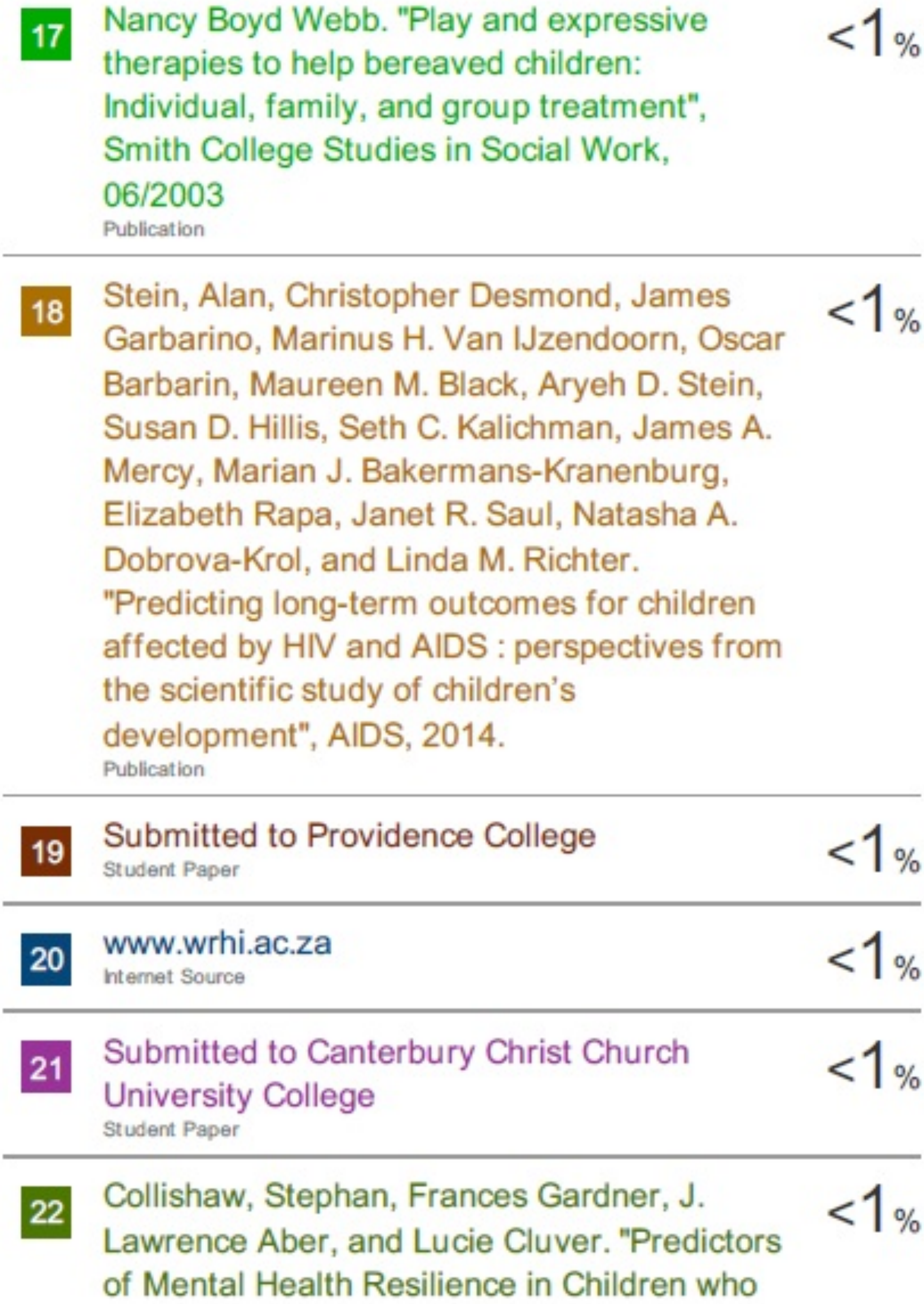

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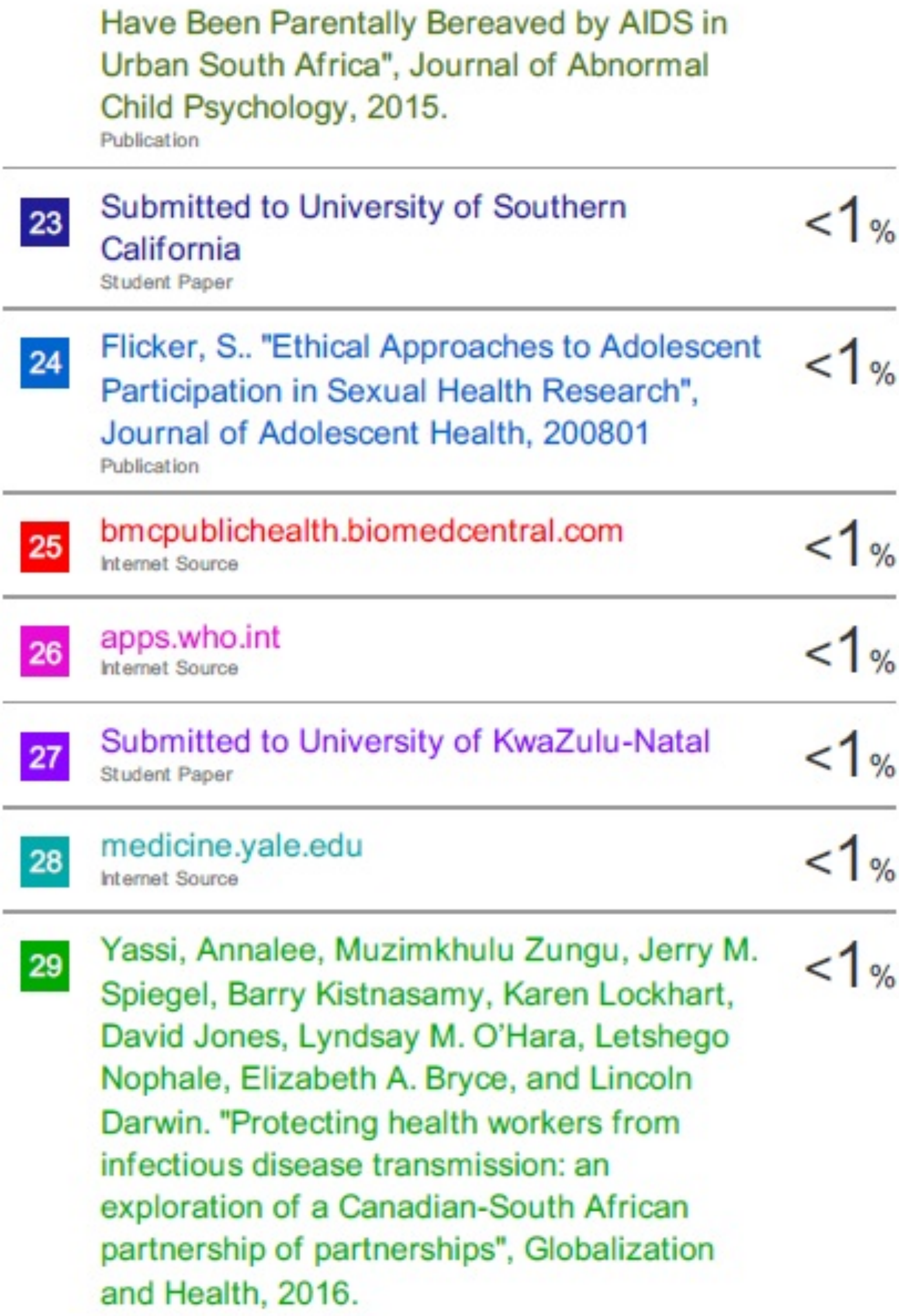

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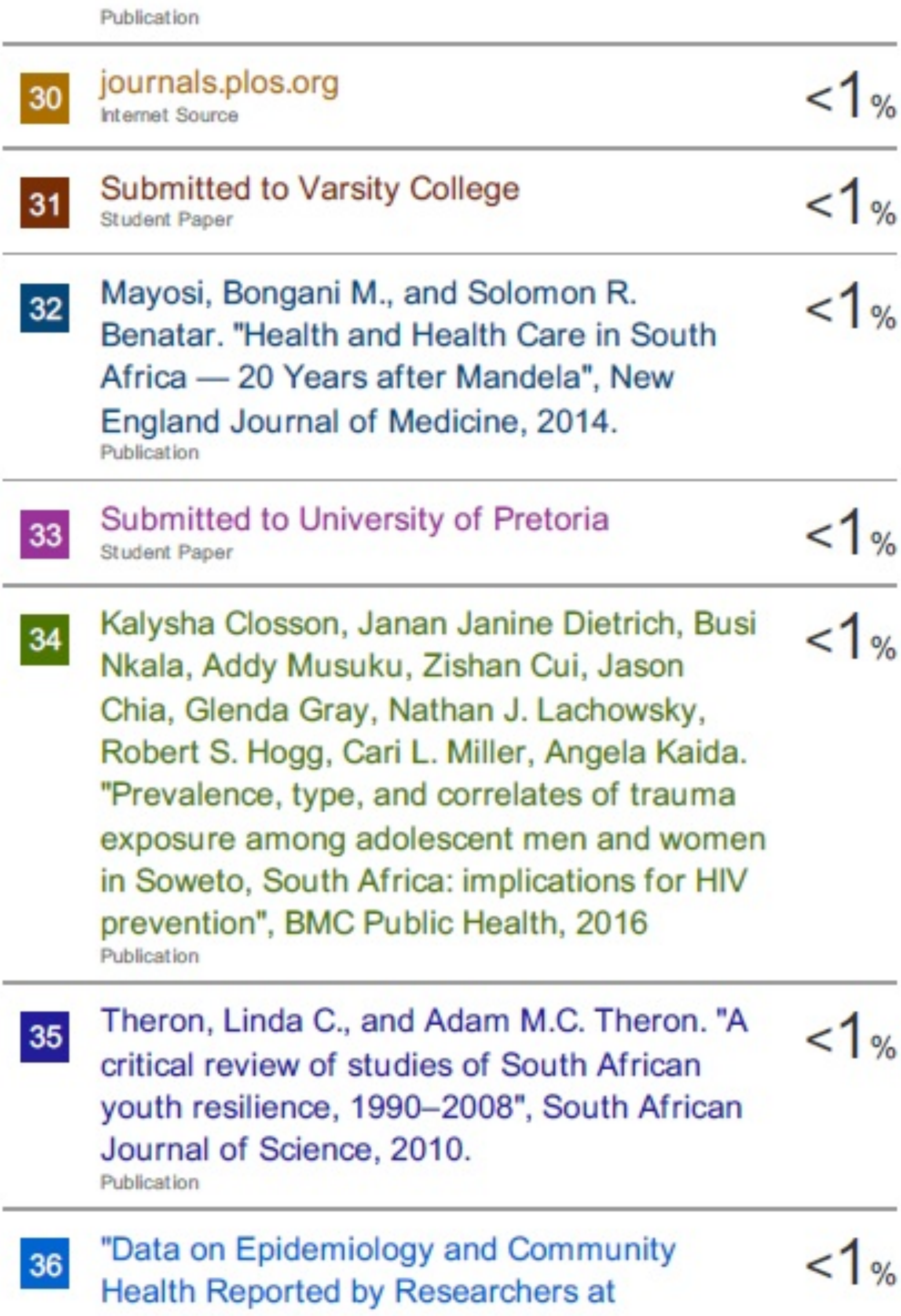

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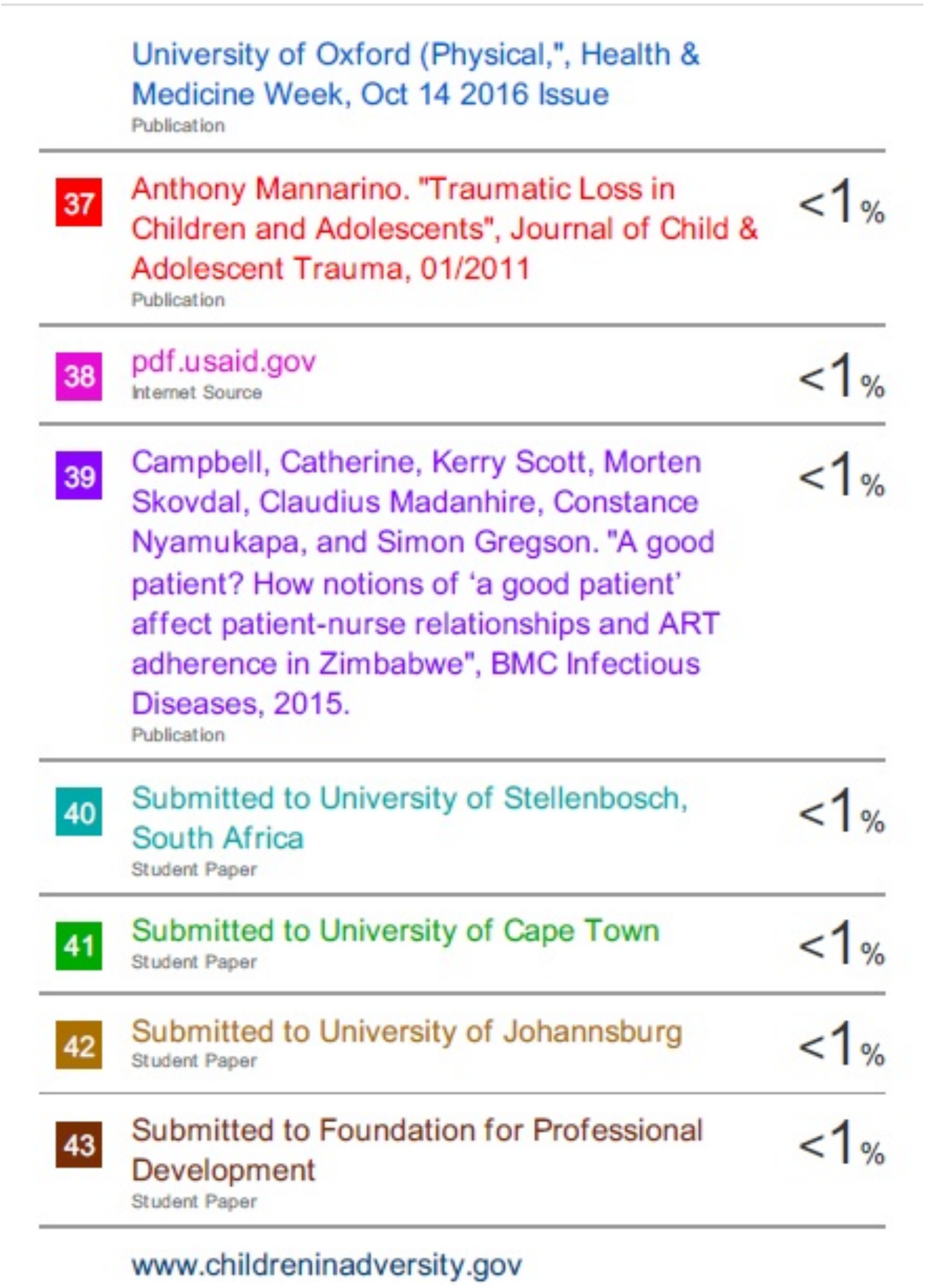

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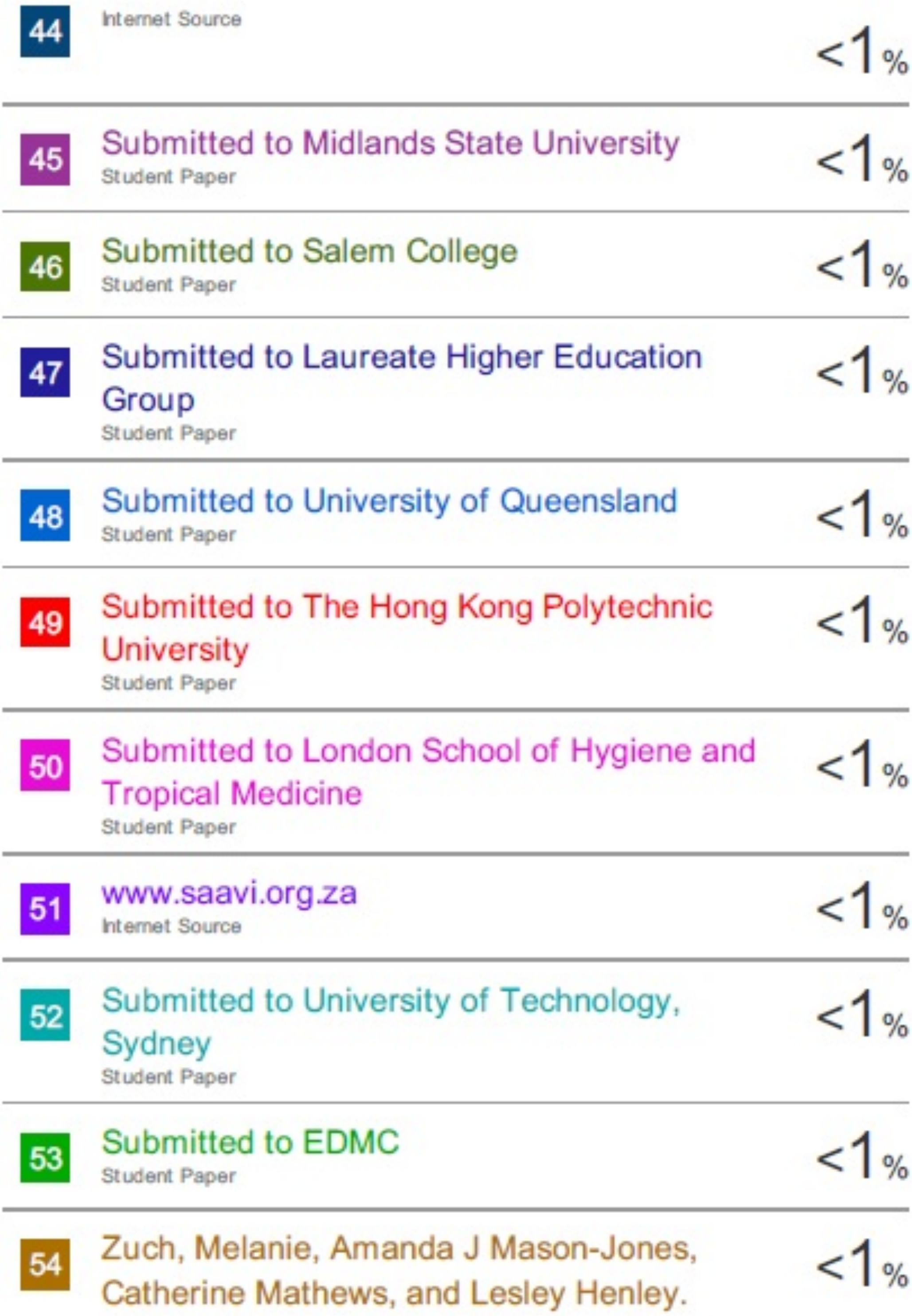

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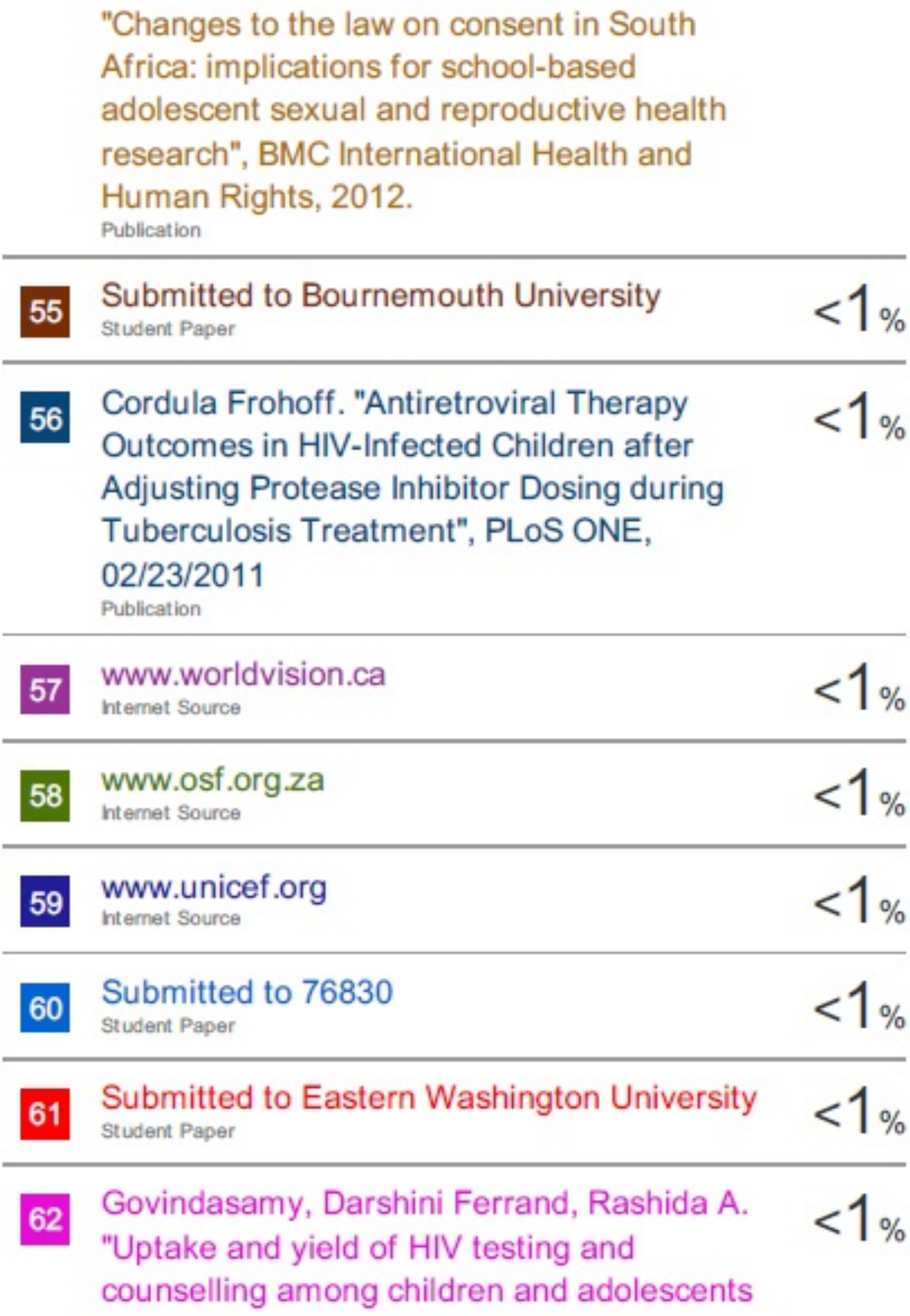

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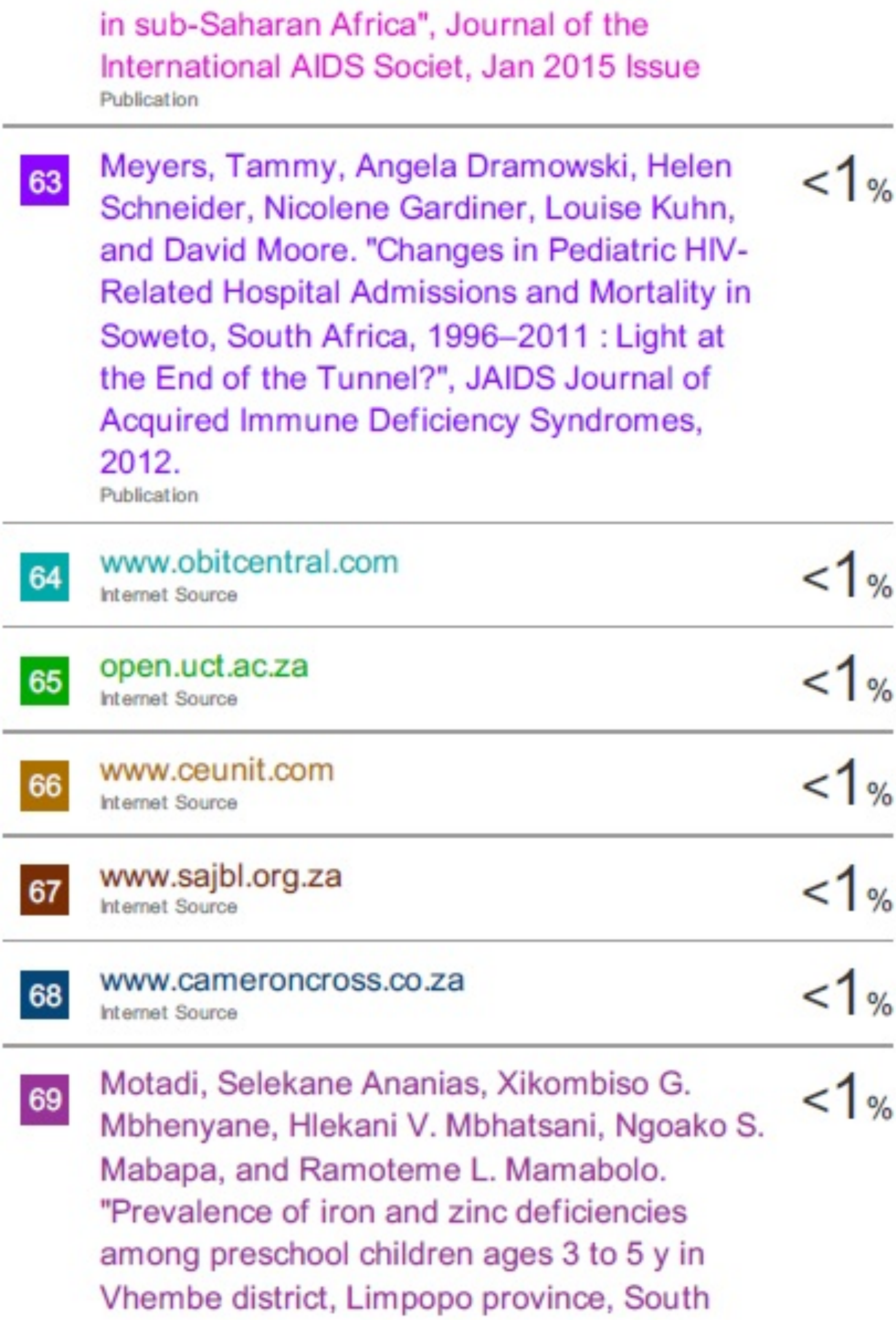

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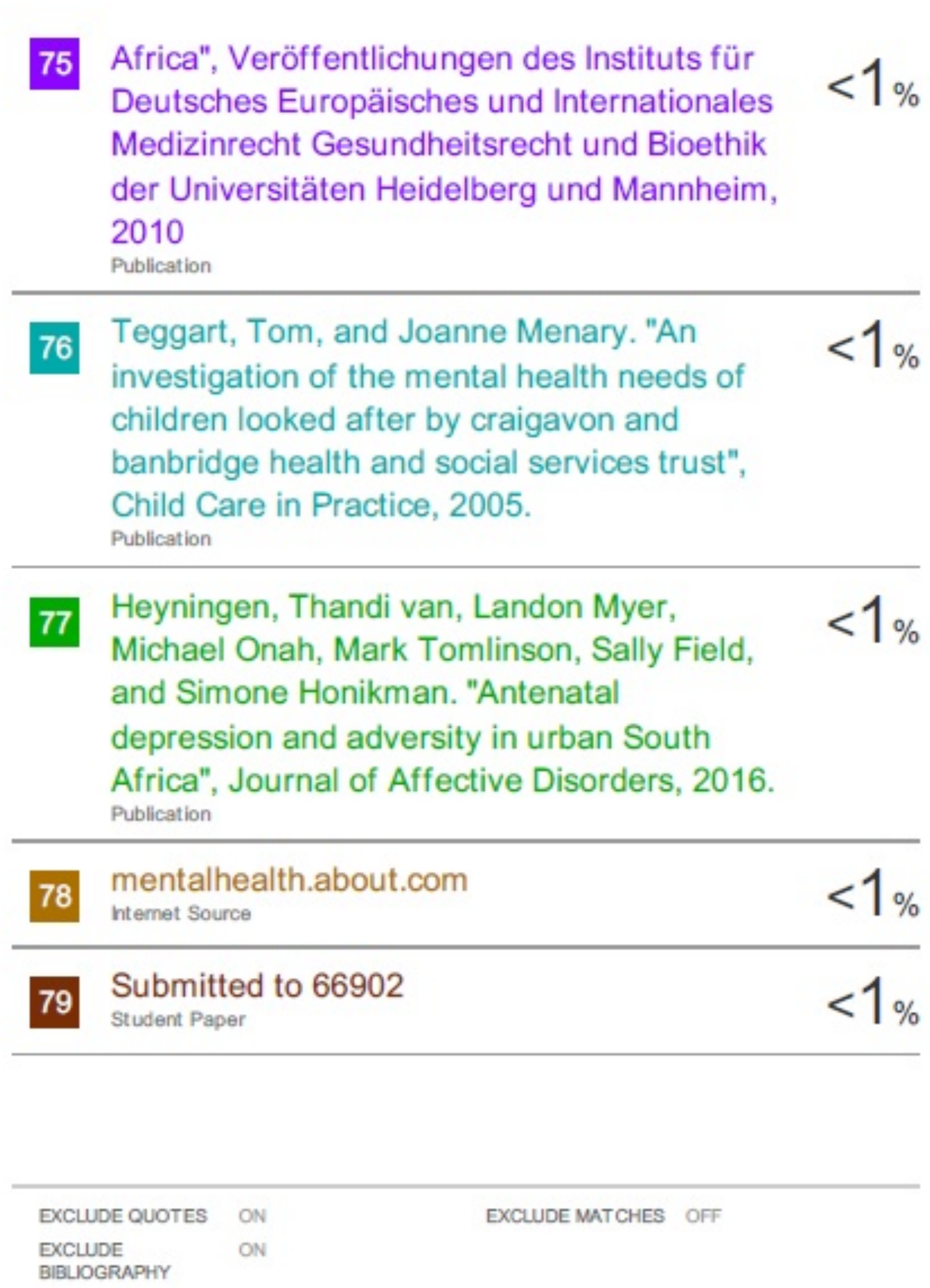

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