

# Revealing the impact of loss: Exploring mental health through the use of drawing/writing with HIV positive adolescents in Johannesburg<sup>☆</sup>

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## 1. 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 (UNAIDS, 2014; WHO, 2013). The HIV pandemic has increasingly brought attention to the unmet mental health needs of children and adolescents (Breuer, Myer, Struthers, & Joska, 2011), highlighting the comorbidity of HIV and mental health problems especially among those perinatally infected (Mellins & Malee, 2013; Lowenthal et al., 2014; Sherr, Cluver, et al., 2014; Sherr, Croome, et al., 2014; Stein et al., 2014). These children and adolescents tend to experience enduring adversity. Multiple losses and bereavement, numerous sicknesses and hospitalisations, 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 (Bernays, Jarrett, Kranzer, & Ferrand, 2014; Lowenthal et al., 2014; Mavhu et al., 2013).

One of the key risks for poor mental health, especially among orphans (many of whom are perinatally infected), is bereavement (Cluver, Orkin, Gardner, & Boyes, 2012; Willis et al., 2014). In a recent local study of perinatally infected adolescents, 74% were orphaned indicating high prevalence rates of bereavement (Woollett, Cluver, Bandeira, & Brahmhatt, 2017). Evidence shows 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, Holland, & Neimeyer, 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, Chase, & Aggleton, 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, Layne, Pynoos, Cohen, & Lieberman, 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, and is especially 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 whilst they are sleeping and speaking about the dead is discouraged (Daniel, Apila, Bjorgo, & Lie, 2007; Van der Heijden & Swartz, 2010). 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

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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, Frank, Houck, & Reynolds, 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). Utilising unconventional means of understanding mental health in HIV positive patients, such as drawing and writing, may be of particular benefit (Campbell, Skovdal, Mupambireyi, & Gregson, 2010; LeRoux-Rutledge et al., 2015; Skovdal, Ogutu, Aoro, & Campbell, 2009; Willis et al., 2014). These can also add value to interventions that meet the mental health challenges of HIV infected young people that are gaining traction with varying success, in neighbouring African countries (Mavhu et al., 2013; Strasser & Gibbons, 2014) and locally (Bhana et al., 2014). 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, including improved adherence and retention in care (Patel, Flisher, Nikapota, & Malhotra, 2008; Kagee, Tsai, Lund, & Tomlinson, 2012), 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.

## 2. Theoretical framework

### 2.1. 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 that 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, 1997) 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).

Patient ill-health is prone to activate the attachment system because of distress and perceived vulnerability. Healthcare providers such as doctors, nurses and lay counsellors can be influential 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 person but also the total

environmental provision of this ability to ‘hold’ (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. Creativity in the context of the provider relationship is valuable in nurturing emotional development and mitigating mental health risk.

### 2.2. Nonverbal 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) (Goodman, 2005; Goodman, Chapman, & Gantt, 2009; van der Kolk, 2007; Webb, 2003). 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, Gerrit, Knipscheer, Kleber, & Hutschemaekers, 2015).

### 2.3. 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 (Berman, 2016; Clacherty & Donald, 2007; Coad, 2007; D'Amico, Denov, Khan, Linds, & Akesson, 2016; Driessnack, 2005). Non-verbal methods thus offer children/adolescents and adults an easier platform for communication.

## 3. Methods

### 3.1. 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 ( $n = 343$ ; 96% response rate). Adolescents between 13 and 19 years volunteered to participate in a 90 minute questionnaire administered on tablet computers, known to improve reporting of stigmatised behaviors (Jaspan et al., 2007; Toska, Cluver, Hodes, & Kidia, 2015), and interspersed with drawing tasks. The ‘research counsellors’ routinely provided direct

services to the adolescents as counsellors, were trained in paediatric 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 h) 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.

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) constituted for this research.

The mean age of participants was 16 years, and 52% were female. The vast majority were orphaned (74%; 32% double orphans) and living either with extended family members (285 participants, 83%) or in children's homes (5 participants, 1.5%). Only 18% of the sample had not experienced a major loss (parent, sibling, primary caregiver) in their lives to date, indicating that loss was a major event occurring during early development, and losses were reasonably recent (within last 3–6 years). In addition, a third of participants had experienced more than one major loss of a family member. One third (27%) of the sample was symptomatic for depression, anxiety or PTSD and 24% indicated signs of suicidality (Woollett et al., 2017).

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). Participants were interviewed for 60 min by the principal researcher using a semi-structured interview guide discussing topics such as initial impressions of content and style of artwork/writing, differences and similarities in artwork/writing especially between symptomatic and non-symptomatic groups, and how the artwork/writing expressed bereavement. The interviews were recorded with participant consent and conducted in English as all participants spoke English comfortably. For each FGD, all drawings and written accounts were exhibited on the walls of the room for easy access to the visual material. A brief history of participants was conveyed through a visual timeline they had completed that accompanied the drawings/

written accounts providing brief insights on major events (such as timing and death of loved ones) in participants' lives. 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 and utilised non-verbal means of therapy such as drawing and writing 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. This group had also been exposed to manifold children and adolescent drawings through their role as counsellors in their clinical practice and researchers in this study.

### 3.2. Data analysis

Mental health was measured using standardised scales utilised 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, 2013). 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, Cluver, & Gardner, 2012). Suicidal behavior was measured with the MINI International Psychiatric Interview for children and adolescents suicide scale (Sheehan, Shytle, & Milo, 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  $n = 4$  participants were excluded on account of missing information (all in the most symptomatic group). A balance of gender and age, as well as number from either group (most and least symptomatic) were sought which led to  $n = 26$  participants being 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 through a series of meetings to gain consensus and to select the most representative drawings/written account to ensure themes were properly represented through the imagery identified and examined.

### 3.3. 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,

**Table 1**  
Descriptive table.

	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	Number moves	Age started ARV treatment	Age of disclosure	Who disclosed status
Lease symptomatic	Female	15 yrs	Mother	3 yrs	Elder sister	3 yrs	Drawing	2 – mother, uncle, (father unknown)	2	10 yrs	14 yrs	Elder sister
	Male	18 yrs	Uncle	8 yrs	Bio mother	–	Drawing	1 – uncle (both bio parents alive)	3	17 yrs	17 yrs	Bio mother
	Male	16 yrs	Grandmother	10 yrs	Children's home	3 yrs	Drawing	3 – mother, father, grandmother	2	8 yrs	10 yrs	Grandmother
	Male	16 yrs	Grandfather	Unknown	Bio mother	–	Drawing	3 – father, grandfather, grandmother	–	11 yrs	11 yrs	Bio mother
	Male	15 yrs	Sister	12 yrs	Elder sister	4 yrs	Drawing	2 – mother, sister, (father unknown)	3	13 yrs	14 yrs	Sister
	Female	16 yrs	Mother	5 yrs	Grandmother	5 yrs	Writing	2 – mother, uncle, (father unknown)	3	5 yrs	5 yrs	Family member
	Female	13 yrs	Uncle	10 yrs	Grandmother	3 yrs	Drawing	2 – mother, uncle, (father unknown)	2	9 yrs	–	–
	Male	15 yrs	Mother	4 yrs	Grandmother	4 yrs	Drawing	2 – mother, uncle, (father unknown)	3	12 yrs	12 yrs	Grandmother
	Male	13 yrs	Father	8 yrs	Maternal aunt	3 yrs	Drawing	4 – mother, father, grandmother, uncle	3	7 yrs	–	–
	Female	15 yrs	Mother	3 yrs	Grandmother	3 yrs	Drawing	2 – mother, uncle, (father unknown)	2	10 yrs	14 yrs	Grandmother
Most symptomatic	Male	14 yrs	Father	5 yrs	Aunt	7 yrs	Writing	2 – mother, father	3	8 yrs	12 yrs	Family member
	Female	17 yrs	Mother	6 yrs	Grandmother	6 yrs	Writing	1 – mother (father unknown)	2	7 yrs	–	–
	Female	13 yrs	Mother	8 yrs	Grandmother	8 yrs	Drawing	4 – mother, father, sibling	3	12 yrs	12 yrs	Doctor
	Male	15 yrs	Father	7 yrs	Bio mother	–	Drawing	1 – father	3	8 yrs	14 yrs	Bio mother
	Female	13 yrs	Father	10 yrs	Bio mother	–	Writing	1 – father	4	5 yrs	13 yrs	Bio mother
	Male	15 yrs	Aunt	9 yrs	Bio mother	–	Drawing	1 – aunt, (father unknown)	3	12 yrs	14 yrs	Counsellor
	Female	14 yrs	Mother	6 yrs	Aunt	6 yrs	Writing	4 – mother, father, grandmother, sibling	4	13 yrs	13 yrs	Counsellor
	Female	14 yrs	Uncle	7 yrs	Bio mother	–	Drawing	3 – uncle, grandmother, grandfather	1	10 yrs	10 yrs	Bio mother
	Female	16 yrs	Mother	5 yrs	Aunt	5 yrs	Drawing	1 – mother, (father unknown)	5	8 yrs	9 yrs	Aunt
	Male	13 yrs	Mother	8 yrs	Grandmother	8 yrs	Drawing	2 – mother, father	3	11 yrs	11 yrs	Brother
	Female	16 yrs	Mother	5 yrs	Grandmother	5 yrs	Writing	2 – mother, father	2	9 yrs	9 yrs	Grandmother
	Male	19 yrs	Mother	12 yrs	Cousin	12 yrs	Writing	3 – mother, father, grandmother	5	10 yrs	10 yrs	Counsellor
	Female	19 yrs	Mother	11 yrs	Aunt	11 yrs	Drawing	3 – mother, grandfather, grandmother, (father unknown)	4	11 yrs	12 yrs	Social worker
	Male	13 yrs	Mother	4 yrs	Children's home	4 yrs	Drawing	4 – mother, father, grandmother, grandfather	4	11 yrs	11 yrs	Counsellor
	Female	17 yrs	Mother	5 yrs	Grandmother	5 yrs	Drawing	3 – mother, father, brother	4	9 yrs	11 yrs	Grandmother
	Male	18 yrs	Mother	6 yrs	Aunt	6 yrs	Drawing	2 – mother, father	3	14 yrs	14 yrs	Counsellor

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).

#### 4. Results

Table 1 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 (7 males, 4 females; age range 13–18 years with mean age 15 years) and 15 from the group with most overall mental health problem symptoms (6 males, 9 females; age range 13–19 years with mean age 15 years). 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 5 years (range 3 years–12 years), 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 and 3 significant losses in their lives.

##### 4.1. Contextual deprivation and impoverishment

As indicated in Table 1, 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.

Early loss of mothers leads to major disruptions in care and, typically, additional loss. Fig. 1 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 hospitalised the following year and started antiretroviral treatment then, i.e. his physical health deteriorated after this significant loss. The following year he experienced a traumatic event, a neighbour he was close to was shot and died in the street, an event he witnessed. This participant at 15 years old was repeating grade 8 (usually grade 8

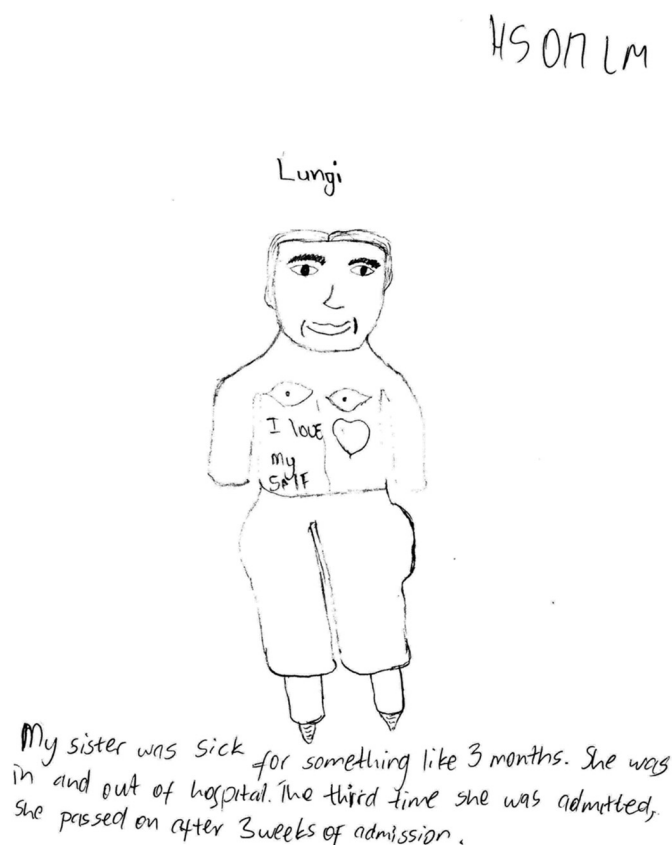


Fig. 1. 15 year old male, least symptomatic group.

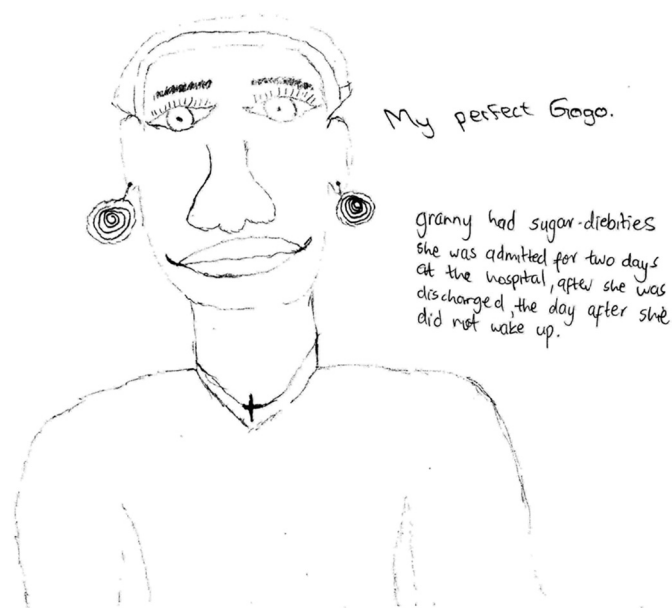


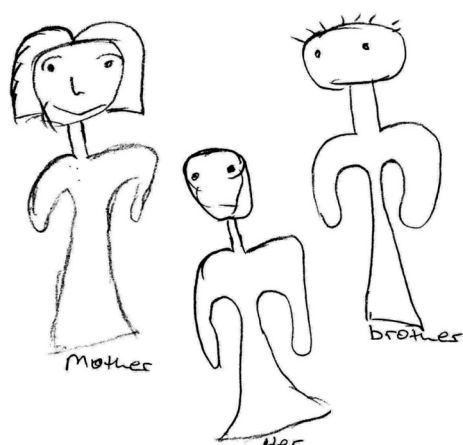
Fig. 2. 16 year old male, least symptomatic group.

learners are 13–14 years old).

Similarly, in Fig. 2 this participant lost his mother at age 3, his father at age 5. This led to a move to another province to live with his grandmother. He became ill with shingles at age 8 and was hospitalised, leading to a diagnosis of HIV and initiation of antiretroviral therapy. At 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



HS044 HN



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

Fig. 3. 17 year old female, most symptomatic group.

[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'.

Losses of biological parents in early childhood often led to outcomes of poor access to birth certificates and legal documents. In Fig. 3 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. 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 working with the social workers to get both birth certificates for the children and access to 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 (i.e. grief from loss that does not go away or doesn't seem to have been worked through). The memory appears fragmented and the imagery ghost-like and not grounded.

#### 4.2. Emotional deprivation and impoverishment

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 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). 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.

Developmental delays seemed evident in some drawings represented. Fig. 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. 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.

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 (Fig. 7).

Similarly, Fig. 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 figure 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.

By way of comparison, Fig. 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. 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.

#### 4.3. Missed opportunities

Particularly for the most symptomatic group, mental health challenges had been evident for many years in most participants but were seemingly unrecognised by caregivers and not addressed in terms of access to care, leading to negative consequences in adolescence. Fig. 10 below, however, 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

WWO08J  
 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.

Fig. 4. 14 year old male, most symptomatic group.

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.

## 5. 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 unresolved, 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, various themes became evident, even though prevalence was not indicated on account of the small sample size of the study. 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. This exacerbates suicidality, potentially affecting 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 (i.e. guarding against or distancing from a full awareness of feeling) in its presentation. Conversely, the imagery of the least symptomatic group appeared more grounded, more detailed and integrated, depicting a real and obviously known person.

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

Life without my parents

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 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 me behind without saying anything.

The end!

Fig. 5. 16 year old female, most symptomatic group.



- My mother passed away when I was 8 years, 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 father passed away first, don't remember anything about him, but He use to buy me toys and clothes.

Fig. 6. 13 year old male, most symptomatic group.

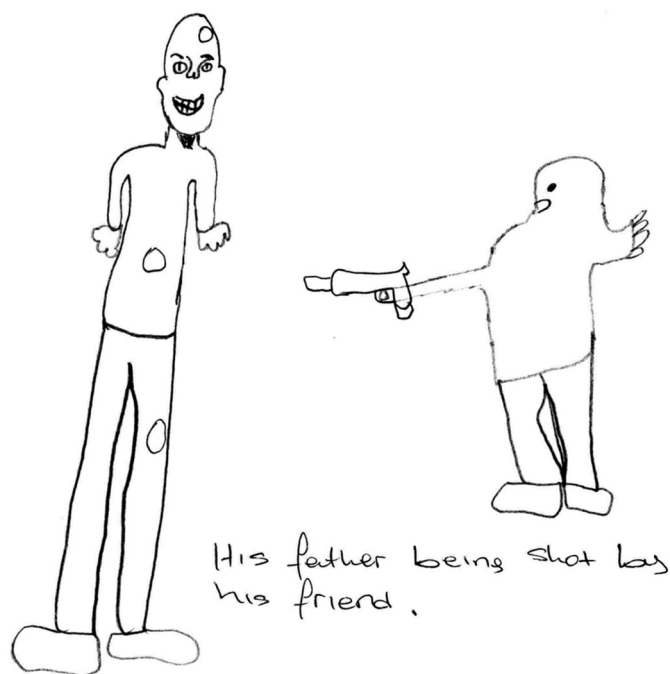


Fig. 7. 15 year old male, most symptomatic group.

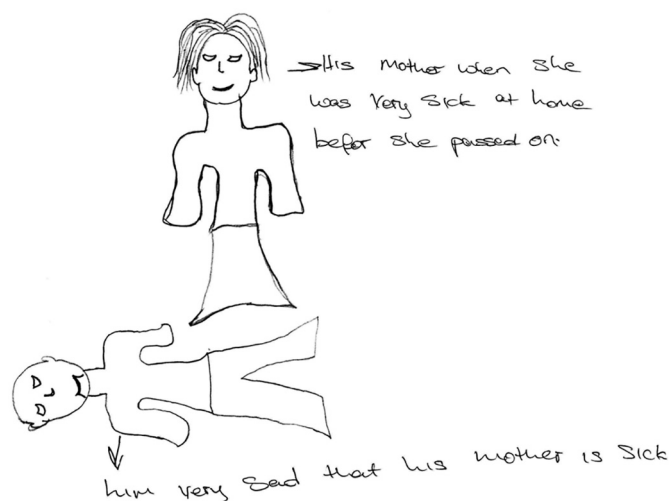


Fig. 8. 18 year old male, most symptomatic group.

watching them (although these barriers to engagement were addressed through continuous training and supervision of the research counselors). Children's drawing behavior tends to develop along with their cognitive skills (such as thinking, problem-solving and remembering)

and emotional development (Kortesluoma, Punamaki, & Nikkonen, 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, Cluver, et al., 2014; Sherr, Croome, 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



# Alex's Picture

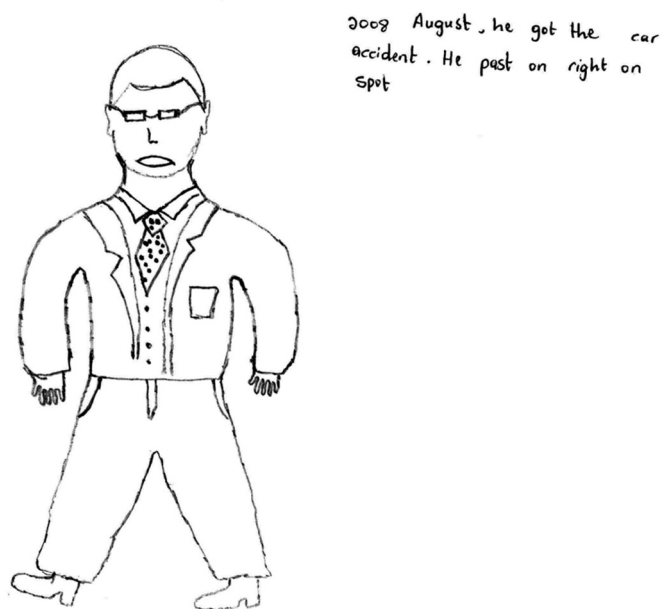


Fig. 9. 18 year old male, least symptomatic group.



I donot remember much because I was very young. mam was very sick and she was admitted at the hospital in mpumalanga and she passed on.

Fig. 10. 15 year old female, least symptomatic group, synonym used.

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 beneficial 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. Paediatric patients often utilise the same clinic if they don't move provinces, even though they may relocate within the province. 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 beneficial 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, Cluver, Hatcher, & Brahmabhatt, 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 (Mannarino & Cohen, 2011; Wood et al., 2006). 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, Fairall, Egbe, & Bhana, 2014; Padmanathan & De Silva, 2013; 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 discussed and explained with the research counsellors and participants gave voice to their imagery and written accounts in this containing relationship. 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 hospitalisation 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. Also current clinical status of participants was not retrieved or reported in this study. 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 underutilised in the health system.

## 6. Conclusion

It is only in recent years that HIV positive 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 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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