AN INTERPRETIVE USE OF DRAWINGS TO EXPLORE THE LIVED EXPERIENCES OF ORPHANED CHILDREN LIVING WITH HIV/AIDS IN SOUTH AFRICA

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ABSTRACT

Against the backdrop of the growing problem of AIDS orphans in South Africa and greater sub-Saharan Africa, this qualitative enquiry examines the lives of three South African orphaned children living with HIV/AIDS in a children's home in Cape Town. It aims to generate rich, child-centred descriptions of some of the significant experiences of the children's lives. Drawings, dialogue and narrative were employed to generate the primary data. This was supplemented by collateral interviews and other relevant records, e.g. medical and biographical. Existential-phenomenological theory informed the approach to data collection and analysis. Each child produced a series of ten to twelve impromptu drawings over a period of ten weeks. These drawings and transcripts of the children's verbal descriptions of their drawings were extensively analysed. Significant themes for each participant as well as themes common to all three were identified. Some of the central themes emerging include loss, abandonment, death, disease awareness and coping. The children's ability to develop adaptive coping mechanisms and resilience in the face of traumatic loss and terminal illness was a particularly outstanding feature of the findings. Recommendations are made regarding future research to address the lack of qualitative, child-focused investigations as well as appropriate interventions for addressing the psychosocial needs of orphaned children living with HIV/AIDS.

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CHAPTER 1: INTRODUCTION

The impetus for this study was a conversation held between the author and the caregiver of a home for AIDS orphans in Cape Town, South Africa. The conversation took place within the context of the neuropsychological assessment of one of the HIV-positive children from the home during the internship year of the author's training as a clinical psychologist. The caregiver informed the author of the unique and challenging circumstances of the children living at the home. The children are HIV-positive. Since 1992, the home had been providing care and residence for children orphaned and abandoned due to parental AIDS-related illnesses, death and stigmatization. They are well cared for by trained and experienced staff, volunteers, sponsors and donors. They receive adequate education and medical support. They are also exposed to a range of extra-mural and entertainment activities. In many ways, they are well resourced.

In addition to their supportive environment, they are exposed to their own and others' illness episodes and to the AIDS-related deaths of their peers and parents. Many of the children have survived for longer than expected. The home is currently at the point where they are forced to plan around the adolescent futures of the children. They have discovered that, as the children get older, they start to express more of an interest in, and awareness of, their health and HIV status. Their caregivers have also found that, even when the children do not communicate verbally about their condition, they include themes of family, illness and death in their play. Some of the children display behavioural and emotional problems like aggression, anxiety, withdrawal and oppositional tendencies that concern the staff. There is a commonly held feeling at the home that the children need to speak more openly about their feelings and experiences as Orphaned Children Living with HIV/AIDS (OCWA's). The staff members do not always know how to communicate with the children and are sometimes uncertain as to how much the children are aware of.

As the next section will indicate, psychological research on OCWA's and other AIDS orphans in South Africa is lacking. Furthermore, qualitative research in the international arena on AIDS orphans has rarely pursued the voices of the children. The literature reveals that empirical research has focused on the perceptions of caring and concerned adults of the experiences of AIDS orphans. As a result, their experiences are often couched in psychiatric discourse and outsider perceptions and expectations of their vulnerability and fragility. This

study aimed to redress this imbalance by creating a space for a trio of children from the aforementioned home to express their views and perceptions based on their experiences. They have used the language of drawing and story-telling to communicate. It is the children's expressions that have been analysed. This study therefore presents their experiences framed in a discourse co-constructed by them and the author/researcher. By listening to these children, it is hoped that many more children facing similar circumstances will be listened to. Not all their experiences fit the diagnostic categories often used to describe them. As the analysis indicates, there may be a need for a new "category" to be included in psychiatric discourse: resiliency.

CHAPTER 2: LITERATURE REVIEW

My lover Samuel used to tell a story about himself. It was when he was first working with the Theater of the Deaf. The company had been improvising a new piece from an outline that Samuel had devised, when he said something that provoked a headstrong and violent young actor, deaf since birth. "I understand you," Samuel said in sign, attempting to silence him, if that's the word. The young actor's eyes became as wild as a horse caught in a burning barn; his arms flew this way and that, as if furious at his own imprecision. Samuel needed an interpreter. "You do not understand this"' the actor was saying, pointing to his ears. "You will never understand."

- Barnett (in Leavitt & Mitchell, 1994).

2.1. Introduction

This section examines literature spanning the last two decades relating to the topic of the lived experiences of orphaned children living with HIV/AIDS. In addition, this section addresses the psychological implications of early parental loss and chronic disability through a consideration of relevant theory and empirical research. Subsection 1 begins by constructing a definition of the group of children being investigated, since the terms "child", "orphan" and "AIDS orphan" are used differently in different contexts. What follows is a systematic psychologically-emphasised overview of the literature based on a *de*-construction or unpacking of the term "Orphaned Children Living with HIV/AIDS (OCWA's)." Each component part of this term is looked at, highlighting the psychological impact of orphanhood, orphanages, chronic illness, and the HIV/AIDS pandemic on children. In subsection 2, this review then makes a transition to examine effective ways of researching children and particularly the techniques of art therapy and narrative communication. This introduces the section on **Methodology** that follows.

2.2. SUBSECTION 1: UNPACKING THE TERM "ORPHANED CHILDREN LIVING WITH HIV/AIDS"

2.2.1. Defining who and what is being investigated

According to the Section 28(3) of the Constitution of the Republic of South Africa, Act 108 of 1996 as well as the Child Care Act 74 of 1983 and Child Care Amendment Act 96 of 1996, a child is any person under the age of 18 years. This is consistent with the definition enshrined in Article 1 of the Convention of the Rights of the Child (UNICEF, 2003). In spite of this age guideline, UNICEF has defined orphans as children under the age of 15 years who have lost one or both parents. The rationale behind this difference in terms of defining a child versus an *orphaned* child is unknown and perhaps confusing.

Logically, if a child is any person under the age of 18 years, then any child who has lost his/her parents under the age of 18 years should be defined as an orphan. In certain instances,

differentiation according to which parent and how many parents were lost is made. Therefore, a maternal orphan would have lost his/her mother, a paternal orphan is a child who has lost his/her father only, and a double orphan has lost both parents (through death) or deprivation of relationships with his/her parents (through abandonment). This author wishes to emphasise that a child may be labelled as an "orphan" under a variety of circumstances. Regardless of how the parents were lost, an orphan cannot access consistent parenting from their biological or birth parent(s). Their parent(s) may have died, but may also be alive but unavailable if their whereabouts are unknown. The parent may have abandoned the child or is unfit to provide adequate care for the child.

As a result, the orphaned child does not have contact with the parent(s) and to all intents and purposes has lost the parent or more specifically, has lost the parental relationship. This loss may take place at any stage in the child's life, and such a child may be identified as an orphan as long as s/he fits the definition of a child. It is this experience of parental loss and deprivation that is the source of comment and debate about the psychological development and make-up of orphaned children.

Without a consistent definition of "child" or "orphan" in the literature, this study shall create its own definition. The term "orphan" shall refer to any person under the age of 18 years who has had no significant relationship with his/her parent(s) since infancy (0-3 years) due to the death of the parent(s), abandonment by the parent(s) or highly inconsistent contact with the parent(s). The children in this study have all also been diagnosed HIV-positive in infancy, and are currently living with HIV/AIDS. Wild (2001) has defined AIDS orphans as children whose parents have died of AIDS, but who are not themselves HIV-positive. In this study, the term "AIDS orphan" will refer to children who have lost one or both parents to AIDS and who may or may not be HIV-positive themselves. The more specific term "orphans living with HIV/AIDS" or OCWA's will refer to children who have lost one or both parents to AIDS and who have been diagnosed as HIV-positive.

2.2.2. Orphaned children

Expanding on the definition of "orphan", The Chambers Concise 20th Century Dictionary (Davidson, Seaton & Simpson, 1985) says that an orphan is "one bereft of father or mother [or both]". Secular writing, for example the Charles Dickens (1908) story of *Oliver Twist* and the story of *Orphan Annie*, both popularised through stage and film productions, as well as

academic writing (e.g. Bowlby, 1951 in Cassidy & Shaver, 1999), acknowledge that someone "bereft" of their parent(s) often manifests behavioural, emotional and psychosocial experiences different from those who have not been orphaned. In such stories, orphans are generally depicted as responding to their circumstances by becoming miserable, withdrawn and pessimistic, defiant and rebellious or hopeful and resourceful.

Parental loss in childhood may lead to negative or positive outcomes for the psychological development of the child. Often, the expectation and focus is on the negative outcomes. An Australian study set out to map the long-term psychosocial development of children who lose their parent(s) through death (Raphael, Cubis, Dunne, Lewin & Kelly, 1990). The researchers' intention was to assess whether early parental loss resulted in higher psychosocial problems in adolescence than individuals who had not suffered such a loss. Results showed that adolescents who experienced parental loss in childhood exhibited more negative perceptions of self and scholastic ability, experienced (and presented with) a higher incidence of emotional problems and generally used mental health services more often than adolescents who had not experienced earlier parental loss. Another study demonstrated that parentally bereaved children and adolescents aged 7-17 years displayed more of a predisposition for developing Post-traumatic Stress Disorder (PTSD) than same-age participants who survived a natural disaster as well as non-trauma controls (Stoppelbein & Greening, 2000). It is suggested that what places parentally bereaved children at risk for developing PTSD is a compromised sense of invincibility or invulnerability in the face of negative life events (Gibbs, 1989 as in Stoppelbein & Greening, 2000). These individuals develop a perception of being vulnerable to randomly occurring negative events in their lives (Gibbs, 1989; Greening & Dollinger, 1992 in Stoppelein & Greening, 2000). In the lives of children orphaned through HIV/AIDS in South Africa, this vulnerability is not just a mere perception, but also an objective reality for them.

Commenting on the relationship between actual experience and a sense of the potential for that experience to occur in human infants, Ogden (1990), in his reading of Klein (1958, 1963) proposes that the actual experience of something confirms for the infant what is understood by Klein as an inbuilt expectation for that thing to occur. For example, an infant has an inbuilt sense of the potential for danger to occur in its life; if that infant has an actual experience of danger, this "…simply confirms the infant's anticipation that such danger exists." (Ogden,1990, p. 17). It is postulated here then, that when actual experience crystallises and

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brings into awareness that which previously existed only as a preconception, the experiencing individual has a full, first-hand somatic and emotional experience of whatever was preconceived; should this experience be dangerous or in any way threatening to the biological or emotional integrity of that individual, s/he is at risk of being traumatised by the experience.

What this means for children who are orphaned and who live with HIV/AIDS is that they are likely to be traumatised by their actual experiences of danger that takes the form of their multiple losses: loss of parental relationships through death or abandonment, loss of bodily integrity and functioning when they fall ill. From the psychoanalytic viewpoint expressed by Ogden (1990), these children regularly have their anticipation of danger, death and loss concretised through their lived realities. The idea that children carry their formative experiences with them throughout their lives and that they tend to repeat these experiences, is reiterated in the attachment theories of John Bowlby (1973 in Weinfeld, Sroufe, Egeland & Carlson, 1999). Bowlby addressed this dynamic within the context of relationships and relationship patterns. He clearly postulated that children who lose their parents or primary caregivers become insecure about future intimate and caring relationships. As a result, these children may behave in a way that is suggestive of their mistrust in the availability and sustainability of affectionate relationships. Bowlby (1973) identified anger at others as a significant indicator of this mistrust (in Weinfeld *et al.*, 1999). Subsequent experiences of relationships will either reinforce or refute the child's formative relational experience. Therefore, repeated losses and inconsistencies in important relationships in the life of a child who has endured early parental loss will reinforce the child's mistrust, fear and insecurity regarding intimacy (Weinfeld *et al.*, 1999).

By the same token that people are born with a sense of the potential for dangerous or life-threatening events to occur, they are also born with a sense of the potential for nurturing, loving and life-enhancing events to occur (Ogden, 1990). When they have actual experiences of such events, they have a full, felt and real experience of that which promotes life and caring. It is possible that if the life-enhancing experiences outweigh the life-threatening experiences, the individual's trauma may be buffered and its deleterious effects diminished. On this basis, children who are orphaned and living with HIV/AIDS may not present with overt, overwhelming and chronic emotional or behavioural problems if they are provided with sufficient actual experiences of being loved and cared for.

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A study investigating the psychological and emotional impact of orphanhood in Uganda – where the majority of children and adolescents are orphaned through AIDS – emphasises the negative outcomes for this group of parentally bereaved children (Sengendo & Nambi, 1997). Fear (of death), anxiety, hopelessness, anger, depression, self-deprecation were amongst the affective states cited by the authors when describing the psychology and emotionality of these children. Commentary on the negative effects of orphanhood is echoed by Foster (1997) who identifies low self-esteem, aggression, anxiety and depression as more severe and common amongst orphaned children than other children.

The findings in these aforementioned studies were reportedly consistent with that of similar previous studies, and illustrate some of the more negative outcomes of (early) parental loss. The flip side of this coin is examined by Eisenstadt, Haynal, Rentchnick and De Senarclens (1989) who expound the psycho-biographies of people historically renowned for their eminence. They suggest there is a plausible correlation between high levels of achievement and a history of early parental loss that has been appropriately and adequately resolved or worked through. Thus, the loss experience has presumably been understood and integrated into the developing personality of the child, rather than overwhelmed the personality. It is postulated that early parental loss may very well contribute to the development of genius.

Three variables are said to increase a child's chances of developing resilience as a response to difficult life circumstances (Demos, 1989; Garmezy, 1993; Luther & Zigler, 1991; Rutter, 1993; Werner & Smith, 1989 in Geballe & Gruendel, 1998). The child variable focuses on the child's innate or learnt problem-solving skills that incorporate both appropriate independent and dependent modes of problem-solving. The family variable highlights the need for an affirming, empathic and supportive relational experience for the child in his/her family context, while the variable of external support addresses the importance for the child of adequate social support for the child's family that may be sourced from the extended family, community structures, educational and health institutions, faith-based or religious organisations and peer groups (Gruendel & Anderson, 1995; Luthar & Zigler, 1991 in Geballe & Gruendel, 1998).

This model for the development of resiliency in children who have been psychosocially stressed has been applied to AIDS-affected children in various studies. The recommendations that follow advocate for the prevention of psychological distress for AIDS orphans through:

the provision of meaningful and nurturing relational experiences both during the parent's illness as well as after the parent has died (Furman, 1974; Rutter, 1966, 1979, 1983); explicit planning for permanent placement of the child after the death of the parent (Geballe, 1995) together with the provision of support for the child's new family (Ginchild & Perez-Porter, 1996; Mandelbaum, 1995; Mullen, 1996 in Geballe & Gruendel, 1998). Of pertinence to the current study and its methodology of involving child participants in generating and developing an understanding of their experiences and needs as OCWAs, it is furthermore suggested that the child and his/her needs must be included in all decisions and planning regarding his/her future (Geballe & Gruendel, 1998). Also of pertinence to the approach and attitude of the current study towards the child participants is the suggestion that the child is engaged in open conversation about sensitive matters like illness and death that have direct bearing on their lives (Geballe & Gruendel, 1998). Specifically, the authors recommend that space be provided for the child to express his/her feelings about their life events (Geballe & Gruendel, 1998). Lastly, because of the high risk that the multiple losses and stigmatisation places on AIDS-affected children, it is recommended that these children will need to develop as much of a sense of consistency and stability as possible. This notion is consistent with the earlier mentioned comment that orphaned children are prone to develop a perception of being vulnerable to randomly occurring negative events in their lives (Gibbs, 1989; Greening & Dollinger, 1992 in Stoppelbein & Greening, 2000), which may place them at greater risk for negative psychological outcomes such as Post-traumatic Stress Disorder (PTSD). Ensuring and structuring consistency in their lives therefore becomes a stabilising factor in the child's life.

The age at which a child loses his/her parent is said to be significant in terms of the psychological capacity of the child to resolve and integrate this loss and use it in a psychologically advantageous manner (Haynal, 1987 in Eisenstad, Haynak, Rentchnick & De Senarclens, 1989). Generally, younger children and infants experience parental loss more traumatically than older children, due to the importance of the parent-child relationship for the psychosocial development of the child in those formative years. Haynal (1987) cites research postulating that due to disruptions in (personality) development such as that imposed by parental loss, orphans may tend towards creativity as a means of ensuring balance and stability (Aimard, Guyotat, Laurent & Confavreux, 1976). What psycho-biographical research into eminence highlights is the potential for a more positive, adaptive and psychologically healthy response to early parental loss. The potential for resiliency in children who have been

traumatised is echoed by Karlenza (1998) in his comment on the impact of HIV/AIDS on children living in sub-Saharan Africa. He reinforces the notion that older children are more likely to develop resilience in the face of trauma due to their generally higher level of cognitive and emotional development relative to younger children.

As noted earlier in this section, orphaned children experience emotional difficulties due to the many losses and changes that come with the death of one or both parents (Sengendo & Nambi, 1997). These emotional difficulties are exacerbated if the parent's death was due to AIDS and further intensified if the child is infected with HIV. Understanding and perception of the unique plight of AIDS orphans is summed up in the following statement: "Children orphaned by AIDS have the same problems as other orphans, but worsened by stigmatisation and multiple loss (Karlenza,1998, p. 5)." The emotional challenges of HIV infection for children may include effects of the disease itself and its treatment, stigmatisation and multiple losses. The one loss that is perhaps the most devastating for children is the loss of a parent. For children who were abandoned or orphaned in infancy, this loss recurs as they move through their lives and come into contact with others, discovering and re-discovering the absence of a mother and/or father. For children who endure multiple illness episodes shrouded in uncertainty and having seen others die when they too have taken ill, the need for the loving comfort of a "mommy" and/or a "daddy" must be profoundly present. To then realise that they are deprived of the loving comfort and protection of their parent/s at those very moments of vulnerability, must be profoundly painful, to say nothing of the realisation that mommy or daddy gave me this illness.

The children in this study were born HIV-positive; their "mommies" and "daddies" passed the illness onto them through conceiving them. Their "mommies" and "daddies" left them by dying or by abandoning them. They live through their own episodes of illness and hospitalisation related to their HIV status. They live through the illness episodes of others that share the children's home with them. They have seen others die. They continue to experience loss. They are treated differently and are seen to be different because they do not have parents, because they "have" HIV or AIDS. This treatment may more often than not be empathic and sensitive, but it is different nonetheless. At school, many of them end up in the "Special Class" because they cannot cope with the scholastic demands of a grade class. Their learning barriers and emotional and behavioural difficulties may be the effects of their illness, the effects of early parental loss, the effects of living in a children's home with nineteen-or-so

other children without access to an exclusive relationship with a single caregiver, the effects of being different, the effects of multiple illness episodes that take them away from school and peers, the effects of being treated differently, and not being pushed and driven like some of the other children for fear of overburdening these already overburdened children. Some of this thinking is speculation, some of it based on empirical research evidence. This study intends to discover and describe the experiences of these children and so add to the growing body of psychological research on children living with HIV/AIDS. Brown, Lourie and Pao (2000) and Lwin and Melvin (2001) note that the way that children and adolescents psychologically cope with or adjust to living with HIV/AIDS has not been as extensively studied as the response of adults. This study aims to assist in redressing this imbalance. Furthermore, Brown, Lourie and Pao (2000) also suggest that the needs of those who are born with HIV may be different from those who become infected later in life; they underscore the need for research to examine these two groups separately. The current research looks at the former group exclusively.

2.2.3. Living in orphanages

The current study seeks to describe and understand the lived experiences of OCWA's. In addition to living with HIV/AIDS and having endured parental loss, these children have been placed in a children's home by the Children's Court in South Africa. They have been living in this home since infancy. Such a home may be alternatively referred to as an "orphanage". The term orphanage may conjure up not altogether favourable images of children being maltreated en masse, perhaps informed by fiction such as Dickens' *Oliver Twist* (1908). It seems that perceptions of the negative impact of institutionalisation on children are not merely fictitious. Frank, Klass, Earls and Eisenberg (1996) offered commentary on a then-current debate in the USA between proponents and opponents of orphanages as a way to deal with abandoned, neglected and impoverished children. In their delivery, these authors review a vast amount of literature that examines the medical, psychological and social short- and long-term effects of institutionalised versus foster/adoptive/biological parent residential living arrangements, on children. Commenting on the psychological impact of institutionalised care on children, the authors highlight studies that point to the slower and impaired cognitive development amongst institutionalised children where the children were deprived of sensory and social stimulation (Rutter, 1981; Casler, 1961; Glaser & Eisenberg, 1956 in Frank *et al.*, 1996). But even when stimulation was improved through higher staff to child ratios, children who were institutionalised before the age of one year suffered developmental delays when compared

with children who were in a foster or biological parent home in from within the first month of life (Hansen, 1971; Klackenberg, 1956 in Frank *et al.*, 1996).

John Bowlby and Mary Ainsworth, pioneers of attachment theory, developed ideas around children's relationships with their parents and others close to them (Cassidy & Shaver, 1999). Bowlby (1951) in particular, commented on the effects of concomitant separation of an infant from its mother and the subsequent institutionalisation of the child on the emotional well being of that child (in Cassidy & Shaver, 1999). He reported to the World Health Organisation that children placed in institutions were challenged when it came to building meaningful and deep emotional ties with others; these children, according to Bowlby were also at risk of developing antisocial and aggressive behaviour patterns (in Cassidy & Shaver, 1999). Other theorists and clinicians, e.g. Burlingham and Freud (1944), concurred with these findings, highlighting the importance of a sustained parent-child bond for the sustained emotional well being of a child (in Cassidy & Shaver, 1999). Specifically, it is the gambit of the mother-child relationship and the impact of the child being deprived of that relationship that has received much attention in clinical practice and theory in the twentieth century. For example, the school of object relations theory has examined, in great detail, the effect of the mother-child relationship on the psychological development of the child (Ogden, 1990). The basic idea of this and other related theories is that the child needs to have an adequate relationship with his/he mother from birth in order to achieve normal psychological developmental milestones. Thus, children who have been deprived of this bond as a consequence of being abandoned by their mothers or having lost their mothers through death – as is the case of the children in the current study – are predicted to exhibit many signs and symptoms of distorted psychological and emotional development.

In looking at the psychological development of institutionalised children, Frank *et al.* (1996) turned to studies and theorising that demonstrated the imperative of a consistent, reciprocal relationship between primary caregiver and child (Spitz, 1945; Spitz & Wolf, 1946; Lowrey, 1940; Bowlby, 1969; Tizard & Rees, 1975; Hodges & Tizard, 1989; Tizard & Hodges, 1978). What these studies and writings emphasise is the great potential for emotional, personality, social and behavioural distortions in children who are deprived of a consistent primary attachment figure within a family-orientated environment, as would be the case with institutionalised children. The effects of this kind of deprivation have been shown to persist into adolescence and adulthood (Frank *et al.*, 1996). The gist of the commentary by Frank *et*

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al. (1996) is that in spite of attempts to improve conditions in orphanages, children reared in an institutionalised setting will be at a disadvantage socially, emotionally, cognitively and psychologically when compared with children reared in family homes.

2.2.4. Children with chronic illnesses

"The available evidence suggests that most children [living] with [a] chronic illness do not manifest psychological disturbance and that there is no 'personality type' that characterizes this population (Midence, 1994, p. 321)." And yet, much like the approach to understanding the psychological and emotional needs and development of children who have experienced parental loss has focused on negative outcomes, it has been noted that the approach to understanding the effects of *chronic illness* on children's development has also traditionally focused on negative aspects, almost to the point of ignoring the capacity of some children to cope and adjust in healthy ways to challenging life circumstances such as ongoing and debilitating illness (Midence, 1994) and death.

For example, Cadman, Boyle, Szatmari and Offord (1975) and Newacheck and Taylor (1991) (in Miller, 1995), put forward evidence for the deleterious effects of chronic illness on the psychological functioning of affected children. Furthermore, writing on disability and chronic illness, Falvo (1991) identifies the following characteristics in people who live with a chronic illness or disability: perceived poorer quality of life; perceived and experienced negative changes in attitudes towards, and notions of, the person themselves and his/her body; uncertainty related to disease course and prognosis; stigmatisation by society; grief or a sense of loss due to impending death or loss of functions; fear and anxiety; anger; depression; guilt. Falvo (1991) also summarises some coping responses to chronic illness or disability: denial; avoidance; regression; compensation; rationalisation; diversion of feelings. In line with the view presented by Midence (1994), Falvo (1991) emphasises that the person living with a chronic illness does not have to be rendered psychologically and emotionally overwhelmed, incapable and dysfunctional rather it is entirely possible for a person to display adaptive behaviour in the face of living with a chronic illness.

There appear to be many factors that influence a person's response to living with a chronic medical condition. The nature of the illness, the extent to which it physically and mentally debilitates an individual, the degree to which the illness is apparent to outsiders and illness prognosis and severity are some of the factors said to influence the manner in which a chronic

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illness impacts on a child's development (Perrin & Gerrity, 1984 in Midence, 1994). To this, Falvo (1991) adds developmental stage. The study at hand focuses on children of school-going age and from Falvo's (1991) description of the developmental tasks of infancy and early childhood and the school-aged child, it is possible that the following areas of development are impeded or challenged in the children who participated in this study: development of a sense of trust in other people; development of a sense of autonomy; development of a sense of initiative, frustrations and limitations through discovery and exploration of the immediate environment; development of a sense of capability or competence; development of a sense of confidence in newly explored and discovered skills and abilities; development of peer relationships; development of a notion of the world beyond the family or home.

Therefore, the children in the current sturdy may present with a sense of mistrust in others, a lack of drive and initiative, a lack of a sense of limits or boundaries, or otherwise an overly-cautious and overly-anxious approach to situations and people, a poor awareness of their own abilities with a concomitant low self-esteem, an inability to make friends and sustain meaningful friendships, and a limited view of the world which may be observed as a fear of the world or a lack of understanding and tolerance of anything and anyone that is different.

It was noted earlier that an AIDS-affected child is more likely to respond in a resilient and adaptive fashion to his/her life circumstances associated with HIV/AIDS if s/he has a characteristically proactive approach to life, has a supportive family network and is able to access appropriate and effective support from outside the family (Geballe & Gruendel, 1998). Similarly, the author of the current study postulates that a child who has a chronic illness may also tend towards a more adaptive response to the challenges of living with the illness if the same aforementioned characteristics of the child, the family and the broader environment are in place. In addition to these factors, a child's response is influenced by characteristics of the illness itself (Gil, Abrams, Phillips & Keefe, 1989; Gil, Williams, Thompson & Kinney, 1991; Thompson, Gil, Abrams & Phillips, 1992 in Midence, 1994). Solano, Costa, Temoshok, Salvatti, Coda, Aiuti, Di Sora, D'Offizi, Figa-Talamanca, Mezzaroma, Montella and Bertini (2002) showed that lower levels of emotional expression and awareness in individuals living with HIV/AIDS, led to more rapid disease progression only if the infected individuals' illness had already progressed to a specifically low level of immune suppression. Their study reinforces the idea that there are a myriad personal/individual and illness factors that may

intersect – often in quite a complex fashion – to generate a resilient or alternatively, a distressed response to chronic illness.

Midence (1994, p. 315) adds: "Physiological aspects of the disease itself, medications and other forms of treatment, frequent hospitalisations, disruptions in daily activities, and alterations in family relationships are some of the potential factors that may restrict the normal development in chronically ill children." Further on in this chapter, for instance, it is discussed how the "invisibility" of an illness may influence the affected person's adaptation to their condition (cf. Falvo, 1991, pp. 15-16). It has been suggested that the most significant source of psychological stress for children living with a chronic illness is the unpredictability of the course of the illness and therefore, the course and outcome of these children's lives (Koocher, 1984 in Midence, 1994). Grzesiak and Hicok (1994) and Wright (1983) purport that the quality of psychosocial adaptation in a child who is ill or disabled depends on whether the illness is congenital or acquired (in Livneh & Antonak, 1997). The understanding is that a child who is born with an illness or disability will develop in more or less the same way as a normal child (Lussier, 1980), due to the fact that this child knows him or her self as a whole – if disfigured or ill – person (in Livneh & Antonak, 1997). So, the identity of a child living under such circumstances incorporates the child's disability or illness.

This is contrasted with children who acquire illness or disability later in life. Initially, these children build identities and have experiences of themselves in the world and the world in relation to themselves as 'not-ill' or 'not-disabled'. When they become ill or disabled later in their lives, their developed sense of who and what they are (sense of self) is therefore disrupted and contested by changes in their bodies as well as changes in their daily routines, lifestyles and relationships. These children are more likely to experience a sense of loss and uncertainty – within themselves and about themselves – than children who have been living with disease and disability since birth or infancy. Furthermore, it is noted that if a disease is progressively deteriorating or degenerative, the illness experience is peppered with greater uncertainty and unpredictability than an acute illness episode or accident after which there may be a quicker recovery and return to a functional state. This kind of uncertainty is said to have a negative impact on the person's psychosocial development and adjustment (Livneh & Antonak, 1997). Diseases that fall into this category include, amongst others, cancer, multiple sclerosis and rheumatoid arthritis.

Due to the progressive nature and course of HIV illness, from initial infection to the development of full-blown AIDS, HIV falls into the category of chronic illnesses that fluctuate and are unpredictable. Duggan (1994) points out that recovery or death cannot be anticipated. She empathises with those who look after children living with HIV/AIDS, who may prepare for the death of a child when s/he becomes severely symptomatic, only to be met with an incredible recovery in the child. With the advent of anti-retroviral therapies, the course of HIV infection is even more unpredictable, and the staging of the disease has become somewhat superfluous as people may be treated back to an asymptomatic state (Lwin & Melvin, 2001).

HIV illness also falls into the category of "terminal" illnesses in that it ultimately leads to death. However, use of antiretroviral therapies as well as the implementation of lifestyle and dietary changes to maintain and enhance the functioning of the immune system, make it possible for a person infected with HIV to live for many years without entering a predictably terminal phase. Thus, it may ultimately be the uncertainty of the course of HIV infection that is responsible for disrupted psychosocial adjustment to the illness in infected individuals. This is combined with the social stigma the disease carries, partly due to its (sometimes over-emphasised) associations with sensitive subjects like sex, homosexuality and promiscuity, partly because it is associated with the sensitive subject of death, and partly because there is so much about the nature of this disease that is still unknown and under debate in scientific circles. The impact of social stigmatisation will be examined further on.

The notion that a person's experience of his/her body and the person's concept of their body influences their self-concept (i.e. the way they view themselves and understand themselves) has led to the belief that if a person has a chronic illness or disability, their idea of themselves must surely change to accommodate the physical and physiological changes that their illness determines (Falvo, 1991). Bramble (1995 in Livneh & Antonak, 1997) and Falvo (1991) have suggested that when a person successfully adapts to his/her illness or disability, s/he has managed to integrate the changes imposed by the condition into his/her understanding of him/herself in the world; unsuccessful adaptation, on the other hand, is characterised by psychiatric, psychological as well as psychosomatic problems. It is the *potential* for an adaptive as well as a maladaptive response to living with HIV/AIDS that provides part of the impetus for the current study, which aims to explore and describe some of the experiences of children living with HIV/AIDS. Without pre-empting the findings, and on the basis of writing

about adjustment to chronic illness and disability as presented here in part, this study opens itself up to a discovery of both positive and negative, adaptive and maladaptive experiences by these children who continue to live (as opposed to die) with their terminal illness. This study expects that each child participant's experience will be unique.

This expectation is to some extent congruous with a Gestalt approach to psychotherapy which, *inter alia*, incorporates a focus on embodied experience as well as an existential approach to psychotherapy, which "...attends carefully to how clients construe what happens to them, what meanings they assign to events in their lives, and how they relate to their disease and to the possibility of death." (Imes, Clance, Gailis & Atkeson, 2002, p.1362). Imes *et al.* (2002), in writing about a Gestalt/Existential approach to psychotherapy for people with chronic or life-threatening illnesses, also stress the importance of honouring the individual's subjective experience in order to arrive at an understanding of the person's relationship with that illness that reflects the singular characteristics of that person's illness, life and self experience. It is implicit in their writing that they have counterpoised their position with an approach of predetermining a client's reaction to what may be perceived as adversity by some and as opportunity by others: disease.

Working in a more Family Therapy/Systems Theory oriented paradigm, Shapiro (2002, p.1375) explains the value in the approach of "...focusing on the family's own definition of the current problem and relevant history, constructing a multidimensional, coherent story of the illness and its impact that recognises stressors yet highlights strengths..." in cultivating a family's resilience in response to chronic illness and disability in one of its members. Herein, Shapiro (2002) offers support for uncovering subjective experience as well as highlights the potential for the development of resilience in the face of chronic illness. With this in mind, the present study has set out to describe some of the unique, subjective experiences of children living with the illness experience of HIV/AIDS, but who have also had to deal with the experiences of being orphans and of living in a children's home.

From a review of literature that addresses a phase-orientated model of adaptation to chronic illness and disability, Livneh and Antonak (1997, p.20) offer a summary of the phases a person goes through in response to their illness or disability: shock, anxiety, denial, depression, internalised anger, externalised hostility, acknowledgement and adjustment. Other authors have also discussed the various phases a child may go through when faced with

his/her own impending death as a result of terminal illness. For example, Judd (1989, pp. 48-59), drawing from writing by Parkes (1972), Geist (1979) and Kubler-Ross (1970), identifies the following reactions to terminal illness: numbness; denial; assimilation; regression; anger; depression; bargaining; and acceptance. Judd (1989) with reference to writing on World War Two concentration camp victims by Bettelheim (1967) attributes some of these reactions to an attempt by the child to gain some sense of autonomy amidst an overriding experience of loss of independent functioning. She suggests that this is particularly true of children and adolescents who, developmentally, seek to gain more of a sense of autonomy and independence. What may therefore be observed in children living with a terminal illness, are behaviours that reflect a need and desire to gain control over that which appears to have taken control of their bodies.

In response to this body of knowledge on phase-dependent adjustment or adaptation to illness, it has been pointed out that each person's process is different (Livneh & Antonak, 1997; Judd, 1989), and that some will not ever go through a phase of depression or sorrow as a reaction and that some will never become as fully integrated as the phase-based models suggest (Livneh & Antonak, 1997). Therefore, it is not incumbent on a person with a chronic illness to present with crippling emotional or psychological reactions as a way of dealing with their illness. For this reason, it would be prudent to investigate individuals' perceptions and experience of illness in order to honour the idiosyncratic and not always adverse ways in which people respond to illness, adversity, trauma and loss. The present study seeks to offer some of the findings of just such an investigation by taking a closer look into the lives of three children living with HIV/AIDS and describing what some of their experiences are, rather than prescribing or predicting what those experiences should be.

Research has shown that children living with chronic illnesses display signs of mild to severe impairment of cognitive functioning, regardless of whether the disease or treatment directly acts on the central nervous system (Rovet, Erlich & Hoppe, 1987; Eiser, 1980; Brown, Armstrong & Eckman, 1993 in Midence, 1994). Furthermore, age may be a differentiating factor in terms of the kind of deficit or maladjustment exhibited by a child: younger children have been shown to present with scholastic and performance difficulties (Rovet *et al.*, 1987) while older children and adolescents tend to present with problems of social adjustment (Ungerer, Horgan, Chaitow & Champion, 1988 in Midence, 1994). Midence (1994) notes that often the research on children with chronic illness has examined children with cancer, while

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other illnesses have not been as extensively investigated. Thus, much of the understanding of the psychological adjustment of children with chronic illness is based on the experiences of children diagnosed with cancer. Of course, the nature of the cancer, the body system(s) affected and the nature of its treatment and management are different from other chronic illnesses like diabetes for instance. For example, the management of paediatric diabetes does not require chemotherapy or irradiation therapy. Hospital admissions for diabetes treatment are generally not as long as stays for cancer treatment.

The nature of an illness and its treatment significantly influences the experience the ill child or person will have. Different illnesses therefore make for different illness and life experiences: children living with HIV/AIDS will have different concerns, challenges and care provision than children living with leukaemia, juvenile diabetes or rheumatoid arthritis. The stage of HIV infection will, whether or not there have been multiple illness episodes and/or hospitalisations and whether or not the child has developed full-blown AIDS, further differentiate the illness experiences of children living with HIV/AIDS. Breslau and Marshall (1985) concur and suggest that the type of illness will also inform the child's level of adjustment (in Midence, 1994).

Furthermore, it has been shown that milder forms of chronic disease result in a greater preponderance of maladjustment amongst children (McAnarney, Pless, Satterwhite & Friedman, 1974; Markova, Lockyer & Forbes, 1980 in Midence, 1994). Similarly, amongst children with physical deformities or disabilities, a higher incidence of psychiatric morbidity has been demonstrated amongst those children in whom the defects were mild as compared with children with more severe defects, who were shown to be better adjusted (Williams, 1970; McFie & Robertson, 1973; Seidel, Chadwick & Rutter, 1975 in Midence, 1994).

There are many reasons why the prevalence of psychiatric morbidity may be higher amongst children who are mildly – as opposed to severely – affected by disease or deformity. For example, these children may experience conflict regarding which of two worlds they belong to and therefore conflict about how they should behave: as members of the disabled or members of the able-bodied group (Barker, Wright, Myerson & Gonick, 1953 in Midence, 1994). Wright (1983) likened the borderline position of children with milder disease or deformity to the position of minority groups in society. Members of minority groups may feel

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confused about whether they belong and should act according to the norms and values of the dominant group or the minority group.

Marginalised and borderline realities are certainly relevant for people living with HIV/AIDS. Looking at the agendas of human rights and advocacy groups such as the Treatment Action Campaign (TAC) and the National Association of People With AIDS (Napwa) in South Africa, it would seem that the struggle for the rights of people living with HIV/AIDS is similar to that of marginalised and oppressed race groups in South Africa, both of whom fight for the right to visibility, recognition, understanding, acceptance, belonging, dignity and to be treated with respect and sensitivity. A link between experiences of AIDS and experiences of racism was made pertinent by a participant in a psychoanalytic group in Australia (Henry, Wesley, Jones, Cohen & Fairhall,1997). The participant's comments implied that the pain and suffering of racism is akin to the pain and suffering of the HIV/AIDS pandemic and both issues need to be approached seriously.

It is the stigmatisation and discrimination of people who are living with and affected by HIV/AIDS that is often cited as the reason for their psychological and emotional problems (Giese, 2002; Clacherty & Associates, 2001). An article in a local South African newspaper entitled *SA cities under threat from Aids orphan gangs* (Clarke, 2002) does nothing to challenge the reality of stigmatisation and discrimination faced by AIDS orphans. On the contrary, article such as this reach the homes of thousands of people, and perpetuate stigmatisation. The article claims that "[r]esearchers fear that 'angry' children will band together and turn streets into no-go areas (Clarke, 2002, p. 13)." The phenomenon of "gangs" of abandoned AIDS orphans is not real, and the damaging effects of this kind irresponsible reporting is apparent. On the same theme of unaccounted for anticipation of poor mental health amongst those who are "ill" in our societies, Midence (1994, p. 321) concludes that "[i]t is also clear that a simple or direct relationship between chronic illness and poor psychological functioning does not exist."

This section has elucidated arguments for striving towards developing rich, complex descriptions of people's lived experiences, and particularly the experiences of children living with a life-threatening illness like HIV/AIDS. The premise of this study is that experience is complex and multi-dimensional. How a child copes with his/her chronic illness is the result of a complex interplay of many factors, and any one of them or any combination of any number

of them – from characteristics of the child to characteristics of the family to characteristics of the illness to characteristics of the child's social environment – may help to explain the degree of psychological adjustment or maladjustment in a child living with a chronic illness.

2.2.5. The HIV/AIDS Pandemic

A child may become infected with HIV via vertical (mother-to-child) or horizontal (infected blood, blood products, sexually or needle-sharing amongst intravenous drug users) transmission routes (Lwin & Melvin, 2001). The first reported cases of paediatric HIV infection appeared in the early 1980's (Lwin & Melvin, 2001): 1982 in the USA and 1984 in Europe (Duggan, 1994). UNAIDS/WHO (2002) reported 42 million cases of HIV/AIDS worldwide globally as of December 2002: 38.6 million adults and 3.2 million children under the age of 15 years. The number of new infections in 2002 totalled 5 million: 4.2 million adults and 800 000 children under 15 years old. The number of AIDS related deaths in 2002 was 3.1 million: 2.5 million adults and 610 000 children under the age of 15 years. Without even examining year-by-year trends, these figures on their own reflect the severity of this disease. Sub-Saharan Africa is reported to be the region most adversely affected by HIV/AIDS. The following figures were reported in this region in December 2002: 29.4 million total infections; 3.5 million new infections in 2002; 2.4 million deaths in 2002; 3 million children under the age of 15 years living with HIV/AIDS (UNAIDS/WHO, 2002).

The situation in South Africa was reported as an illustration of potential for improvement due to adequate campaigns and programmes, in that the rate of infection amongst pregnant women dropped from 21% in 1998 to 15.4 % in 2001 (UNAIDS/WHO, 2002). Despite this, the prevalence of HIV infection in South Africa (extrapolated from prevalence amongst women presenting to antenatal clinics) increased dramatically from 1% in 1990 to 25% in 2000 (Medical Research Council of South Africa, 2001). The implication, even in the face of apparent changing infection trends for pregnant women, is that there are millions of people in South Africa who are infected and who will develop full-blown AIDS at some inevitable point and will die. It was projected that approximately 4 to 7 million South Africans will die of AIDS between 2000 and 2010 (MRC, 2001).

The impact of so many deaths will likely be felt at many different macro and micro levels in all sectors of society. For example, the projected economic impact has led to a private sector response including raising awareness of the potential impact on production as well as devising

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strategies to manage and presumably, forestall or diminish the negative effects. This response stems from the fact that the economically active 30-40 year old age group will be the worst affected in South Africa (Myslik, 2000). Another anticipated effect of the HIV/AIDS epidemic in South Africa is that there will be no more burial space in an urban centre like Johannesburg about five years from now (Crewe, 2001). Lobbyists and activists continue to work to influence government health, social and economic policies in the direction of acknowledging the severity of the problem and making significant decisions to alleviate some of the strain of the impact of the disease on the citizens of South Africa.

2.2.6. Psychiatric morbidity in HIV/AIDS

It is not just the future of the private sector or governance that will be affected; it is also the current and future state of the physical and mental health of individuals, families and communities. Noore (1994) identifies four psychiatric syndromes known to be AIDS-related: adjustment disorders; psychotic disorders; mood disorders and organic disorders. These effects may be the result of a primarily emotional response to the disease and its health, psychological and social ramifications and/or may be the result of the virus or an opportunistic infection destroying the central nervous system and/or the side effects of biomedical treatment (Noore, 1994). A South African prevalence study – the first of its kind examining a black, heterosexual population in a developing nation – of known HIV-positive patients in attendance at two hospitals, demonstrated that it is not uncommon for individuals living with HIV/AIDS to develop and exhibit symptoms of more than one psychiatric disorder at a time, most commonly depressive and anxiety disorders (Els, Boshoff, Scott, Strydom, Joubert & van der Ryst, 1999). Furthermore, these researchers reported that the incidence of depressive and anxiety disorders was significantly higher amongst patients living with HIV/AIDS than in the broader population. Similar findings of poor emotional and psychological adaptation have been reported where the researchers, using a scale to assess adjustment to illness, found that HIV-infected participants scored high on items related to lack of will to overcome the illness, lack of hope, worry, and fatalism (Grassi, Righi, Sighinolfi, Makoui & Ghinelli, 1998 in Brown, Lourie & Pao, 2000).

2.2.7. Children and orphans of the HIV/AIDS pandemic

Different categories may be delineated to facilitate discussion about children living in the time of the HIV/AIDS pandemic. These categories may include children who are affected by HIV/AIDS, children infected, or living with HIV, children diagnosed and living with full-

blown AIDS. Each of these categories may then be divided into two subcategories: orphaned children and non-orphaned children.

The psychological impact of HIV/AIDS on children has been repeatedly demonstrated, even though much of the research has not been located in South Africa. Longitudinal research conducted in the USA has particular relevance for the current study, in that it examines the psychological effects of HIV illness on infected children of school-going age (Wiener, Battles & Riekert, 1999). Children aged 6 to 11 years were assessed for symptoms of psychological distress by means of a pictorial tool, on three different occasions over a two-and-a half-year period. While the researchers found that the 44 children from varied demographic backgrounds who participated in the study were reasonably stable psychologically with results yielding only mild to moderate levels of psychological distress, they also found that the incidence of symptoms of anxiety and depression increased over time (Wiener *et al.*, 1999). Furthermore, perhaps contradicting some of the thinking around children with chronic illnesses, as addressed, for example, by Falvo (1991), Wiener *et al.* (1999) showed that children did not become more distressed the more their disease progressed and worsened. Their study aimed at mapping the adjustment of children living with HIV/AIDS using a vocabulary that is specific to psychiatric and symptom- and diagnosis-orientated discourse. The current study aims to describe or map the experiences of orphaned children living with HIV/AIDS using a vocabulary that is closer to that which belongs to the children; it specifically seeks not to define the children's experiences as a psychiatric diagnosis or criteria for a psychiatric diagnosis. Some of the possible significant ameliorating factors amongst this group of children are that they were not orphaned (they were drawn from families) and the children, together with their families were in attendance at a National Cancer Institute. Presumably therefore, these children did not have to face the loss of a parent or absence of a family, and had access to resources at least in the form of information and personnel for support.

It is recognised that one of the more devastating social consequences of the HIV/AIDS pandemic globally, and especially in Africa, is the growing number of AIDS orphans: children who are left behind when a parent dies of AIDS or abandons them within a context of living with HIV/AIDS (the parents or the children). The United Nations Children's Fund (UNICEF) reported that the number of children under the age of 15 years, worldwide, that have lost their mother or both parents to AIDS has been steadily increasing from under 2

million in 1990 to just over 10 million in 2000 (UNICEF, 2002). Currently, approximately 13 million children have lost one or both parents to AIDS, most of who come from sub-Saharan Africa (USAID, UNICEF & UNAIDS, 2002). Projected figures are staggering: by the year 2010, there will be 25-30 million AIDS orphans living in sub-Saharan Africa (Robinson, 1999; USAID, UNICEF & UNAIDS, 2002).

It has become obvious that the psychosocial experiences of AIDS orphans are that much harder and fraught with greater difficulty and pain than other orphan groups. The difficulties faced by AIDS orphans are often expressed through behavioural patterns that underscore the need for psychiatric, psychological or social intervention (Geballe & Gruendel, 1998 in Books, 1998). Amongst school-going children, truancy and generally defiant and oppositional behaviour patterns have been reported (Geballe & Gruendel, 1998 in Books, 1998). It is acknowledged that many older children orphaned by AIDS endure a process of protracted loss and stigmatisation from the time that they witness their parent(s) dying. These effects are said to be worse for the children if they are of school-going age (Geballe & Gruendel, 1998 in Books, 1998), ostensibly due to their 'difference' from fellow learners, e.g. with regard to lifestyle. Ongoing stigmatisation through the course of their parent's illness can be deeply traumatic, compounded by the inevitable and actual loss of the parent through death (Karlenza, 1998).

Henry *et al.* (1997) worked with two groups of incarcerated youths in order to understand the psychology behind risk-taking behaviour. They applied a psychodynamic framework in formulating their understanding, and discovered a number of pertinent themes at the intersection of AIDS, the unconscious and youth. Their study revealed that, in response to the HIV/AIDS pandemic, young people experience and express: fragility, vulnerability, hopefulness, hopelessness, feeling overwhelmed, paranoia, confusion, complacency, denial, anger, self-reliance, anxiety, neglect, destruction, shame, difference, fantasies of escapism. This mixture of themes and experiences highlights the complexity of living with HIV/AIDS and reinforces the need to penetrate beyond the superficial layers of understanding responses to the pandemic. This Australian study encourages a replication of similar efforts elsewhere. This is what the current study hopes to achieve: an in-depth understanding and explication of the themes that reside at the meeting place of children, parental loss and HIV/AIDS.

A qualitative enquiry conducted in Zimbabwe used focus groups with orphans – aged 9-16 years – and caregivers to identify the concerns of AIDS orphans. Identified concerns included feelings of difference in relation to children not affected or infected by HIV, stress, social stigma, vulnerability to being exploited, education, social isolation (Foster, Makufa, Drew, Mashumba & Kambeu, 1997). Similarly, Trad, Kentros, Solomon and Greenblatt (1994) indicate that children living with HIV/AIDS endure greater subjective stress compared to uninfected children (as in Brown, Lourie & Pao, 2000). Feelings of loss, guilt, fear, uncertainty, fantasies of self-blame, recovery and the development of resilience all characterised the documented experience of a 4-year old boy living in Africa whose parents were refugees of war as well as HIV-positive (Meldelsohn, 1997). Again, this study demonstrates the complexity of experience for a young child confronted by HIV/AIDS and promotes the use of in-depth qualitative techniques to understand children in relation to this pandemic.

Negative perceptions and attitudes towards the disease and people affected and infected by HIV can result in detrimental effects on learning at school and on accessibility to appropriate health care for AIDS orphans: "…[T]he shame, fear and rejection that often surrounds people affected by HIV/AIDS can create additional stress and isolation for children (Schönteich, 2001). Clacherty and Associates (2001) report extensively on the negative effects of stigma and discrimination on South African children rendered vulnerable by the HIV/AIDS pandemic. These authors demonstrate that AIDS-affected children are discriminated against across many different contexts such as their own families and homes, peer groups, places of worship, schools, hospitals and clinics. Their findings reveal that AIDS-affected children experience emotional pain, anger, powerlessness, grief and worry as a result of being stigmatised as well as having to face the realities of living with HIV/AIDS as infected or affected individuals (Clacherty and Associates, 2001). Their study offers support for the research practice of using the more developmentally appropriate technique of drawings to communicate with child participants between the ages of 8 and 10 years. The present study also adopts this technique to enter into dialogue with child participants. This method is further elaborated in the **Methodology** section below.

Presenting a variant viewpoint on the matter of stigmatisation, Falvo (1991) comments on what he calls "invisible disability" (p.15-16). By this, he refers to conditions like diabetes and cardiac conditions that are chronic and/or debilitating, but that are not visible to the naked

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eye; often, only those who are close to the affected individual are aware of the condition and the impact of the condition on daily and long-term functioning and development. While living with or being affected by HIV/AIDS is reported to be stigmatised, those infected and affected will presumably only experience stigmatisation if their circumstances are known to those around them. The point that Falvo (1991) therefore raises is that if others do not know that someone is living with HIV/AIDS – whether through ignorance or a desire to protect the individual from ridicule – that individual is deprived of feedback regarding how others perceive and experience his/her condition; his/her relationships will be deprived of the opportunity to integrate the illness. The result, postulates Falvo (1991), is a delayed or distorted adjustment to the illness, as the person him/herself as well as those s/he interacts with, live in denial of something that is, in fact, quite integral to the ill person's life. Falvo's (1991) notion of "invisible disabilities" (p.15-16) may thus also indirectly support illness disclosure to those the affected or infected person comes into regular contact with; this may expose the individual to stigmatisation and discrimination. Through therapeutic facilitation, these discriminatory attitudes may be integrated into the illness experience for an individual. This kind of guided integration has the potential to trigger the development of an understanding of self that is more holistic, as opposed to fragmented.

Some of the experiences and needs of AIDS orphans in sub-Saharan Africa have been identified by speaking directly to these children themselves and asking them what they feel they need. In addition to acknowledging the children's needs, reports that allow the children to speak appears to have been a strategy applied by lobbying groups to inform recommendations to shift government policy towards attending to the problems faced by AIDS orphans. For example, in South Africa, the National Children's Forum on HIV/AIDS conducted a workshop with children between the ages of 7-18 years infected and affected by HIV/AIDS in August 2001 (Giese, 2002). The explicitly stated aim of the workshop was to create an opportunity for children to speak openly about their experiences of HIV/AIDS; their voices were intended to be heard by policy makers in government, who were invited to the final day of the three-day event. Through conversations and art, the child workshop-participants highlighted those aspects of their lives wherein they experienced lack or deprivation.

Some of their problems were the result of not having money, e.g. denied access to education because they were unable to pay their school fees. With regard to the more psychosocially-

oriented issues they grapple with, they spoke about the challenge of stigma and discrimination faced by people living with HIV/AIDS; they also described their feelings of suffering in watching a parent die and the subsequent feelings of financial, physical and emotional vulnerability due to the loss of the parent (Giese, 2002). These children often ended up living on their own or with extended family members after their parents' death. They spoke of their ambivalent experiences of support and affection in the context of their extended families and communities: they felt supported by their families and church communities, but in receiving this support graciously, they sometimes were subjected to experiences of abuse and rejection (Giese, 2002). The aforementioned forum also illustrates a move towards accessing the experiences of children directly. Furthermore, it resonates with the present study's use of creative arts techniques to access conversation with children.

Wild (2001) conducted a comprehensive literature review on research conducted with AIDS orphans to date. The literature reviewed addressed the population of children who were not infected with HIV. However, she asserts that the needs and problems facing uninfected AIDS orphans are compounded for HIV-infected AIDS orphans. Much of the literature has overlooked the psychosocial adjustment of AIDS orphans; by 1994, no empirical research addressing this issue had been published (Siegel & Gorey, 1994 in Wild, 2001). The conclusion drawn from the largely quantitative research indicates that AIDS orphans exhibit signs and symptoms of both internalising and externalising psychiatric disorders, fuelled by the following recurring factors: (1) economic burdens; (2) educational disruptions; (3) multiple losses; (4) uncertainty and severity of the illness; (5) inadequate care; (6) discrimination (Dane, 1997; McKerrow, 1995; Nagler, Adnopoz & Forsyth, 1995 in Wild, 2001). Wild (2001) suggests that future research apply quantitative methodology to enhance the understanding of the psychosocial adjustment of AIDS orphans. She also recommends that "such quantitative research... be complemented by more qualitative studies describing children's experience of living with AIDS." (Wild, 2001, p.18) Almost in direct response to this suggestion, the current study uses qualitative and interpretive methodology to develop rich descriptions of the experiences of OCWA's.

2.3. SUBSECTION 2: REDRESSING THE IMBALANCE – RESEARCHING OCWA's

2.3.1. Researching children

Walsh (1998 in Graue & Walsh, 1998) explains that research with children can be challenging due to the differences and distances between adults and children insofar as intellect, physicality, emotionality and social roles, *inter alia*, are concerned. These differences – and therefore the challenge of working with children – are exacerbated in the research context by the researcher/enquirer status of the researcher. Walsh contends that is often therefore with ease that adults working with children tend to describe the experiences of children and the phenomena of childhood within pre-existing 'authoritative' frameworks of understanding and systems of interpretation that may belie children's actual experiences. He emphasises the need to study children to "…find it out, because if we do not find it out, someone will make it up." (Walsh, 1998, p.xvi). The "it" Walsh refers to, is "…what we know as a culture about children…" (p.xvi). It is possible, according to Walsh (1998) that "it" has already been "made … up", and that these "made up" stories about children affects their lives in terms of how they are perceived, understood and treated. And so, "[f]inding it out challenges dominant images. Making it up maintains them." (p.xvi). Thus, the current study intends to "find it out" rather than "make it up" about the lived realities of children orphaned by AIDS and themselves living with HIV/AIDS.

This research is grounded in a qualitative paradigm, the value of which is that it allows for insights to emerge that illuminate the meanings people attach to their unique personal experiences (Tindall, 1994 in Banister, Burman, Parker, Taylor & Tindall, 1994). An avoidance of the reduction of the "complex [and nuanced] realities" (Graue & Walsh, 1998, p.3) of the lives of children being investigated and an attempt to illuminate their everyday lives necessitates an exclusion of a quantitative approach in this study. The proposed study aims to adhere to an interpretive methodology that not only imbues the research process with an iterative quality; it also facilitates the generation of multiple meanings of a single phenomenon or experience, and therefore, adds to the richness of the insights gained (Denzin, 1994 in Graue & Walsh, 1998).

2.3.2. A theoretical framework for researching children

For this study, an existential-phenomenological approach to gathering and interpreting data was opted for. The existentialist philosophical tradition outlined by Buber (1975) and Marcel

(1971), operates, in part, from the premise that life is a mystery that one should have an openness towards. Existentialism was born from the mind of Danish philosopher, Soren Kierkegaard (1813-1855), and, *inter alia*, understands people and their experiences to be "active, dynamic, creative, and larger and richer than theories." (Becker, 1992, p.9). Phenomenology was developed by German philosopher, Edward Husserl (1859-1938) as a method of investigating phenomena, framed in the existentialist philosophy (Becker, 1992), and it is fundamentally, "…the study of phenomena, of things or events, in the everyday world." (Becker, 1992, p.7).

In phenomenology, these "things" are understood from the perspective of those experiencing them. This means that research framed in this tradition investigates phenomena by immersing itself in the perceptual and experiential domain of the participants, in an attempt to observe, describe and discover the meanings of the lived experiences of participants. In addition to this, the researcher – at least at the outset – suspends most, it not all, preconceived meanings and/or interpretations of particular phenomena (Rieman, 1986 in Creswell,1998). This position has been referred to as "bracketing" (Terre Blanche & Kelly, 1999 in Terre Blanche & Durrheim, 1999, p.140).

The phenomenological approach to work with children tends to minimise meaning and assumption making that serves adults' or others' perceptions rather than that of the child in question. This approach emphasises an openness to multiple meanings, context, and an acknowledgement of, and respect for, the client's/patient's/participant's view. Seeing the drawings from multiple perspectives allows for an integration of these perspectives and ultimately, a richness of understanding and meaning. Malan (1995) refers to the concepts of "condensation (p.10) and "over-determination (p.10)." He has applied these concepts to the interpretation of what a client brings to psychotherapy, and suggests that material presented by the client has multiple meanings. One meaning does not replace or contradict any of the others; rather, all these meanings combine to form a multifaceted understanding of phenomena in the client's life. Malan (1995) contrasts this notion with the "principle of economy of hypothesis (p. 17), according to which a single explanation of an event is satisfactory.

The initial position adopted by the therapist or researcher in phenomenologically designed studies, is that of not knowing, which overlaps with the social constructivist perspective in

psychotherapy that locates meaning and understanding in the co-creative, intersubjective relationship between therapist and client. Thus, the therapist or researcher is not set up as the expert of interpretation and meaning-making, but rather, as a facilitator of the relationship that will produce the meaning.

Therefore, the philosophical and research stance adopted afforded the current researcher the opportunity to explore and describe some of the lived experiences (and their associated meanings for the participants) of orphaned children living with HIV/AIDS in a children's home in South Africa at the start of the 21st century. This exploration was designed to be free from the constraints of preordained meaning systems. Much like a traveller entering unknown territory, a navigation through the territory of the lived experiences of three HIV-positive children ensued. The tools of navigation included the researcher's clinical training and experience, the map of his own life path and a few 'tried-and-tested' research tools and techniques. The landmarks and beacons of the journey were those things the children themselves knew and told about their own lives.

The approach in this phenomenologically-framed study of the experiences of South African orphans living with HIV/AIDS is both empirical and hermeneutical, creating opportunities to work "interpretively" with data in any form, including textual and pictorial. The definition of "text" in the current study was expanded to include words and pictures. This expanded conceptualisation of "text" is congruent with examples cited by Kelly (1999), wherein researchers approached graffiti walls and dead bodies "as texts" (p. 380). The hermeneutic strand of phenomenological research allows the researcher to explore and discover meaning in more than just textual data: pictorial data, for example, is also valid. The crux of the hermeneutic approach is that data and/or artefacts are read "interpretively" (Becker, 1992, p. 32 in Kelly, 1999).

The phenomenological approach to working with the drawings in collection and analysis favours a focus on, and explication of, idiosyncratic experience, to demonstrate the benefits of understanding the uniqueness of the life process of each and every HIV-positive orphan, above the generation of statistical and clinical norms. According to Malchiodi (1998), the phenomenological approach also acknowledges the many different influences on artistic expression, including: cognitive ability, emotional maturity, interpersonal skill, general maturity and somatic and spiritual factors. This approach therefore facilitates a respect for

individuality and uniqueness, which is likely to be reflected in the art making process as well as the artistic products. In this study, interpretation revolves around the children's own meanings as well as a myriad other potential meanings that have relevance for, and resonance with, the children's frameworks of meaning. As Malchiodi (1998) asserts: "In the case of children's art expressions, no one theory of interpreting or deciphering them is... erroneous, and each does contribute some useful knowledge to understanding children's work." (p. 38).

2.3.3. Children communicate about their illnesses

Rushforth (1999) points out that prevailing attitudes to children's ability to understand their illnesses has a Piagetian orientation, which incorporates the notion that children go through changes in their cognitive capacities in a stage-like, progressive fashion, and focuses on children's limitations and inability to understand things. Rushforth (1999) also presents the counter-argument of more contemporary theorists, who suggest that children – regardless of age or level of development – have a more comprehensive understanding of their illness and hospitalisation experiences than is often acknowledged by adherents of stage theories of development. The current study concurs with proponents of this more progressive viewpoint (Kister & Patterson, 1980; Bird & Podmore, 1990 in Rushforth, 1999), and works from the premise that children living with HIV/AIDS have experiences and understandings of their bodies and illness that are not always readily acknowledged.

The current research uses verbal and nonverbal techniques to speak with children about some of their lived experiences, with the intention of describing and identifying those things that matter most to them. It is assumed that the children will use drawings and story-telling to identify those experiences and concerns that they are mentally and emotionally preoccupied with. It is anticipated that their life and illness circumstances will be amongst their concerns. Such exploration will thus provide those working with and caring for these children some insight into their needs and concerns, as told by them. Children's (Unruh, McGrath, Cunningham & Humphreys, 1983) and adults' (Ginzburg, Merskey & Lau, 1988) drawings of pain has demonstrated that there is a link between the body and what is artistically expressed.

A study by Clarke and Newell (1997) has acknowledged the importance of accessing children's perceptions and understanding of their illnesses in order to communicate more effectively with them about their conditions and treatment for these conditions. Treatment or

management plans address different aspects of care, e.g. biomedical, social educational and psychological aspects. It is intended that the findings of this study will assist to address the psychosocial and emotional needs of orphaned children living with HIV/AIDS from a position of knowing more about what the children themselves say about some of their experiences, than from a position of assumed knowing based on predetermined categories of experience. So, as has been demonstrated, children living with a chronic illness may not always respond in a dysfunctional manner in the short or long-term to their condition (Midence, 1994).

2.3.4. Children's art: A brief background

A comprehensive historical overview of children's art is beyond the scope of this study. A brief look at the history should suffice. Children's art has been studied since the late 1800's initially as a way of understanding cognitive development (Malchiodi, 1998). Lukens (1896), Verwon (1907), Burt (1921), Lowenveld (1947) and Piaget (1950) were all instrumental in refining the use of art as developmental indicators (Dubowski, 1984 in Dalley, 1984). Later, children's art and specifically children's drawings of the human figure was used to assess intelligence (Burt, 1921; Goodenough, 1926; Harris, 1963 in Malchiodi, 1998). Then, practitioners and researchers started to use art as a way of assessing development (Koppitz, 1968) and personality (Koppitz, 1968; Machover, 1949; Hammer, 1958 in Malchiodi, 1998). This led to the emergence of tests to assess personality and emotional state. An example of this kind of projective testing is the House-Tree-Person drawing devised by Buck (1948, 1966 in Malchiodi, 1998). As widely used as such tests have been and still are, they have been criticised for their reductionist and limited interpretations of a person that do not take into account the complexities of human experience, especially the context within which people live (Golomb, 1990; Martin, 1988; Roeback, 1968; Swenson, 1968 in Malchiodi, 1998).

Arnheim (1969, 1972, 1974) worked with children's art in a different and less rigid way: he saw children's art not just as en expression of inner conflicts or an indicator of intellectual capacity; he saw it also as a tool for communication and therapy (Malchiodi, 1998). Using children's art in this way has led to the development of the field of art therapy. A seminal feature of this new approach was to involve the children themselves in the meaning-making and interpretation of their art work

The 1940's saw Margaret Naumberg (e.g. 1958) as a pioneering figure in the therapeutic use of art (in Dalley, 1984; Malchiodi, 1998). Naumberg's assertion was that images are the communication tool of a person's deepest thoughts, feelings and experiences, or unconscious experience (Dalley, 1984). Expanding on Furth's (1988) idea that difficult experiences and reactions to experience repressed – as opposed to displayed – by an individual can be accessed through art or drawing, Naumberg posited that the *manner* of art production influences the extent to which repressed material can be accessed (in Malchiodi, 1998). Naumberg said that if art is *spontaneously* generated, rather than within the structure of projective tests, it is more likely to permit access to unconscious or repressed material, which she claimed, is presented in pictorial form when people are allowed to draw spontaneously. Edith Kramer (1958) was responsible for developing the field of art therapy specifically with children: "'Art is a means of widening the range of human experiences by creating equivalents for such experiences. It is an area wherein experiences can be chosen, varied, repeated at will. In the creative act, conflict is re-experienced, resolved and integrated' (Kramer, 1958, p. 6 in Dalley, 1984, p. xiv)." She posited that children's art is a sublimation of impulses and feelings (Malchiodi, 1998). Dalley (1984) explains that therapeutic effects of artistic expression are achieved when the artist's work is discussed with a trained therapist. Through dialogue about the work, the artist or client is able to identify and gain clarity on those thoughts, feelings and experiences that have been represented in the art. Through this process of interaction around the artwork, the artist is also helped to articulate that which may previously have existed in an inchoate and perhaps confusing, even overwhelming form before the image and before the word.

Another psychoanalytically trained practitioner and theorist, Donald Winnicott (e.g. 1971), reinforced the notion that art is a powerful medium of communication between therapist and child. His "squiggle game" – which involved the child and therapist creating a scribbled drawing together – was not a projective technique. The aim of this game was to facilitate communication between the therapist and the child; it allowed the child to speak about his/her inner world of feelings and perceptions by telling a story about the picture that was produced (Malchiodi, 1998). He thus underscored the vital role that the child him/herself plays in the generation and communication of meaning (Malchiodi, 1998).

Susan Bach (1990) produced a seminal volume on the diagnostic value of using drawings in work with children living with terminal illnesses. It was 1947 when she became aware of how

drawings of patients revealed "not only the mental and psychological state… but also the condition of the body (Bach, 1990, p. 8)." Bach used and recorded cases of children whose illness prognoses have been revealed through careful interpretation of their drawings they produced spontaneously. Similar work has been documented by Keipenheuer (1980) and by Furth (1981 in Bertoia, 1993). Allan (1988) has also reinforced the use of drawings with children in order to access what they think and feel but find difficult to express in words (in Bertoia, 1993).

The use of creative art in therapeutic settings has been reported according to different theoretical perspectives on the creative process. A Freudian understanding of creativity understands the creative act to be a way in which a person may try to work through and fix the unresolved conflicts of the different stages of psychosexual development (Stern, 1952 in Dalley, 1984). In much the same way that he understood dreams, Freud (1972 in Dalley, 1984) himself saw art as a gateway to the unconscious and therefore to understanding unconscious processes and content and its connection with reality. While Freud and Freudian analysts see art as a pictorial representation of the unconscious and of inner experience, Jung and Jungian analysts approach art slightly differently. A Jungian view of art claims that the symbols found in images and dreams serve the purpose of restoring balance to the psyche (Furth, 1988; Dalley, 1984). Symbols, according to a Jungian perspective, alert the artist or individual to those aspects of experience and self which are usually neglected. It is through the formation of symbols that psychic balance is achieved.

The basic psychodynamic approach to art sees it as an expression of stored up bodily, emotional and relational experiences that infants and children were unable to articulate in their pre-verbal years (Wood, 1984 in Dalley 1984). Also common to psychodynamic approaches to art is the idea that art allows for an expression of a level of experience that cannot be articulated: the unconscious. A person-centred approach to art therapy draws upon Rogers' (1980 in Giles and Mendelson, 1999) notion of person-centred therapy that was developed in the 1940's and 1950's around the same time that therapeutic approaches to art emerged. This approach to art and art therapy reinforces the value of including the artist in attaching meaning the artwork. A behaviourist approach to art focuses on the acquisition of drawing and other motor and cognitive skills associated with artistic production; no meaning is attached to what is produced (Dalley, 1984).

Malchiodi (1998, p. 44) succinctly argues for the use of a combination of verbal and non-verbal techniques when working towards understanding children: "Many have noted the limits of using only verbal approaches with children (Axline, 1969; Case & Dalley, 1990; Gil, 1994; Malchiodi, 1990, 1997), highlighting the need for nonverbal forms of communication … The combination of both drawings and children's verbal descriptions provides therapists with an integrative means of understanding children." Allowing children to express themselves through art, allows them to relate their experiences in a way that is appropriate for their age. Malchiodi (1998) elaborates on this notion and says that the overriding goal of using art in a therapeutic context with children is to offer them a means to articulate their emotions, thoughts, imaginings and general internal processing of their experiences in life. With such a tool for self-expression and communication, the child can be more effectively understood, especially since art is imbued with "personal meaning (Malchiodi, 1998, p.11). " Malchiodi (1998) notes that the twentieth century started to see an emerging use of children's art and what they had to say about their art as a way of engendering an enhanced understanding of children. This goes beyond the more traditional uses of children's art as an assessment tool for intelligence or as a projective technique in personality assessment.

In South Africa, Magwaza, Killian, Petersen and Pillay (1993) used drawings in a research – as opposed to therapeutic – context with children in order to assess the emotional states of children who had been exposed to chronic violence. While these researchers acknowledge the difficulties regarding the reliability and validity of this method, they present an argument for its use based on the value that other researchers and clinicians have placed on it (Richter, Griesel & Wortley, 1989), as well as the "ease with which children's drawings can be obtained." (Magaza *et al.*, 1993, p. 798). Using drawings to communicate with and assess children with a chronic, life-threatening illness was implemented by Di Gallo (2001), as part of the initial interview with Swiss children with cancer. Di Gallo (2001) states that verbal communication is inadequate as a means of describing and understanding the experiences of cancer for children as well as the meanings they may ascribe to their illness. In further support for the use of drawings in psychosocial work with children, Di Gallo (1993) explains that verbal communication may be threatening for a child, while "[d]rawings offer… a … creative space between phantasy and reality, and make it easier for the child to express his/her feelings without having to relinquish repression entirely." (p. 197). Di Gallo (1993) operates within a psychoanalytic framework, hence the terminology used in this statement.

Phrased differently, Di Gallo (1993) is saying that children find it easier to draw and to play than to talk; the creativity and spontaneity that is part of picking up a crayon or pencil and applying it without rules to a blank page allows the child to freely express him/herself without necessarily having to answer for it. Referring to a Freudian conceptualisation of psychosexual development, Di Gallo (1993) comments that latency age children will make pictures of that which they experience and that which they are interested in; they do not always draw reality as an adolescent might. This kind of realistic drawing is not based then on what is seen to be, but also what is experienced to be and what is important. This has bearing on the decision to use the technique of drawing as part of the methodology used in the current study, in that latency age children are between 7 and 12 years old (Atkinson, Atkinson, Smith, Bem & Hilgard, 1990), and the children selected for the study fall in this age group. Since the aim of the study is to describe the children's experiences, on the basis of what Di Gallo (1993) is saying, drawings are the most appropriate tool for accessing their experiences as well as accessing that which matters most to the children, as they are at an age where they will represent these aspects of their realities through and in their drawings.

The current study is supported by a history of using drawings or art to describe the illness or bodily experiences of children. Lowenfeld (1947), followed by Uhlin (1979) (in Malchiodi, 1998), highlighted that children with somatic complaints and physical defects reflected their illnesses or somatic disturbances in their drawings of themselves. Bach (1966, 1975, 1990) focused on the phenomenon of children's expressions of physical illness in their art, for diagnostic purposes. Bach (1975 in Malchiodi, 1998) has also indicated that children not only express their experiences of their current physical and emotional states, but also of past disturbances. Furth (1988) also highlighted the prognostic value of drawings in children who are ill, suggesting that children's drawings may reveal conditions before they are diagnosed by medical practitioners. Malchiodi's (1998) own experiences with ill children has shown that these children express their reactions to their physical condition as well as their treatment through their drawings. Bach (1993) explained that children have a pre-conscious, pre-verbal, felt sense and understanding of physiological and psychological changes, disturbances and even prognosis, which they are able to effectively communicate through drawings. This notion has been endorsed and further developed by Keipenheuer (1980) and Furth (1981 in Bertoia, 1993). Perkins (1977 in Malchiodi, 1998) compared the drawings of 3-12 year olds who had terminal illnesses with those who did not, and found that the former group did reflect their somatic disturbance as well as prognostic elements in their artwork.

Children with cancer and other chronic illnesses have been shown to respond to their condition by repressing their feelings about their condition more than healthier children (Phipps & Steele, 2002). These researchers have postulated that this "repressive adaptive style" (Phipps & Steele, 2002. p.34) is a psychic defence that may lead to erroneous perceptions that children with chronic illnesses are more mentally stable than they actually are. A finding such as this motivates for the development and use of techniques that explore the inner worlds of thoughts, emotions and experiences of children living with chronic illnesses more effectively. One of these techniques may be to use the children's own drawings. Furth (1988, p.xviii) agrees that the "conscious" mind will defend against that which is experienced as dissonant (by the body) and supports the use of drawings to allow repressed experience – what he refers to as the "unconscious" – to emerge. Giese (2002) has demonstrated how children's drawings can be used to identify their needs and concerns about living with HIV/AIDS in South Africa.

This study uses the approach of using children's art to access their unexpressed internal processes, permitting, as Bertoia (1993) puts it, "…the adult to see what is happening from the child's view, and hopefully thereby avoid projections onto the child's work (p. 4)."
In the context of the current study, there are many experiences and circumstances that the child participants have been exposed to in their lives thus far that they are reported to hardly ever speak about, or that they pose pertinent questions about to the caregivers who have felt uncertain as to how to answer some of these questions. Some of these experiences relate to the fact that they are orphans, some to their HIV illness, some to the fact that they live in a children's home. The children are also exposed to the illness episodes and deaths of other children living at the home. Their circumstances suggest that they carry with them experiences that they have rarely had the opportunity to describe. Given the history of the use of drawings as a communication and therapeutic tool, the current study adopts the approach of encouraging these children to use drawings to express their feelings, thoughts and perceptions of some of what they have so far experienced.

2.3.5. Drawing and Telling
As discussed, Bertoia (1993) underscores the value of nonverbal expression in children who may not be entirely confident in their verbal communication skills, and indicates that drawing encourages richer verbal descriptions of experience than talking alone would. Dr Paul

Brutsche (1988 in Furth, 1988), emphasised the value of using drawings as a medium of communication with patients who have an unstable ego due to their age (as with children) or some kind of pathology. He goes on to suggest that it is important to pursue interpretations of the drawing as a way of helping the patient to move beyond judging his/her production according to some set of external aesthetic criteria, and towards a further and deepened exploration of the inner world of the patient. Bertoia (1993) reinforces the value of artistic expression as a means of freeing the artist to express him/herself. It is this kind of personalised expression that was indeed sought after by this researcher.

Both Furth (1988) and Malchiodi (1998) assert that a series of drawings collected from a child provides a more complete picture of the child and his/her "psychological and somatic condition" (Furth, 1988, p.36). According to Furth (1988), a single drawing is a snap-shot of one moment of the child's inner world and experience, and the achievement of a fuller picture of the child is elicited from a series such snap-shots. It is on the basis of these authors' assertions and experiences that the method used in the current investigation was to collect a series of drawings from each of the child participants, as the aim of the study is to obtain as full a picture as possible of the children's experiences as orphans diagnosed with HIV/AIDS.

Very little, if any, direction or instruction was given to the children about what and how to draw beyond the first week, when the research process and the purpose of the research were explained to the children. The intention was not to influence or contaminate the children's drawings and drawing process. In this way, it was hoped that the children would depict those aspects of their realities that have most significance for them. The drawings produced would therefore be classified as "impromptu", as they were produced upon request by the researcher in weekly sessions without any preparation and the content was determined by the children themselves (Furth, 1988, p. xix). This is distinguished from "spontaneous' drawings (Furth, 1988, p. xix) that are produced when people decide to draw without being asked to do so. In addition to the drawings that the child participants were encouraged to produce with the adult researcher, they were also encouraged to provide verbal descriptions or stories about their drawings. This incorporation of a narrative orientation to developing an understanding of children offers an opportunity for child participants to formulate and contribute to an understanding of them from their angle (Malchiodi, 1998). "A narrative, by definition, is a story or a recounting of past events, or a history, statement, report, account, description or chronicle." (Malchiodi, 1998, p. 43). By talking about their drawings, children are able to

communicate various aspects of their unique realities. For children, drawings are a way of communicating their personal narratives, as they may not have the same resources as adults for effective verbal communication (Malchiodi, 1998). She advocates the use of the drawing to further what the child has already said through the images on the page, by using the drawing as a tool for verbal engagement, and therefore meaning-making, with the therapist.

Having examined some of the more effective ways of communicating with children, and the modes in which children feel comfortable to express themselves, a subsequent section on methodology takes a look at what was done practically to collect and analyse the data.

CHAPTER 3: METHODOLOGY

3.1. Aims of the current study

The position and intention of the current researcher is consistent with that expressed by Graue & Walsh (1998, p. 5): "We suggest that researchers spend less time attempting to develop ground theories and more time learning to portray the richness of children's lives...". These authors recommend a focus on the specificity of children's lives, environments, experiences, and contend that "grand theories" do not have much sway or significance in a post-modernist world. The relative lack of material such as this on orphaned children living with HIV/AIDS in South Africa means that this study will not have a specific agenda about what themes will emerge from the children's artistic expressions. Instead, it is open to discovering all salient themes in these children's experiences, including those themes that have already been identified by previous research: death, anxiety, depression, stigmatisation, etc. Research beyond this could take a closer look at the specific themes that the children in this study reveal.

The aim is to construct rich descriptions of three different South African school-age children who have been orphaned through HIV/AIDS, are living with HIV/AIDS and reside in a children's home. The intention is that this will contribute to a richer understanding of these children's experiences and positively influence the development of measures to effectively meet the psychological needs of these children. It is often clinically useful and relevant to understand the emotional worlds and expressions of children according to commonly used classification systems of mental disorders such as the *DSM-IV* (American Psychiatric Association, 1994). Knowing that a child is depressed due to insomnia, irritability, disordered conduct, and a low frustration tolerance may provide the child, caregivers and mental health practitioners with a context for understanding the demeanour and behaviour of the child, as well as inform a management plan. However, where a rigidly psychiatric and diagnostic approach may fall short is in the failure to capture the experience of the child, in the child's words, from the child's perspective. Thus, insights gained through strict adherence to psychiatric discourse may be limited to a current presentation of signs and symptoms rather than a life history and narrative. Kleinman (1988) promotes the development of understanding the life stories of people living with chronic illnesses as a way of developing nuanced, individualised, culturally sensitive interventions.

The current study aims to illustrate how using age appropriate methods of communication and story telling can elicit, in rich and nuanced detail, some of the significant experiences of children living with HIV/AIDS. This study focuses on the lives of three children infected with HIV, abandoned by their biological families and residing in a children's home in South Africa. The aim of presenting their stories is to demonstrate the profound knowledge that children have about their experiences, and that this knowledge is as potent as any psychiatric classification system. Thereby, this study aims at creating a platform for these often marginalised children to speak and to be heard.

It is also hoped that the knowledge and understanding produced through the current research will assist caregivers working with children in the field of HIV/AIDS to manage and intervene in a manner that is closer to the experience of the children than the experience of the adults. Thus, this study additionally aims to generate some recommendations for working with children living with HIV/AIDS in the contexts of research, caring and ongoing support.

3.2. Introduction
Predicated on the benefits of using drawings in working with children, as well as the added value of understanding children through the stories they tell, this study has used the approach of collecting drawings and stories about or descriptions of their drawings from the child participants. A series of drawings was collected from each child over a period of ten weeks. With each child producing between one and three drawings every week, a collection of ten to thirteen drawings was accumulated for each child, together with audio recordings of their descriptions of their drawings and dialogue between the principal researcher and the children about their drawings. This section presents the ethical structure of the investigation as well as the practical steps taken in data collection and interpretation.

3.3. Responsible and ethical research
Consciously built into the design of the study was the intention to protect and preserve the psychological and emotional well-being of the participating children. Research techniques and principles were chosen to maintain and even enhance their psychic integrity. The decision to use drawings and stories not only held the potential of yielding rich data; it also held the potential for therapeutic benefits for the children.

The said therapeutic spin-off of a narrative orientation is that the story-tellers are able to distance themselves from their own stories, separating the experiencing person from the experienced event or problem (White & Epston, 1990). The current study facilitates the children telling stories or providing descriptions of their drawings. As White and Epston (1990) suggest, this kind of narration separates the narrator from potentially distressing events and experiences that s/he narrates. This distanciation minimises the potential for the research process and experience to be distressing for the participants. By the same token, drawings themselves may be seen as a kind of visual narrative. Thus, the double narrative technique of drawing and telling applied in this study has the potential to distinguish the child from whatever distressing experiences s/he may represent on paper or in words. There is therefore no conflation of problem and child. There is a separation between experiencing subject and expressed problem.

Speaking from a more psychoanalytic perspective, Schaverien (1987) elaborates on the value of drawing: she purports that the picture is a useful "scapegoat" in art therapy. The criteria for successful scapegoating – projection and disposal – are fulfilled through the drawing process: firstly, there is a projection of parts of the person's experience onto an object, in this case, the drawing paper; and secondly, there is the possibility of disposal of the object, as the page may be thrown away or got rid of in some other way. This two-part process of projection and disposal, suggests Schaverien (1987), is healthy scapegoating and may achieved through therapeutic artistic expression (in Dalley, Case, Schaverien, Weir, Halliday, Nowell Hall & Waller, 1987). The process of drawing not only distinguishes the person from the distressing aspects of his/her affective experience; it also presents an opportunity for the artist to be validated and acknowledged through a validation of something s/he has produced: the drawing. Schavarien (1987, p. 82) elaborates: "[The drawing] …may also be guarded and kept" – a way of protecting and preserving certain aspects of the person's experience. The drawing process can therefore function as both a conduit for relieving the artist of burdensome and broken parts of his/her experience and as a conduit for preserving and affirming the more uplifting and restorative aspects of his/her experience, since both aspects of personal experience tend to be expressed in people's drawings.

Using drawings to communicate with children is promoted as a relatively safe technique. Bertoia (1998) worked with a terminally ill nine-year old child and reinforced the therapeutic benefits of artistic expression and particularly serial drawing. Bertoia (1998) simultaneously

indicates that self-expression is held in check by an inbuilt mental mechanism (the ego) that prevents the mind from being overwhelmed by potentially unnerving mental contents. This mechanism confines the expression of material to that which the individual is capable of coping with. Artistic expression such as the kind carried out by participants in this study is therefore largely safe and non-threatening.

3.4. Consent and assent

The research design adhered to recommended guidelines for ethical research practice as outlined by Rhodes University Ethical Standards Committee (1997). Research design also took cognisance of principles addressing child participation enshrined in the United Nations Convention of the Rights of the Child. The most pertinent of these states that a child has the right to participate in all decisions about matters that directly affect him or her, and that all children have the right to participate in programmes about children as well as the right to withdraw from such programmes. The research proposal, intended process, aims, intention, possible outcomes, benefits and pitfalls were presented verbally as well as in writing to the caregivers and social worker at the children's home over a number of meetings prior to commencement. A written proposal was compiled and submitted to the Research Proposal Committee of Rhodes University Psychology Department for approval prior to commencement of data collection.

Upon approval of the research proposal, written informed consent from adults (see Appendix A for an example of this form) as well as verbal consent or "assent" from the children for participation was carefully and sensitively obtained according to guidelines for ethical practice delineated by Graue and Walsh (1998), Malchiodi (1998) and Koocher and Keith-Spiegel (1990). In the first session with the children, the research process was explained to them in a manner and using terminology that they would understand (see Appendix B). The children were given the opportunity to ask any questions and make any comments. They did not necessarily do this immediately, and instead asked questions and passed remarks pertaining to the research process, the researcher's role and their relationship with the researcher on different occasions over the weeks that followed. Once consent had been obtained, data collection commenced.

3.5. Sampling

A nonrandom, purposive technique was used to select a convenience sample (Miles & Huberman, 1994) of three HIV-positive children from the six- to ten-year old contingent of orphaned and abandoned children residing at a children's home in Cape Town. The researcher approached one of the children's principal caregivers at the home to collaborate with around selection. Thus, the sampling technique held potential for the needs and aims of the researcher, the caregivers and the children to be met. The caregiver identified children who may benefit from the kind of research process implemented in this study.

Ultimately, the children who were selected and who agreed to participate in the study were children that the staff at the home had experienced difficulties or challenges with insofar as the children's behaviour and affective expression were concerned. Children were also identified according to whether they would be able to comply with the basic instructions to draw, speak about their drawings and engage with an adult researcher. This led to the initial selection of two boys and a girl. After the first week, one of the boys was withdrawn by the staff at the home and replaced with another girl, as his emotional and behavioural difficulties had escalated to such an extent that he was going to be assessed by a qualified child psychiatrist. It was felt that the research process and his assessment process may have undermined each other.

While only three children participated, a total of 33 drawings and 29 session transcripts were generated and meticulously analysed. The reason for focusing on three children is that this study was not intending to generate statistically relevant and generalisable findings. Instead, the intention was to produce rich information on individual children whose life experiences are unique. At the same time, aspects of their lived experiences are common to other HIV-positive children living in children's homes in South Africa. With an in-depth understanding of some of the experiences of the three children who participated in this study, aspects of the experiences of similar children may be better understood and responded to. Therefore, while whatever the children in this study have revealed about their experiences cannot be used to understand all experiences of all children exposed to the same circumstances, their stories can alert those taking care of similar children to these children's experiences and experiencing. The findings of this study will hopefully contribute to developing a mindfulness of the complex life experiences of orphaned children living with HIV/AIDS. Milner and Carolin (1999) and Books (1998) respectively call for the hearing and unveiling or making visible of

those children in our societies who are often not heard properly and to whom we turn a blind eye: the marginalised groups.

3.6. Data collection and processing

Data triangulation helps to contextualise experience, and builds rich descriptions (Terre Blanche & Kelly, 1999), and was applied in this study. Material for developing a rich description of each child was obtained in a number of different ways, from a number of different sources. The primary data included impromptu drawings by the children and their own descriptions of their drawings. These were collected in weekly sixty-minute sessions with the children over a period of nine to ten weeks. At the first three sessions the children were worked with as a group of three. However, due to contamination of one another's drawings and stories, and the small size of the room, the researcher decided that one-on-one sessions would be more valuable for the research process as well as the children. Each child ultimately produced a series of ten to thirteen drawings.

Sessions took place in the play therapy room of a local child and family unit. They comprised of a range of anything up to seven different activities so as to prevent boredom for the children. These activities included drawing, talking about the drawing, being read a story by the researcher, piping icing shapes over biscuits, playing in the sand tray, playing with the audio recorder and microphone, and general conversation with the researcher. Except for the first two activities, the children were given a choice of what else they wanted to do for the remainder of the time. They could also decide on the sequence of activities. The rationale behind the use of different activities was to alleviate boredom and facilitate creative expression. It is possible that the stories read to the children may have provided them with ideas for the content of their drawings and own stories. However, Malchiodi (1998) insists that while children may borrow ideas from external sources, the manner in which they choose to express and convey those ideas is specific to them and what they would like to communicate.

Once the drawing was produced, the child was encouraged to "tell a story" about the drawing. This more often than not led to dialogue between researcher and child about the drawing. Sessions were recorded onto audio cassette and later transcribed. As mentioned earlier, the drawings and transcriptions of the children's descriptions of their drawings comprised the primary data.

Supportive data was obtained from a range of sources through the use of semi-structured individual and group interviews as well as records of significant events in the children's lives, kept at the children's home. All collateral interviews were recorded onto audio cassette and transcribed: (i) the primary caregiver at the home; (ii) staff members involved in domestic and caring work with the children; (iii) the children's school teachers; (iv) the children's medical doctor; (v) the social worker at the home. Other relevant information was recorded in writing at monthly consultation meetings with the staff at the home, which the researcher had been attending even prior to the commencement of data collection. The children's confidential folders kept at the home were yet another source of collateral information. The researcher read these and recorded information that facilitated the development of a chronological sketch of each child's life up to the point at which they entered the research process. Conversations between the researcher and the children both inside and outside the research room also proved to be a source of rich, contextual information. The most salient points from these conversations were recorded by the researcher after the sessions as confidential case notes.

All drawn, written, recorded and transcribed data was appropriately secured by being locked up in a cabinet in the researcher's personal work space. Decisions around ongoing management of the material will be collaboratively made by the researcher and the children's caregivers.

3.7. Data interpretation

The approach of being more concerned with newly emerging insights in interpreting the data than with preconceived and constructed notions of participants' experiences, is based on the "grounded theory" approach developed by Glaser and Strauss (1967, p. 1). This position of allowing theory or understanding to emerge from the data, and the iterative process of interacting with the data, is referred to as "not logical... [but] ...phenomenological." (Glaser & Strauss, 1967, p. 6). In this study the generation of new theory was secondary to the generation of rich descriptions of unique experiences that will hopefully enhance the understanding of, and facilitate more individualised and appropriate responses to, orphaned children living with HIV/AIDS. Results may not be generalisable to broader populations of children living with HIV/AIDS; however, the method, process and attitude through which the rich understanding is obtained may be transferred to various contexts for the purpose of understanding children and mobilising their voices. The procedure followed in analysing the

data was based on a comprehensive four-tiered phenomenological methodology espoused by Moustakas (1994). This methodology or variations of it has been successfully applied by previous researchers (Dalla, 2002).

The first step in the interpretation of the children's drawings took the form of their descriptions of their own drawings. Their descriptions of the drawings may be understood as their interpretations of what they put down on the page. It is one step removed from the actual drawing. These descriptions were elicited through a dialogue between researcher and participants. Drawing on a Rogerian-informed person-centred model of art therapy Giles and Mendelson (1999) advocate for expressly including participants in the interpretation of their drawings through entering into dialogue with them about it.

The second step in the interpretation or analysis of the primary data was to work with the drawings only. Each child's drawings were focused on without the accompanying transcripts of their descriptions of the drawings. A rich description of the drawings was developed using a guideline compiled by Furth (1988, p. 32-100). Common and repeated elements as well as unusual and significant elements were highlighted and developed into themes. These elements may have been present within each child's series or across the series of different children. Each series was also viewed as a whole, and description of the visual narrative was developed.

At this stage, the researcher drew upon the principles of primarily phenomenological research methodology (Moustakas, 1994), narrative research methodology (Riessman, 1993) and guidelines for interpreting drawings (Furth, 1988; Di Leo, 1983). Each child's series of drawings was lined up in front of the researcher like a story board. Furth's (1988) guidelines provided a useful structure for looking at things like the feelings evoked by looking at the picture, repeated features, central features, unusual features, how the artist used colour, consistency and inconsistency, amongst other things. The narrative approach was useful in that it provided the impetus for looking at the series of drawings as a whole story or narrative communicated by each participant. The narrative method also encouraged an attempt to understand how the narrator (the children who produced the drawings) *constructs* his/her life experiences, and where and how s/he positions himself in the world. The phenomenological method was useful in that it encouraged approaching the drawings ("text") with minimal

preconceptions or presuppositions and therefore facilitated a more "pure" description of what was seen in the pictures.

The third step was to focus on the transcripts of the descriptions of, and dialogues about the drawings. Again, each transcript for each child was worked with individually and later together, so that a rich and detailed description of each child's transcript included comments on repetitive ideas, patterns and unique and unusual notions within each child's words, as well as across transcripts.

The fourth step was incorporated into steps two and three and involved referring to all collateral information in order to enrich descriptions and contextualise drawings and aspects of drawings and transcripts.

The fifth step was also embedded in steps two and three. This involved interpretation based more on the researcher's own associations and ideas, influenced by his knowledge of the participants' circumstances, his own training, his own life experience, and various sources of psychological theory. (Moustakas, 1994, p. 33) calls this step – which incorporates associations made by the researcher to the texts and descriptions that have been developed so far – "imaginative variation'. This level also included associations to the illness history of the participant, as the study specifically aims to enhance understanding the lived experiences of children living with HIV/AIDS.

Within the context of psychotherapy, intersubjectivity refers to the notion that the therapist and client work collaboratively to develop meaning and understanding of the client's experiences (Natterson & Friedman, 1995). The therapist draws on his/her own life experience and associations in order to give meaning to the material the client presents. Sluzki (1992) also comments on how meaning is co-constructed in a therapeutic context. He provides examples of how associations to a client's material differs from therapist to therapist, depending on what the therapist has read, experienced or witnessed. Ultimately, the meaning and understanding that emerges is one that both client and therapist have generated; it belongs to neither, but to both (Sluzki, 1992). The current research, most especially in the fifth step of the data interpretation, applies this principle quality of intersubjectivity to the material that the children presented in their drawings and stories. The researcher imbues the meaning making

with his own knowledge and life experiences, as much as the understanding of the children that emerges is imbued with their knowledge and life experiences.

The sixth step involved a synthesis of steps one to five for each participant. This was written up as an individual analysis or interpretive case study of each child, highlighting the themes for each child as well as the common and overlapping themes amongst the three participants. These findings are presented and discussed in the ensuing section.

Throughout all the steps in the data interpretation process, the researcher adopted an approach to the drawings that treated them as metaphoric communication. The idea and practice of pictures and stories as metaphors, forms of symbolic communication and analogies, has been endorsed by both literary and psychological disciplines (Angus, 1992; Combs & Freedman, 1990). In this respect, the drawings and stories were treated as pictures and words representing experiences, feelings, thoughts, perceptions, ideas, wishes, desires, fantasies and memories. In the absence of observing the children's experiences directly, their pictorial, descriptive and narrative expressions were understood to depict these experiences. As the ensuing **Analysis and Discussion** section reveals, the children seemed implicitly aware of the representational quality of their drawings and stories. They used words and phrases like "play house" and "pretend", indirectly and directly referring to the metaphoric tone of their communication with the researcher.

3.8. Validity and reliability

"*Reliability* in a picture… means that the content is trustworthy, it keeps working time after time, more or less for all people at all times (Furth, 1988, p. 21)," and "[v]*alidity* in a picture means that it shows (or tests) what it purports to show (or test), e.g. repressed or undeveloped psychological contents… In brief, the content of a picture is always supported by, and is well grounded in, actual fact… We are always working from the patient's perspective of his reality; that is, as he perceives it to be (Furth, 1988, p. 21)."

A number of features of the design of this study contribute to the reliability and validity of the methodology: (1) the documented use of children's drawings in previous research and therapeutic contexts; (2) method triangulation; (3) checking interpretations with the participants through dialogue between them and the researcher; (4) involving the participants in the interpretation process by asking them to describe or explain their drawings in words;

(5) checking interpretations of the drawings against the children's verbal descriptions of their drawings and vice versa; (6) checking interpretations against collateral and contextual information from key informants and information documents on the children's lives; (7) referring to previous studies and writing on interpretation of children's drawings, particularly in reading the emotional, interpersonal and somatic aspects of children's drawings (Malchiodi, 1998; Bertoia, 1993; Bach, 1990); (8) collecting a series of drawings for each child as recommended by Malchiodi (1998) and Furth (1988). A series of drawings therefore enhances the reliability and validity of the technique of drawing, since an assessment can be made of whether the patient repeatedly uses the medium as a tool for communication and expression of mood, fantasies, wishes, drives, desires and other relevant psychic material. If more than one patient is exposed to the same method of data collection, this provides a further opportunity to assess and also improves the reliability and validity of the method; and (9) following basic guidelines for ensuring reliability and validity in qualitative investigations as outlined by Miles and Huberman (1994, pp. 278-279), Perakyla (1997 in Silverman, 1998, pp. 203-216) and Graue and Walsh (1998, pp. 244-248).

CHAPTER 4: ANALYSIS AND DISCUSSION

Any idea seriously entertained tends to bring about the realisation of itself

- Joseph Chilton Pearce

4.1. Introduction to the analysis

The drawings and the transcripts of the children's descriptions, comments and stories about their drawings have been analysed and discussed. Each drawing was approached in the same way. Thus, each drawing has its own set of themes. These themes as whole represent the significant concerns, thoughts, feelings, perceptions and fantasies of the children during the time that they were participants in the research process. Some of these themes have been identified by previous authors, researchers and practitioners in the broad field of working with children. Where there are links to the literature, this is acknowledged and explained. There are also new themes emerging from these drawings. In order to protect their identities, the children's names have been omitted and replaced by randomly chosen initials that bear no resemblance to their real names.

Metaphors are things that stand for other things; they represent other things. In this way, it is suggested that pictures are metaphorical in that they stand for something else (Combs & Freedman, 1990). This something else may be a real lived experience, a relationship, a feeling, a thought, a perception, a desire or a fantasy. In many ways, the children's drawings and their stories about their drawings are managed as metaphors for all of these things. As a result, the drawings are interpreted as representations of objective as well as subjective reality. As will become apparent in the analysis and discussion below, the drawings and aspects of the drawings were dealt with as metaphors for the children's experiences, ideas and feelings about living with HIV/AIDS and other associated and significant somatic, emotional, relational, fantastical, perceptual, developmental, cognitive and spiritual experiences.

This table below (Table 1) is an arrangement of each of the themes generated from each of the children's drawings. Some of them have been colour coded as a way of grouping some of the themes common to all three participants as well as themes that are repeated within the work of each individual participant. What follows is a brief discussion of some of the common themes. This serves as a brief introduction and orientation to the more elaborate analysis and discussion of each child's work.

This author felt that it was necessary to provide an in-depth, drawing-by-drawing, week-by-week discussion for each child. The rationale behind this is that the drawings were not produced in isolation. While each one conveys its own message, they all form part of a series of drawings produced over nine to ten weeks. It is necessary to 'view' the series as a whole and to observe the sequence of the drawings in each series. This perspective also facilitates a more holistic and contextual understanding of each child. The discussion around each child's drawings is preceded by a copy of the entire set of drawings produced by each child.

Table 1: Themes

Participant No.1: YN	Participant No.2: BT	Participant No.3: CU
Opening statement: The "nice" things in life	*Opening statement: My family home of containment and goodness*	*Opening statement: Containment, security and belonging*
The sun as a symbol of goodness and pleasantness	*Two parts make up the whole*	*Ascension*
Ambivalence, uncertainty and the clouds	*Play house*	*Visibility versus Invisibility*
Home is safe and pleasant	*Relationships of intimacy and affection*	*Connection and Belonging*
Water as a symbol of fun	*The unpredictable collision of intimacy*	*Sun and Clouds, Part I: Neither here nor there*
Paradox	*Sadness as a response to the ravages of extraneous forces*	*From ascent to descent*
The research dance	*Feelings are important too*	*Death averted*
Withdrawn energy	*The sun versus the clouds: An expression of conflict*	*It's possible to love even monsters and pigs*
Valuable relationships: Adult caregiver and child	*Anger, violence and rage*	*Splitting: Protecting vulnerability*

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Table 1: Themes (cont.)

Participant No.1: YN	Participant No.2: BT	Participant No.3: CU
The story of intimate familial interactions	Abating the rage	Change and growth from illness and adversity
Discarded, unwanted parts of the child and/or her experience	Drawing on the resources of others	The Ticklish Lady
Concealing the discomfort of imperfection	Transient happiness and overwhelming rage	The "fat mama": A possible fantasy of health
Renewed hope	Determination and desire to be good	Health is not absolute
Health versus Ill-health	Transformation	Vulnerability and Resilience
Planting seeds of growth and competence	Conflict evokes sadness	Protectiveness
Signs of growth and security	The happy sun and the sad sun	A time for healing?
Resilience as a response to loss	Attack, counter-attack and victory	Seeking help for bleeding wounds
Competence as a response to illness: "Damping"	Relentless onslaught	A depiction of lived reality
Self-doubt and self-deprecation	The value of external sources of support	Sun and Clouds, Part II: A dissonant relationship
Visibility, invisibility and denial	A reminder of the onslaught	Putting on a brave face
Difference and distance	Attachment, separation and loneliness	Separation and Reunion
Conflicting interests: Work or play?	Limitations	An expression of loss and pain
Striving to accept imperfection	Orphanhood, death, loss and mourning	Sun and Clouds, Part III: Taking sides
When the sun goes down, the darkness emerges	Vulnerability and protection	Discarded protection

Table 1: Themes (cont.)

Participant No.1: YN	Participant No.2: BT	Participant No.3: CU
Appearances can be deceiving	"Strangers": a perception of harm	Redressing loss through the provision of care
Rain: a likely symbol of nurturance and growth	Love in the home	Transformation: Letting go of fear
Getting rid of sadness and ugliness	Emotional fluctuation	Sun and Clouds, Part IV: Fighting back
Awareness of her HIV status	Loss, despair, loneliness and fear	Consolidated change
Symptoms of HIV/AIDS; Illness; and Death	Family, fantasy and desire	Normalcy and health
Stigmatisation	The "strangers" (a continuation)	Desire for a normal family
Difference	Reinforcing the strength and value of the sun	Impending danger and death
The need for a mothering figure	A happy sun	Current containment of danger
The need to be looked after	The value of kinship: Protection	Perceptions of normality
Mistrust of the availability of mothering	Friendship as a response to parental loss	Markers of health and growth
Transformation	Emotional vulnerability	Sun and Clouds, Part V: Symbolic confirmation
Dependency and Trust	The need for friendship reiterated	"Unprotection"
Life savers	Terror	
The need for affirmation and approval	Assessing the merits of his symbols of strength and protection	

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Table 1: Themes (cont.)

Participant No.1: YN	Participant No.2: BT	Participant No.3: CU
Glimmering hope	*The value of clinical research*	
	Separation, loss, illness and death	
	Survival	
	Hospitals and death	
	The irony of HIV/AIDS	
	Appropriate grieving	

The suns and the clouds

The sun and clouds were significant aspects of the drawings of all three participants. Commonly, the sun was depicted as a symbol of goodness, resourcefulness, strength and health. Bach (1990) reinforces children's use of the sun as a symbolic source of power.

The movement of the sun was also used to convey ambivalence, as in when it was neither rising or setting, or movement as in when it was descending or ascending. The movement conveyed by the sun allowed for a communication of things shifting and changing. Bach (1990) suggests that the sun in different guises in the drawings of children with chronic illnesses is an indication of the different states and stages of illness the child may endure through the course of the illness. The different position and 'faces' or facial expressions of the sun in the participants' drawings may be a reflection of the different states of health and ill-health they have experienced throughout the course of their lives thus far.

The sun was also used to reflect the children's feelings, while the clouds represented the opposite emotional state. The sun and clouds were often depicted as rivals, with the clouds representing that which is "bad", undesirable or threatening. There was one anomaly, where YN used the clouds to bring rain, and the rain was used as a symbol of growth and nurturance. Ultimately, it was important – for BT and CU especially – that the sun triumphed over the clouds, a distinct eradication of the "bad."

Traditionally, the sun is seen as a symbol of "parental love and support" (Klepsch & Logie, 1982, p. 45) and when clouds occlude the sun, this may be a sign that the child experiences that love and support as inaccessible. In the context of the three participants' use of the sun and clouds in their drawings, this idea is plausible, since they have experienced love and support from their biological parents as inconsistently available (if the parent/s are still alive), unavailable (as a result of early abandonment) or lost (due to parental death). In terms of their relationships with their caregivers at the children's home, the same caregivers or child care workers have generally not been consistently available to the children across their life-spans thus far. Members of staff at the home are occasionally transferred to other places of work, or have intermittently come and gone due to circumstances in the lives of these adults. This has meant that there has often been a conflict between the availability and non-availability of the love and support that the children need. It is likely that the relationship between the suns and the clouds in the children's drawings are representative of this.

The battlefields

In addition to the conflicts between the sun and the clouds, the children repeated the idea of fighting back against something that attacks. It is important that there is a victory of "good" over "bad", and yet still a sense that the "bad" cannot be totally eradicated. This is indicative of a sense of the persistent nature of a chronic illness. Still, the smaller victories seem significant to the children, empowering them with skills and the experience of their own survival, to carry on. This warring discourse is prevalent in the media as well as support group spaces for people living with HIV/AIDS.

Separation and loss

Most pronounced in the drawings of BT and CU, were the themes of loss and separation. Loss occurred in the form of death, abandonment and separation from others. It evoked feelings of distress and sadness. Reunification with others brought about feelings of joy and happiness. Links were made between loss, separation, illness and death, suggesting that the children understand the roles of illness and death in the losses they have experienced. BT is explicit in communicating about the deaths of children and the death of his mother, both of which are seminal experiences in his life.

The distress experienced by children who are separated from their primary source of attachment is emphasised by Bowlby (1946; 1980 in Fraley & Shaver, 1999). Bowlby (1980)

felt that it was imperative that persons who lose their main caregiver express their grief in order to avoid the negative consequences of unexpressed grief (in Fraley & Shaver, 1999). It was the experience of the author/researcher that the children – BT and CU especially – used the research environment to express their feelings about lost parental relationships. This was not as evident in the drawings of YN, possible because her mother was not dead.

Loving homes and "good" experiences

The children's opening and subsequent statements made through their drawings and descriptions of their drawings convey a sense that they feel they live in a home that is loving and nurturing and that offers fun and desirable experiences. This is significant, given the literature that suggests that children living in institutionalised homes generally present with more emotional and psychological problems than children who live in foster, adoptive or family homes (Frank *et al.*, 1996; Bowlby, 1951 in Cassidy & Shaver, 1999). It is possible that these children are developing a sense of the potential for adequacy in relationships with caring adults, based on the relationships they have with some of the caregivers at their home.

The need for caring others

All three children expressed the need to be loved and cared for by significant others. YN expresses a clear need for nurturance, as well as conveys a sense that she has in fact been adequately cared for. There was also an expression of uncertain faith or confidence in the love and caring that others provide. This is consistent with the idea presented earlier, drawn from Bowlby's (1973) theories of attachment that if the formative experiences of primary relationships is disrupted – as is the case of the participants who have lost their parents through death or abandonment – then the child or person goes through life mistrusting most relationships, unless this is challenged by the provision of consistent, adequate and sustainable care and support.

Communicating through their drawings, the children told of the value of nurturing bonds with friends, family and other significant people in their lives. They conveyed the sense that these relationships were protective and mitigating factors in the context of their lives. Apart from John Bowlby, Cashdan (1988) – addressing the value of Object Relations Theory and therapy – also comments that people who have had poor or inadequate relationships early on in life can "correct" these experiences through the availability of adequate relationships later in life.

Danger

Aspects of the children's drawings are indicative of their experiences of horror, trauma and danger. This may be related to their experiences of their illness as well as their experiences of their significant relationships. BT expresses the theme of danger and terror quite graphically. BT and YN demonstrate an awareness of the threats that they face. Ogden (1990) has spoken about the threat and anticipation of danger in the lives of persons who endure life-threatening (physical or psychological) in the early parts of their lives.

Hope, survival, resilience and capacity

These themes are separate but interlinked. The children express their experiences as survivors of a terminal illness. They communicate their abilities to grow stronger and more capable following life-threatening episodes. There is a sense of being able to beat the "bad" using their own resources as well as the resources of others and their environment. YN is especially articulate about her capacity to thrive. Research has proved that children will develop competence and resilience in difficult and stable circumstances if they are properly cared for in their relationships with significant caregivers, if their cognitive development is normal, if they have inherently strong characters and if they are taught appropriate coping styles and mechanisms to manage their emotions (Masten & Coatsworth, 1998). Furthermore, it has been shown that children affected by HIV/AIDS and at risk of developing behavioural and emotional problems, exhibited a much lower than expected incidence of problems when their caregivers were involved in community-based educational and emotional support programmes (Pivnick & Villegas, 2000).

The notion of developing resilience and displaying adaptability as a response to early parental loss (Eisenstadt *et al.*, 1989), living with HIV/AIDS (Geballe & Gruendel, 1998) and living with a chronic illness (Karlenza, 1998; Midence, 1994) with the right combination of factors, has been highlighted. In many ways, the three children in this study are provided with caring adult-child relationships, appropriate education, adequate health care and support, and exposure to well-structured support and extra-mural programmes. It is likely that, combined with their intrinsic resilient natures, they have developed more resilience and competence in the face of adversity.

Uncertainty

In different ways, the children expressed ambivalence and uncertainty, a hallmark of chronic illness. The ambivalence conveyed is not just about the future and future events, but also about being between life and death, as expressed in the ascending house in CU's opening drawing. This uncertainty about belonging on earth or in heaven highlights some of the more transpersonal aspects of the experiences of children living with a terminal illness. Lwin & Melvin (2001), Livneh & Antonak (1997) and Falvo (1991) have all drawn attention to the notion that persons with chronic illness conditions often struggle with the unpredictability and uncertain course of their condition.

Body awareness: Health and illness

Through their drawings, the children also express knowledge of their bodies in health and their bodies in disease. They display an understanding of the links between illness, hospitals and death. CU is especially articulate about the association between body image and illness. Malchiodi (1998) and Bach (1990) have shown that children are in touch with their physical and physiological bodies and that they are able to express their profound awareness of their somatic states through drawings. Apart from YN, the children do not display an obvious awareness of their illness in terms of explicit drawings and conversations about the illness. However, this is not common for children of their ages, unless they are specifically and directly asked, as was the case with YN. The three children in this study certainly revealed a profound and sophisticated metaphoric understanding of the disease their bodies carry as well as many associated aspects.

Seeing is believing?

YN and CU expressed themes of visibility and invisibility as well as the deception of appearances. Very much consistent with HIV infection, it is not possible to diagnose someone with AIDS or to know that they are infected with HIV merely based on their physical appearance. Thus, the virus itself, in the way that it operates (Cotton, 2000) speaks to this theme of sometimes being visible and apparent and sometimes not. It is also postulated that this theme of invisibility addresses the stigmatisation and marginalisation that people infected with and affected by HIV/AIDS often endure (Books, 1998). "Breaking the silence" is a theme that is prevalent at many HIV/AIDS conferences and media presentations in recent years (e.g. Giese, 2002).

A desire for normalcy

The children all express a desire for normalcy and health in their drawings and stories. They depict a small family with at least one parent and sibling as something they would like for themselves. There are also indications that physical health and wholeness are aspired towards.

Protection

The idea of protecting their vulnerability is also commented on by the children. With CU, this protection is not always effective, and this underscores the reality that these children's illnesses and life circumstances are the result of unprotected sexual encounters. The manner in which the children speak about the notion of protection infers that they do not just refer to protection of the physical body against disease, but also protection of emotional vulnerability. From an Object Relations perspective, human beings develop ways of protecting or defending themselves against vulnerability and danger (Ogden, 1990). In their drawings, the children openly express their need for protection.

Transformation

Each of the children exhibited some kind of transformation during the research process. Each one manifested this differently. The changes they underwent were not necessarily huge, but were significant enough for their caregivers to report on small positive differences in the children around the same time that the researcher noticed that something had shifted in their drawings. This offers evidence for the therapeutic value of brief, clinically oriented, participative psychological research with children.

Psychiatric morbidity

This study did not seek to diagnose or classify the participants according to the DSM-IV (APA, 1994). However, it may be useful to be aware that the children's expressions are indicative of certain signs and symptoms of some of the criteria of depression, separation anxiety disorder, conduct disorder, posttraumatic stress disorder and bereavement disorder. The sadness, anger, loss, conflict and fear reflected in the children's drawings do not provide enough information for clinical diagnoses, but do reinforce previous research and hypotheses that children affected and infected by a chronic illness like HIV/AIDS, have lost their parents and who live in children's homes are at risk of developing serious psychiatric disorders (Wild, 2001; Stoppelbein & Greening, 2000; Midence, 1994; Falvo, 1991).

4.2. Analysis and Discussion: Participant no 1 – YN

General comments

Refer to Appendix C for a brief chronological history of significant events in YN's life, and refer to Appendix D for her entire drawing series.

On the whole, YN uses very few human figures in her drawings. She tends towards natural features and objects: trees, flowers, the sun, stars, the moon, and the like. When she does depict more than one human figure in her drawings, there are obstacles to their contact with each other: lack of limbs or water currents. This suggests YN may not invest much of her energy in human relationships, or that she tends to avoid meaningful contact with others. It also suggests that she experiences obstacles to attaining meaningful relationships with others. When there has been a single human figure, it has been a drawing of herself, represented in an extremely capable fashion, and surrounded by numerous signs of growth and health. Her competence may be her way of dealing with the lack of meaningful human relationships in her life. Bowlby (1973) and Ainsworth, Blehar, Waters & Wall (1978) note that a child who has lost her primary attachment figure (parent or caregiver or experienced that figure as inconsistently available, may respond by withdrawing from human relationships, as she does not trust the availability and sustainability of relationships in general; she fears she may lose them (in Weinfeld *et al.*, 1999). Furthermore, Eisenstadt *et al.* (1989) have postulated that early parental loss is highly correlated with, and even precipitates, the development of competence.

The sun seems to be a feature representing health, wellness and resourcefulness in her drawings. The water seems to represent a challenge, even a danger. The way in which she depicts water in her drawings suggests that when confronted with obstacles, challenges or danger in her life, she develops extra means to cope with getting herself out of the situation and rescuing herself. This is suggested by the overgrown arms she drew on the swimming figure in Drawing #9. She may also look to external sources for help, support and "hold"-ing when she is confronted with potentially dangerous or life-threatening situations. Thus, she shows two of her coping mechanisms in her drawings: self-reliance, resiliency and resourcefulness, and dependence on external sources of help and support.

Through her drawings, YN constructs herself as someone who is extremely capable, who aspired to perfection, who struggles to integrate the less-than-perfect parts of herself and her life experience. She sees herself as capable of positive growth and has most likely experienced growth and health in her life to a significant degree. She represents herself as a body-conscious person. In her relationships, she indicates that there is something lacking or missing. She may at times attempt to feel responsible for that which is lacking in her relationships, and attempt to look towards herself to compensate for that which she finds is lacking. She sees her environment as providing her with sustenance for growth, support and resourcefulness. She sees her environment, mostly, as full of life. Her environment is a fun place and offers her things which she delights in and enjoys, e.g. strawberry ice-cream. YN also has had experiences of darkness, coldness and dimness in her life, times when the good, growth-inducing things in her life have felt obscured. She seems to show that these aspects of her life have received and do need or receive care-taking and that she needs to be surrounded by healthy, supportive things during these times. She has been able to pull some of the lighter and warmer aspects of her life and her surroundings into the darker, colder parts of her experience.

A significant feature of YN's drawings is the repeated images and allusions to her own competence. Malchiodi (1998) comments that analyses of children's drawings have largely focused on the negative emotional and psychological aspects and not much on the aspects that reflect a positive sense of self or resilience. In her drawing series, YN highlights her resilience and abilities. This provides evidence for the development of resiliency in children who face difficult life circumstances.

YN's use of colour in her drawings is significant: when she uses bold colour, her drawings denote vitality and health; when the colour is absent or faint, the vitality is ostensibly absent, too. One of the drawings where colour was conspicuous by its absence, was drawing #3. This was one of the few drawings in which she depicts two human figures. Again, this is a strong sign that human relationships – or perhaps more specifically – relationships with her mother, are experienced as devoid of vitality.

Drawing #1, week 1

Opening statement: The "nice" things in life

> **YN:** I've got a sun, and it's yellow and I think it's very nice…

It is significant that YN's opening statement is positive. It suggests that goodness and pleasantness are seminal and forerunning experiences for her. With regards to her HIV infection, this would be true, as YN is one of the healthier children at the home who has not had any serious illness setbacks. She is physically robust and has not lost as much weight as some of the other children. She draws attention to that which is important to her: "nice" things, a home and being surrounded by "people". She indicates that the people inside the house are people from the home she lives in.

The sun – a symbol of goodness and pleasantness

Her opening statement also suggests that the yellow sun is a source of goodness for her. She uses the symbol of the yellow sun repeatedly throughout her drawing series. The inclusion of the sun in her drawings suggests the inclusion of something that makes her feel "nice" or gives her a positive sense of well-being:

> **YN:** I've got the sun and it's yellow and I think it's very nice. And I've got a house and people inside.

Further on she says that the sun "smiles at me when I smile back." Again, this suggests that she uses the sun as a symbol to reflect that which is pleasant for her.

Ambivalence, uncertainty and the clouds

> **R:** What about the clouds? How do they make you feel?
> **YN:** I don't know… It's ok.

YN seems unable to verbally express the significance of the clouds in her drawing. She engages more readily with this further into the research process. For now, the clouds evoke a feeling of uncertainty for her. This may be significant, as the clouds may represent that which is unpredictable and uncertain for her. This may be linked to the notion that the unpredictability of the course of HIV infection is often a source of stress for those infected

and affected (e.g. Duggan, 1994). Thus, the clouds may represent her experience and sense of her HIV infection or the HIV illness she sees around her when other children at the home she lives fall ill and recover unpredictably. This idea needs further verification. Juxtaposed with the obvious positivity of her opening statement, and her focus on the pleasant and feel-good aspects of her drawing, there is the possibility that she does not know how to integrate the not-so-good experiences in her life, e.g. related to HIV/AIDS.

Drawing #2, Week 2

Home is safe and pleasant

YN develops the idea that she derives pleasure and a positive sense of well being from her home and the people who live with her in the home. In this description of her drawing, the generic "people" living in the home have become herself and specific other children. The home is an adequately safe place, as the children feel free enough to "play" there. Flowers and plants are associated with the pleasantness of home, and emerge as symbols of safety and positive well being.

Water as a symbol of fun

Water and the act of swimming are used to denote fun and goodness, as YN describes that there are children "having fun" in the water.

Paradox

In Drawing #1, the sun was represented and described as an unmistakeable source of goodness. Here, she says that the sun is "burning" the eyes of one of the children. This contradicts the message that the sun is exclusively a good symbol. This may suggest that in YN's experience, those things that are good do not last, and are also capable of evoking bad feelings and experiences. The sun becomes a means for her to express the kind of paradoxical experience YN ostensibly has in her life. For example, the children's home is a safe place through which YN is able to access nurturing (she mentions that one of the children "is watering the plants") and fun ("the… children are in the house and playing with the flowers…"), but at the same time, the home is a place of illness that can result in death. Many of the opportunistic infections the children get induce high fevers; this may be the "burning" she is referring to. On a generic level, the "burning" may refer to any bad experience had at the home. The paradox of the sun may be observed on a practical level: the sun and warm

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weather is welcomed by many, but at the same time, too much exposure to the sun is harmful, and can cause "burning" of the skin.

The research dance

In this session, the children still came to the sessions as a group of three. One of the other children in the room added to YN's description of her drawing that "[the researcher] is dancing" with one of the other child participants – also in the room at the time. In some way, it may be plausible to consider that – at this early stage of the research process while the children are adjusting to the different reality of the sessions – YN's description refers to the research situation. Indeed, the children she names as being in the house with her are the other two participants. The other child's use of the word "dancing" may be a reference to some sort of dialogical interaction between researcher and participant. The same child later says that the researcher is "swimming" with the third participant in the water. Water has been used as an element of fun, and it is possible that this denotes a positive experience of the researcher and the research process up to that stage. Furthermore, YN's use of the word "playing" may be a reference to the play therapy room with all its toys, used as the research room.

Speaking about communication in therapy, Malan (1995) says the following: "Whenever a patient speaks … he may unwittingly be making a communication about his *relation to the person he is with, i.e. the therapist, or his feelings about the therapeutic situation* (p. 21)." In the instance presented around YN's drawing in this session, it would thus be a legitimate hypothesis that the children make a reference to the research situation and the researcher, especially since they explicitly state the researcher's name.

Drawing #3, Week 3

Withdrawn energy

In Drawing #3, her use of colour has waned considerably. Her use of shading has disappeared altogether. She uses only red and yellow pencils in this drawing, which is much less bold and substantial than the wax crayons used in Drawings #1 and #2. The sun is the only feature of this drawing that has colour and shading, but it is difficult to see this without straining. This suggests that something is missing here. At the same time, human figures have been added; they appear for the first time. There may be a correlation between the appearance of human figures in her drawings for the first time and her diminished use of colour and shading. Given

that the two figures are of a child and caregiver, it is possible that YN experiences her relationships with her caregivers as insufficient.

Valuable relationships: Adult caregiver and child

YN depicts a scene involving an adult caregiver from the children's home where she lives and one of the other participants. YN uses her depiction of the two figures to explicate three possible dynamics between adult caregivers and children in residence at the home that she has witnessed and/or experienced. The first is contained in the following description of the two figures in the drawing:

> **YN:** [The adult caregiver] has big shoes – boots, cos she's going out in the rain. And [the child] is staying with a bottle on the baby's side…

This suggests that YN perceives the needs of the children at the home to be similar to those of an infant. She is possibly expressing infantile needs to be looked after of her own through this story. This is not surprising given that she has experienced abandonment, loss and inconsistency of primary relationships throughout her life. As Bowlby (1973) suggests, this kind of deprivation is apparent in the behavioural and emotional expressions of children and adults (in Weinfeld *et al.*, 1999).

YN's description also suggests that she perceives the adult caregivers at the home to be protected from potentially harmful elements beyond the home: she has boots when she goes into the rain. It is possible that an AIDS "baby" cannot go out into the rain with the caregiver, as the baby would not be protected in the same way as the caregiver. The children at the home may thus be perceived as more vulnerable than the adult caregivers. Bach's (1990) analysis of chronically ill children's drawings has demonstrated how the depiction of rain may be associated with destruction or with goodness. In this instance, it seems that YN has used the rain as a symbol of destruction.

The second dynamic that YN is likely to have witnessed and experienced between the caregivers and children at the home is one of fun and playfulness:

> **R:** Both of them seem to be smiling. Why is that?
> **YN:** Cos they're going to the park.
> **R:** What are they going to do at the park?

YN: They're going to play and buy them ice-cream…

The third dynamic between adult caregivers and children at the home, as experienced by YN appears to be of a parent-child orientation. Given that the children do not have their own parents, it is not surprising that the relationships they have with their caregivers are described and experienced as parent-child relationships. Some of the caregivers themselves have mentioned how they see the children as their own when they are at work. Thus, this dynamic is fed from both sides. From referring to the caregiver as a caregiver in her story-telling, YN abruptly shifts and transforms the caregiver into the mother of the child in her story:

R: What are [the caregiver and the child] going to do at the park?

YN: They're going to play and buy them ice-cream. And [the child] says, "Mommy! Mommy! Can I go to the shop and she says, "Yes."

The story of intimate familial interactions

Speaking about what the adult caregiver and the child in her drawing are doing, YN tells the following story at the point where she transforms the adult caregiver into a mother to the child:

YN: …And then [the child] is bathing , and she says, "Mommy, mommy! Can I bath with you?" And she says, "Yes, but I'm only closing the curtain"' So she looks at the curtain and then she asks, "Granny, granny! Can I bath with you? And the granny says, "Yes, but I'll close the curtain." And then she says, "Daddy, daddy! Can I bath with you?" And then the daddy says, "Yes, but I'm closing the curtain." And then she said, "Mommy, mommy! Can I have more food?"

(YN laughs loudly at this point)

… "Mommy! Mommy! Mommy!" …

R: And the mommy said?

YN: And so she said, "Yes."… … And she said, "Mommy, mommy! Can I go to the toilet? And so the mommy said, "Yes." And then she said, "Mommy! Mommy! Can I watch TV?" And she said, "Yes." – "Mommy, mommy! What time am I going to bed?' – "Six o'clock." So she said, "Yoo! Mommy, mommy! You always make us early to

bed!" And she said, "No – it's school tomorrow." And she said, "Yooo!" And her
mommy locked her up and she was crying.

In this banter between the child and various members of her family, YN seems to be
expressing a wish for normal and intimate familial interactions. Bathing activities are usually
intimate and private. The child in YN's story wants to have this kind of experience with a
mother, father and grandmother. This is something that is lacking in YN's own life. The latter
part of the conversation between the child and her mother may represent a typical experience
of life at the home: the children desire certain things, and the caregivers or mother-figures are
permissive to a point. When the child complains about these limitations, she is punished quite
harshly by her mother. This leaves the child feeling sad. In reality, the children at the home
are placed in a time-out room when they are persistently defiant as part of a behavioural
management intervention. YN's story seems to describe how she sees and experiences this
intervention.

YN's description of this picture on the whole appears to offer some insight into her
perceptions of the roles and functions of the caregivers and the children's relationships with
the caregivers at the home: as caregivers, nurturers, playmates, mother-figures and generic
parental figures.

Drawing #4, Week 4 (discarded picture)
Discarded, unwanted parts of the child and/or her experience
YN discarded the first picture she started to draw this week. This figure looks either very
elated or very alarmed. It has a disfigured appearance: the one arm is much bigger than the
other. It is not unusual for a child her age to want things to be proportionate and to aspire to
being competent in all tasks. At the same time, there is an aspect of her developing
personality that seeks perfection, and becomes frustrated when that perfection is unattainable.
This has been verified by some of her caregivers and teachers. Her getting rid of this
imperfect picture may be an act of not accepting parts of herself that she perceives as
imperfect, like the fact that she is an orphan, lives in a home, and is HIV-positive. Certainly,
conversations with YN have revealed that she is, at the very least, body-conscious. The
discarded drawing, she said, was a picture of herself, and that she threw it away because it's
"too fat!" and the one arm is "too long." She explained to me that the one arm was "not the
same as the other side", reinforcing the notion that she dislikes imperfection and aspires to

perfection, proportion and competence. Again, her statements suggest that she will not accept imperfections in her self.

Concealing the discomfort of imperfection

When YN was asked what the figure in the discarded drawing was feeling, she answered, quickly and decisively, "Happy!" Yet, the facial expression may also be interpreted as one of alarm, or shock. This would be more consistent with YN's description of this imperfect image of herself, and with the fact that she threw the picture away: there is alarm and horror at the possibility that she may have to live with imperfection and disfigurement. The fact that she says the figure in the drawing feels "happy" therefore suggests a contradiction of experience versus appearance: the experience being one of imbalance and out of proportion, but the appearance or the projection onto the outside world is one of positive affect. This may provide a clue to the manner in which YN lives in the world: some of her experiences are imperfect and imbalanced, but she works to maintain a pleasant demeanour in the 'face' of unpleasantness in her life.

Drawing #5, Week 4 (second attempt)

Renewed hope

Her second attempt at a drawing the same week resulted in this very colourful picture. It has a bold and definite feel to it. Things do not seem out of balance or disproportionate in this drawing, unlike her first discarded attempt. In addition to these signs of growth and ability, the other elements in the drawing appear bold and alive: bright yellow sun, bold blue cloud and orange moon. Her use of pastel crayon and colour in this drawing is a far cry from the faint pencil used in Drawing #3. The cloud stands out in the centre of the drawing. It has a very full appearance. Should it burst and rain, the water would fall onto the flower below, providing nourishment and nurture for this flower. While in an earlier drawing, she used rain as a symbol of destruction, she uses rain here as a symbol of nurturance, or goodness. This is consistent with what Bach (1990) found amongst her European cohorts: that rain can be both a symbol of goodness and of bad. The figure in the drawing looks decidedly happy, almost determined. YN makes a statement in this drawing, and this making of her mark is reflected in the words she writes across the drawing; these words are a description of what she has drawn. This may suggest a need to ensure that the viewer does not misinterpret what she has drawn. Through these written words, she is indicating that she does not wish to be misread.

Health versus Ill-health

This drawing, juxtaposed with the one she discarded earlier on the same day, seems to represent vitality, certainty and health, unlike the discarded drawing which represents disfigurement, disproportion, imperfection and possible ill-health ("fat!" she said). The two drawings may represent these two parts of her own experience and of herself: physically and otherwise: the healthy, capable part and the not-so-healthy part. This, of course, may have nothing to do with her being HIV-positive; it may have everything to do with her process of grappling with perfection and imperfection in herself. However, it would be folly to ignore this obvious inference to the states of health and ill-health she has gone through herself as a result of her HIV illness, as well as the vacillation between these two somatic states she has witnessed in the other HIV-positive children she lives with. It is significant that she is able to devote an entire drawing to health and vitality, and this may have to do with the fact that YN is one of the healthier HIV-positive children living at the home. She has not been significantly ill since she was a toddler, and physically, she is more robust than many of the other children at the home. This picture seems to be a testament to that reality.

YN's depiction of the fluctuation between health and ill-health is a very real experience for people living with a chronic illness, who may often go through periods of somatic stability and instability at random (Miller, 1995; Midence, 1994; Falvo, 1991).

Planting seeds of growth and competence

YN explains that the picture is of her riding a motorbike after she has planted her "bean in wet cotton wool, then cover it with water and it growed – big." In this description of her drawing, YN appears to be displaying her capabilities and competencies. One of the things she is capable of is nurturance of animate objects like plants. Her efforts result in substantial growth. Having displayed this capacity, YN's story indicates that she is capable of operating things on her own, as suggested by the motorbike she is riding in this picture. There is a slight sense that she imagines herself to be more capable than what may be expected of a child her age. Someone her age would not be expected to be capable of riding a motorbike by herself. Yet, in this drawing, this is how YN depicts herself: as being capable of solitary activity beyond expectation. This suggests that she either perceives herself to be extremely competent, or would very much like to be perceived by others in this way. As discussed, competence may be a reaction to early parental loss (Eisenstadt *et al.*, 1989) and chronic illness conditions (Falvo, 1991).

Signs of growth and security

In addition to competence and self-reliance, this drawing appears to represent growth and security. The tree that bears so many ripe apples is suggestive of growth that results in fruitful rewards and nourishment. The same tree houses a rabbit. On her motorbike, she moves from the bean she has planted to the tree that offers nourishment and security. This is a decidedly positive depiction of her experience of herself, her surroundings and possibly her future, too. Again, this appears to suggest the development of resilience in a child at risk – both physically and emotionally.

Resilience as a response to loss

Amidst all these elements of growth, nourishment and security, she proclaims that she is "Very, very happy." She states that what adds to her happiness in the scene she has drawn, are the friends she has to play with. Yet, she has not drawn her friends in this picture. In reality, YN has been separated from her closest friends at the home: a group of the children were moved to live in a smaller, more contained house. YN was not moved with them; she remained behind. She was attending the same school as them, and when the move came about, YN was also moved to a different school. In some way, she lost these friends that make her feel so "[v]ery, very happy". In the face of separation from and loss of, loved ones and loving relationships, this drawing may indicate that YN relies on herself and other aspects of her environment for support and nurturing. It is possible that, through this drawing, she is saying that she copes with loss by becoming more self-reliant and competent. This reiterates ideas put forward by Geballe and Gruendel (1998) as well as Cashdan (1988) regarding the resilience in a child who is living with a chronic illness, and the emotional and psychological "corrections" that can take place for a relationally deprived child exposed to adequate relationships later in life, respectively.

Competence as a response to illness: "Damping"

It may also be significant that this child produces such a drawing of boldness and aliveness the week after she has drawn a rather pale, faint depiction of adult-child relationships, and minutes after she has drawn and discarded a disproportionate, disfigured image of herself. This suggests that YN's response to imperfections and absence of substantial relating in her life is on competence and a sharp focus on that which is good and abundant in her life. Kleinman (1988) acknowledges the fluctuations between health and ill-health experienced by

many people living with chronic illnesses. Kleinman uses the word "damping" (p. 7) to refer to an in-built health-enhancing mechanism that is triggered when a person is able to access positive resources within and outside of him or herself. Of these periods, he also says, "There are rising feelings of mastery, often due to acceptance of a paradigm of care that substitutes a pragmatic notion of illness maintenance and disability reduction for the myth of cure (Kleinman, 1988, p. 8)." It is possible that, in response to her illness circumstances, YN has developed a system of support for herself that draws upon her internal strengths as well as the strengths apparent around her in the form of her caregivers, peers and domestic infrastructure.

Drawing #6, Week 5
Self-doubt and self-deprecation

After playing a kind of game with the researcher of revealing and concealing this drawing, YN's opening statement about this drawing is:

> **YN:** Ja. It's very ugly, hey. So ugly.

She turns her criticism of the drawing into a chant-like tune. In this drawing, YN has used, for the first time, a different drawing technique: she has used the length of the pastel crayons to produce a sweeping effect, giving the drawing a somewhat abstract, fantastical feel. Her criticism of it suggests that she is tentative about new ways of expressing herself. She also pre-empts the viewer's impressions of her drawing, suggesting she carries an expectation of being perceived in a critical manner. The juxtaposition of this statement with the previous week's drawing of competence (Drawing #5) is indicative of an ambivalence or conflict between the developed, polished parts of herself and her experience and the less perfect parts of herself and her experience. It is, however, promising that she is able to depict less-than-perfect images. This shows an awareness of different aspects of herself and possibly a willingness to integrate opposites in her life.

Another interpretation of self-deprecation within the context of drawing is that it is an indicator of a destructive tendency and depression (Malchiodi, 1998). Depictions of the self as unattractive have been found to be a feature of the drawings of children who have been abandoned. In Drawing #4, YN depicts herself in a disfigured and disproportionate way; she then discards this drawing. Here, in Drawing #6, while she does not depict anything or anyone in an unattractive light, she is initially critical of her drawing. It is postulated that YN's self-deprecatory imagery and remarks are not part of a depressive picture, as there are no other

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obvious features of depression in her drawings. However, her self-criticism may very well be linked to her abandonment by her mother: having been rejected by he mother, she may feel undesirable.

Yet, in general, YN's drawings and comments are suggestive of ambivalence about her value and worth. She vacillates between depictions of competence and perfection and depictions of imperfection. Her sense of self-worth appears to be an issue that she is grappling with.

Visibility, invisibility and denial

R: Where is this [scene] that you have drawn?

YN: At the park.

R: You said the children went to the park. I don't see any children [in the drawing]...

YN: You can't see them. You're not supposed to see them – they've gone to the shop.

R: Have they gone to get ice-cream at the shop? Are you part of that group?

YN: No.

R: Are you in the drawing at all?

YN: Not at all.

R: Where are you?

YN: I'm at home.

In this extract of the dialogue between participant and researcher, a phenomenon of being visible versus invisible is implied. YN introduced children into her story about this drawing, yet the children have not been drawn. This theme resonates with her game of shifting between wanting to show me the drawing and not wanting to show it to me initially. This may be a metaphor for things in her life that are present but unseen, perhaps even overlooked, ignored or denied. It may refer to things about her that she knows are real but are unknown to, and unseen by, others. Since she applies this idea of visibility versus invisibility to the children in her story, this may also be a metaphor for the experience of the HIV-positive orphaned children at the home. Geballe and Gruendel (1998) comment on the "[i]nvisible children and youth of AIDS" in reference to children in schools in the USA who are affected by AIDS and whose needs are regularly overlooked in society and in schools. Giese (2002) ran a seminal workshop with children who are infected and affected by HIV/AIDS in order to make their needs more visible to policy-makers in South Africa. Robinson (1999) interviewed children orphaned by AIDS in Zimbabwe to get a sense of their needs because their needs are often

diminished and ignored in their communities, a reality that seems prevalent in most of sub-Saharan Africa (Karlenza, 1998). Wild (2001) agrees: "Despite the potential importance of the topic … the psychosocial adjustment of AIDS orphans has often been overlooked by researchers, international AIDS conferences, governments, nongovernmental organisations and service providers (p. 3)." Henry *et al* (1997) have demonstrated that denial of feelings such as anger is one of the responses of Australian youth to the reality of the HIV/AIDS pandemic. The South African government up until recently denied the reality that HIV causes AIDS. The present, but unseen children in YN's story about her drawing fit the globally pervasive tendency to overlook, ignore and deny the psychosocial impact of HIV/AIDS on children, as evidenced by the aforementioned researchers and authors. YN's use of the phrase "you're not supposed to see them" reinforces the notion that the tangible reality of AIDS orphans is sometimes consciously denied. The effect created by her use of the crayon in parts of this drawing seems also to reflect this idea of visibility versus invisibility in its translucent appearance.

Difference and distance

In her story about this drawing, YN speaks about the children who have gone to the park. When asked whether she is part of this group of children, she indicates that she is not. Instead, she is at home…

R:	What are you doing at home?
YN:	I must clean up, mop the floors.
R:	How come all the other children got to go to the park and you stayed at home?
YN:	Because maybe they don't enjoy it at home, only at the park. So, I let them have fun.
R:	Do you have fun?
YN:	Of course!
R:	When you clean, do you have fun?
YN:	No… Yes! I like cleaning. Cos today I cleaned the floor. Got the dishes.

In her story, as well as in reality at the home, YN often offers to assist with the general cleaning chores, while the other children play outside. Thus, she separates herself from the general group through the role she plays. She perceives herself as different. It is possible that she sees herself as belonging to the group of adults rather than the group of children, at least in the activities she engages in. This identification with an adult world is depicted in Drawing #5, when she drew herself riding a motorbike. In this drawing, her separation from the

children who have gone through the gate she has drawn to go and have fun in the park may also be a comment on her separation from the group of children who have gone to live in a smaller home in a different area. As previously discussed, YN was originally part of this group of children when they still stayed at the larger children's home. This small group of children, YN included, attended a different school to the rest of the school-aged children from the home. A house was bought and a decision was made to move this group of children from the larger home to the smaller, community-based home. All except YN were moved. She was left behind. In addition to being separated from her group – one of which was her closest friend – she was also moved to a different school. The perception of many of the children at the home was that those children who moved to the community-based home were in some way better off than the rest of the group. This perception was shared by the adults working and living at the home: the smaller, community-based home was seen to be an improvement on the larger children's home. It is therefore plausible to consider that YN's drawing and story addresses this event in her life where the children left the home (through the gate) for greener pastures (represented by the park and the beautiful scene with its paradisical feeling depicted in the drawing), and she was separated from them, not playing in the park, but doing work. She has perhaps come to accept these Cinderella-like circumstances of her life, and therefore, claims that she enjoys doing the work. Yet, there was a moment of uncertainty when the researcher asked her whether she has fun cleaning up: "No… Yes!" she said. She seems to suggest that she has to assume a role of responsibility when circumstances are beyond her control.

Identifying herself as different is also consistent with reports and observations that people living with HIV/AIDS are stigmatised in society and perceived as somehow different from others (Giese, 2002; Clacherty & Associates, 2001).

Drawing #7, Week 5
Conflicting interests: Work or play?
While talking about enjoying cleaning up at home, YN has started a second drawing for the session. This turns out to be a drawing of a strawberry ice-cream cone, YN's favourite flavour. She spends a substantial amount of time on this drawing, and produces talking about cleaning up. This seems to represent a conflict of interests, and suggests that her actual desire is to have fun and enjoy the same pleasures as the other children. Simultaneously, she has perhaps convinced herself that she enjoys working while the other children play.

Drawing #8, Week 6

Striving to accept imperfection

Following on the theme of YN's aspirations for perfection and competence (as inferred from Drawings #4 and #5), YN speaks about making mistakes while she completes Drawing #8:

YN: Sometimes, lots of people make mistakes. Even I make lots of mistakes.

R: Right. How does it make you feel when you make mistakes?

YN: (laughing) Good!

R: How come it makes you feel good?

YN: Cos I like making mistakes.

R: You like it? I think it's important to make mistakes.

YN: Why did you say so?

R: Because when you make mistakes you learn and you grow. If you make a mistake with something, then you can say, "Ok. That was a mistake. I can learn to do it differently next time."

YN: (laughs)

R: So it can be very important to make mistakes

YN: (makes incoherent gurgling sounds, almost like an infant...)

The "good" feeling associated with making mistakes may be a feeling of release and relief for YN, who seems to express a focus on being adult, competent and perfect. She may be discovering a sense of relief when she allows herself to be imperfect.

When the sun goes down, the darkness emerges

YN: (while drawing) ..The darkness. The sun is moving down ...And it's pouring with rain. (She makes staccato sounds while drawing, denoting what are most likely raindrops) ....The grass is... I'm just gonna make the grass and the flowers... Here's the dark... Here's the dark... (She makes a howling sound)...

In previous drawings, she has used the yellow sun in a manner that suggests positive well being. Here, the yellow sun is setting. At the same time, she draws an ominous-looking dark patch in the middle of the page. However, the rest of the sky is not in darkness. This is suggestive of a new element emerging in her drawings – an element that is possibly contrary to the sun and therefore opposite in meaning to the sun. It is therefore likely that the darkness

represents negative events, feelings or perceptions. Later on, YN reveals that the dark patch in the drawing represents 'night time." When the researcher attempts to ascertain what the objects in the dark patch are, YN asks the researcher to tell her. It is through the words of the researcher that it is assumed these objects are the moon and stars. When questioned about this dark patch again, she claims she does not know what the objects are. YN is usually articulate about her drawings, but not so this time. This suggests that the dark patch and the objects inside it represent something that she does not want to know about or has not yet formed an idea of yet for herself. There may be aspects of herself and her experience that she still feels 'in the dark' about.

This is an example of how the sun may be used in children's drawings to represent love and support from caring adults (Klepsch & Logie, 1982). When this symbol starts to disappear or set, darker, colder elements become more apparent.

Appearances can be deceiving

The researcher speaks with YN about the apples in the tree she has drawn. In a previous drawing, the apple tree was associated with health and growth; here, the apple tree takes on a different meaning:

R:	And you've got a tree. What are these in the tree?
YN:	Apples.
R:	Are they good apples or bad apples?
YN:	Bad.
R:	Why are they bad apples?
YN:	Because someone's not supposed to eat them from the tree, because it gives germs.
R:	What do the germs do?
YN:	They make you sick.
R:	How do they make you sick?
YN:	Like, if it doesn't taste nice, like if it's... like it's not... like I'm saying it's not apples – something else!
R:	So, these are not apples?
YN:	It is, but it's not apples, but it is apples. I'm saying it's not apples, but it is a apple.
R:	Why are you saying that it's not an apple?
YN:	Because...
R:	Are you saying that something can look like an apple, but it isn't really an apple?
YN:	Ja.

It seems she is slightly confused about what she is saying. What can be extracted from this dialogue is that something that looks healthy is not always healthy, and things that appear from the outside to be one thing, may turn out to be something completely different. In the context of her illness, the appearance of health belies the presence and activity of the virus inside the cells of the body. YN looks quite healthy and has not been significantly ill for a while. It may be that the apples that have "germs" inside them and "make you sick" are a way for her to express and make sense of her experience of her illness. If her two drawings that depict apple trees are looked at in sequence, YN seems to be expressing an awareness of her health, as well as an awareness that beneath that healthy appearance lies a virus ("germ") that has the ability to make her feel "sick." There may be a sense of being deceived by appearances that she is expressing here.

Rain: a likely symbol of nurturance and growth

Since she draws attention to the rain by writing the word "rain" on the page, there may be some significance in the rain in this drawing. The cloud she drew in Drawing #5 looked full, but there was no rain; here, there is rain: a visible and emphasised source of nourishment and nurturing. The rain that makes "the flowers grow" is juxtaposed with the lifeless, black part of the drawing. This seems to be a representation of the two parts of her she has already alluded to in Drawings #4 and #5: the healthy and the not-so-healthy.

Getting rid of sadness and ugliness

The symbol of the sun in YN's drawings seems to relay important messages about how she feels. The first sun she depicted in this drawing is "playing" and hence is likely to represent a more care-free part of her experience. Perhaps not wanting to alter this aspect of her experience, while speaking about her drawing, she started to draw something that she subsequently erased and scratched out:

> **R:** ...[W]hat is this that you started drawing here?
> **YN:** ...Nothing...
> **R:** Nothing. It's quite a full picture. The rain is making the flowers grow...
> **YN:** (now referring to the part she scratched out) This is, uhm, ugly sun
> **R:** What does the ugly sun do?
> **YN:** Spoils the house.
> **R:** What house?

YN:	Huh?
R:	What house does it spoil?
YN:	Uhmmm…
R:	Whose house does it spoil?
YN:	Our house.
R:	Why does it do that?
YN:	Because it's sad. Because it's not a nice sun.
R:	Where does it come from?
YN:	It comes from – I dunno!
R:	…You're rubbing the ugly sun out…?
YN:	Ja.
R:	Why?
YN:	Cos it's ugly.
R:	Okay. (At this point, the page breaks on the spot that she is using the eraser) …You don't want to rub out too hard. Is there anything else you want to tell me about this drawing?
YN:	No!

Unlike previous drawings where the sun has appeared to represent feelings of health and resourcefulness, in this drawing, the second sun seems to reflect feelings of sadness and repulsiveness. These feelings may be related to the "bad" apples with the "germs" inside that "make you sick', since she started drawing this "ugly" sun while talking about the "bad" apples. If there is an association between the sun and the apples, the ugly and sad sun may symbolise feelings of sadness and repulsiveness that she experiences in relation to HIV/AIDS – both her own disease and that of others. There is certainly a connotation between things that are bad, germs, and sadness and ugliness. Whatever the interpretation of this, YN seems to use the image of the sun to convey important messages about her emotional states. Thus, here, she is expressing sadness and repulsiveness or unwantedness.

The sun as a symbol of parental love and support (Klepsch & Logie, 1982), may also be referred to as "ugly" due to the fact that YN has not received adequate love and support from her inconsistently available biological mother. In addition to that the whereabouts of her father are unknown.

Drawing #9, Week 7

Awareness of her HIV status

This is a significant session, in that YN speaks about being HIV-positive, a topic that has intentionally not been explicitly introduced by the researcher for the purpose of not precluding the children's free and spontaneous expressions. The notion of the participants living with HIV/AIDS was openly addressed by the researcher in the first couple of sessions when the children were offered an explanation of the research process, the aims of the research and the reason that the children from that specific children's home were selected. The following transcribed portion of the session takes place in the context of YN wanting to know more about the reason behind drawing:

R: …So, I spoke to [your caregiver at the home], who said that a lot of the children at [your home] have HIV. And I said [to her], "Oh. Okay. I'm quite interested in this thing of children not living with their mommies and daddies; they have big families; and they have HIV. I'd like to find out what they think and feel and know and don't know; and what they do and don't do." So, I though to myself, "How am I going to find this out?"

YN: Have you got, uhm, HIV?

R: No, I don't.

YN: Have I got ?

R: Do you?

YN: *You* must think!

R: According to [your caregiver], you do.

YN: You must think!

R: Well, I trust what [your caregiver] said, so my answer is "Yes."

YN: And [this other child who also lives at the home] – do you know [him]?

R: [Yes].

YN: Ja! …Does he have [HIV], or not?

R: I don't know.

YN: Just say, "Yes," or "No."

R: Uhm… Yes?

YN: No, [he doesn't]. [This other girl] doesn't [either].

R: Is she the one in the wheelchair?

YN: No! That's [someone else]. [he one I'm talking about] is the fat one! (YN giggles). She's not *so* fat. She's about this fat, I think. Nearly my size.

R: Is it good to be fat?

YN: She's bigger… No, [It's not good to be fat]!

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R:	Do you like your body? Your size and everything?
YN:	Yes.
R:	Is there anything about your body that you like especially much?
YN:	It's my, uhm... I dunno! Uhmm...
R:	If you think about your body, which part do you like the most?
YN:	My... (she protrudes her tongue).
R:	Your tongue! Why is that so special?
YN:	Because it makes me – like when I'm eating – it makes me very, very strong or something.
R:	Okay. So, it's the part of your body that takes food in, and makes your body strong.
YN:	Ja. And healthy!
R:	Why is it important to be strong and healthy?
YN:	I think, I think, I think – you must tell me "yes" or "no" – I think it's because it helps you grow. I think.

In this foregoing dialogue, YN displays an awareness of her HIV status, as well as the statuses of some of the other children at the children's home. She correctly identifies those who are living with HIV and those who are not. She does not refute her own HIV status. She also exhibits an awareness of the fact that her body needs food in order to grow and remain strong and healthy. Appropriate and adequate nutrition is one of the ways in which longevity may be increased and wellness enhanced in people living with HIV/AIDS. Thus, YN seems to have an awareness of how she needs to look after her body in the context of her illness, but also in the context of being a growing child. It may be inferred from her use of the word "grow" as well as her references to (plant) growth in previous drawings, that she has a sense of living and growing older and stronger, rather than getting weaker, becoming more ill and dying. YN's experience has presumably shown her the possibilities of managing her illness with positive results.

Symptoms of HIV/AIDS; Illness; and Death

YN displays an awareness of an aspect of HIV symptomatology – skin disorders – that she experienced when she was younger:

R:	...Is there any part of your body that you dislike?
YN:	My ... body. I told you, I don't like my legs.
R:	Because?

YN: Because I keep getting sores on my legs. On my legs. Long time ago, I already fell. I went to the nurse that time. Now it's gone.

She explains that she dislikes her legs and the reason she dislikes them is due to the sores that she had when she was younger. This suggests that she feels uncomfortable with her HIV illness when it is symptomatic. She remembers that she has fallen and hurt herself on her legs, which is likely to have happened. However, the significance of her use of the word "sores", strongly suggestive of HIV-related skin disorders.

The dialogue develops into talking about what causes HIV and how it is transmitted, and YN speaks of a time when she was younger and symptomatic. This is consistent with her medical history:

YN: Sometimes, you can also have a sore mouth, lips and then...

R: You're right.

YN: And then each time they share a cup.

R: Then you got the same sore mouth as the other person.

YN: I used to have my own plate with my name on. Now I don't have anymore.

R: When did the sore lips end?

YN: Long, long ago. Long time ago. Years and years and years.

R: So, now you share plates with the others If you've got sore lips, you can pass the germ to others.

YN: If both children are HIV.

R: If one person has got HIV – that germ inside his or her body – and someone else doesn't, and this person with HIV has a sore or a cut or bleeding; then, the person who doesn't have it – if they don't protect themselves, or if they also have a sore mouth or a cut – [will get it]. If you don't have any cuts or sores, then you're fine, because you can't get HIV by just touching or kissing or hugging somebody. It's only when you've got open sores or there's blood. ...[T]he HIV germ lives inside the blood; it can't live outside the blood. If it is anywhere else, it will die.

YN: What?

R: The germ.

YN: Then *you* die.

YN continues to ask questions about HIV, and also informs the researcher of children from the home who have become severely ill as well as those who have died as a result of AIDS. She speaks about their funerals.

Stigmatisation

Further along the conversation about her body, YN reveals an awareness of the ways in which people living with HIV/AIDS can be hurt by others (Giese, 2002; Clacherty & Associates, 2001). Thus, she displays an awareness of the discrimination experienced by people living with HIV/AIDS:

R: … … What do you know about HIV?

YN: I dunno anything about HIV.

R: If someone says to you, "The children at [the home] have HIV. What is HIV?" what would you say?

YN: Sometimes they [are] so rude!

R: Who?

YN: They. The people. They got kick… They got, uhm, uhm…

R: HIV?

YN: Yes.

R: You say it's rude to kick people when they have HIV?

YN: Yes. When they have.

R: I think so too. Do you think there's something wrong with you if you have HIV?

YN: No.

Difference

YN also refers to the different, but not necessarily, negative treatment of the children from the home by school teachers. In fact, the children's difference means that they are sometimes exempt from punishment. Through this, she highlights an awareness that the children from the home are treated differently from other children. She does not indicate whether this difference has to do with their HIV status or the fact that they are orphaned children living in a children's home. This may not be relevant, since these variables are all inextricably intertwined:

YN: …You know, [one of the boys from the home] always teases the teachers… … But the teachers don't hit him.

R: Do they hit anyone?

YN: No – not us, because they know we are [from the home].

R: How come?

YN: Because they see [the home] before and they know about it.

The need for a mothering figure

In this drawing, YN depicts herself swimming in a pool. On the side of the pool, watching over the figure that represents her, is one of the women from the children's home who look after the children. She says that the reason this woman is watching her swim, is that she is like a "mother" to YN. This suggests a need for a mother figure to look after and watch over her. It is possible that she expresses a need for a mother figure to be available should she need assistance, as adult figures around a poolside where children are swimming generally assume the role of being available to help the children should they get into trouble in the water.

The need to be looked after

YN emphasises the "watching" over function of the caregiver figure she has drawn by spelling and writing out the word "watched." She associates this picture with feeling "happy" and "safe." This underscores the value of an adequate mothering presence in her life.

Mistrust of the availability of mothering

While YN has depicted a mothering figure in her drawing, watching over the figure of herself in the pool, she has drawn the mother figure sans arms. This suggests that is the child figure were to have difficulty in the water, the mother figure would struggle to help her out. By contrast, the figure that represents her (the child) in the drawing has huge arms. It is almost as if the child had to develop her arms to compensate for the lack of arms in the mother figure. Thus, there is a strong implication that YN does not really trust that the mother figures in her life have the capacity to assist or rescue her. Consequently, she has developed capacities and competencies of her own as compensation, possibly even *over*-compensation. Fundamentally, in the face of the mistrust of the availability of adequate caregiving, YN becomes self-sufficient. She is also able to rely on resources in her environment – other than adult figures – to assist her. This is represented by the birds in the water (blue shapes) that look as if they would be able to lift and carry the child figure out of the water should she require it.

Due to the inconsistent presence of her biological mother in her life, and the staff changes at the home, it is not surprising that YN may not have a strong sense of dependable mother figures. This drawing reflects her real lived experiences and circumstances.

Drawing #10, Week 8

Transformation

While previously reluctant to draw, YN starts off this session by spontaneously and eagerly volunteering to draw. According to one of her caregivers at the home, this was the first day in a long while that YN spontaneously approached this caregiver to ask her for help with plaiting her hair before school. This came after weeks of defiance, opposition and antagonism from YN. Her different attitude towards the adult caregivers at the children's home appears to have pervaded the research space as well. It is also significant that YN had relied on one of her caregivers for assistance, given that she is usually extremely self-reliant and independent. It is also significant that this shift in attitude towards a female adult figure at the home came about subsequent to the previous week's session. It was in that session that YN seemed to be engaging with her ambivalent feelings regarding her need for mothering figures and her trust in the capacity of these figures to assist her. It is possible that her drawing process the week before helped her to express some of her feelings about the adult female figures in her life. It is possible that she 'worked through' this issue through drawing and talking about it, and that this process facilitated a shift in a positive direction for her – making her feel more relaxed about relying on adult female figures in her environment.

Dependency and Trust

The theme of dependence on others seems to play itself out further in the session, through YN's interaction with the researcher as well as through her relaying an event from school that day. She uses the idea of "copying" and "patterns" in a way that suggests this is a reference to depending on and trusting others enough to copy them. The first instance of this appears in her interaction with the researcher:

R:	Are you going to draw first today? Would you like to draw first?
YN:	Yes.
R:	Okay. I'll draw, too.
YN:	Are you copying me?
R:	No. I'm going to do my own drawing.
YN:	Are you copying me just cos I said I want to draw?
R:	Well, if you are going to draw, I might as well do some drawing, too, don't; you think?
YN:	Then you are copying me!

R: In a way I am, yes.

A little further into the session, YN harks back to the theme of copying. As mentioned, it carries a tone that suggests copying is a way of expressing trust in someone or something else – relying on someone or something else. This is something YN seems to have struggled with in the past, ostensibly partly due to the unreliability and inconsistency of her relationship with her biological mother:

YN: (while drawing an up-down pattern on her page) …Have you done this pattern before?
R: Yes, when I was your age at school. We used to do the up-down pattern.
YN: And the lines?
R: Yes, we drew lines.
YN: No – did you draw lines in the book? There [are] lines, but then you draw small lines under it?
R: You mean in between the big lines?
YN: Yes. …You know that we can choose whatever pattern we want?
R: At school?
YN: Yes, but I didn't have a chance – someone else chose this one. Not me.
R: Oh. So did you end up copying that person's pattern?
YN: Yes. Then she wrote – the teacher wrote it on the board. First that person wrote it on the board, cos the teacher wants to know, and then she copied, and then you must copy it from the board.

It seems undoubtedly significant that YN's teacher is an adult female figure in her life. Through copying from her teacher, she has been able to trust and rely on what an adult female figure in her life has to offer.

Life savers

The notion of relying on something or someone else emerges in yet another part of the session and her drawing. She has drawn a pool, and above the pool, she has drawn something that she says is there to hold onto in case of drowning:

YN: That's the pool. And here, you hold it. And this is the sun.
R: Hold what?
YN: (pointing to the green, red and yellow oblong object above the pool) You hold this. You hold this when you are drowning; you must hold it.

R:	Oh! Like a life –
YN:	(she cuts in) – Ja! That's it!
R:	What is it called?
YN:	I forgot.
R:	Is it like a round thing?
YN:	Yes, it's round, but it's a long, round thing.
R:	I've seen the ones that are life-savers.
YN:	No.
R:	So, what is it then? Is this what they use to save people when they are drowning?
YN:	Ja.
R:	I'd love to know what it's called. Is it this big – as big as the pool (as it is depicted in her drawing)?
YN:	Ja. Ja.
R:	Really?
YN:	Ja.
R:	A life-boat?
YN:	Huh? It's a life-boat!
R:	Or a dinghy? Or just something you hold onto?
YN:	It's something that you just hold onto.
R:	And it saves your life if you're drowning?
YN:	Ja.

In this drawing, instead of a mother figure to help her feel safe in the water as in Drawing #9, YN has drawn a device that has the ability to save your life. What she portrays here, is a scene of potential danger and the need to be rescued form this threat of danger. This suggests that part of YN's experience is that she finds herself in dangerous or potentially dangerous situations. The danger may lead to death and, as a result, she has to put things in place to rescue her. This would not be untrue for her HIV illness: it has the potential to kill her. While she has not been too severely ill yet in her life as a result of her illness, she has witnessed other children at the home becoming ill and dying of AIDS-related causes. Hence, her situation is such that she lives under a constant threat of dying. As a response to this, those who look after the children at the home have put mechanisms in place to ensure that the children remain as healthy and symptom-free as possible for as long as possible. YN herself has spoken about the need for adequate nutrition to for strength and growth, which demonstrates her awareness of what she needs to avoid the danger of falling ill and dying. This awareness may very well be expressed in this drawing as the generic, nameless object at

the side of the pool that will save you if you are drowning. This life saving device is significant as it is equivalent in size to the pool. She may be saying that the source of potential help must be as big as the source of potential danger in order for it to be effective.

In addition to the object above the pool, YN has also drawn two blue crescent-shaped objects on either side of the pool. Again, she explains, these function to prevent people from drowning:

> **YN:** (referring to the features on either side of the pool in the drawing) That's to not make them fall. Like when they – don't you know – they have it all around there. It looks like a square. You hold the square when you wanna drown. And sometimes when you wanna swim, you hold it there.

She has surrounded this "deep water" pool, a potential source of danger and death, with mechanisms to prevent death. It would be valid to draw an association between this depiction of danger and death and her HIV illness. This implies that it is YN's intention to prevent her death, and that her experience is that of having mechanisms in place to keep her alive.

Yet another symbol and source of possible strength and life in this drawing is the bold yellow sun to the right side of the pool. She has written the word "hold" beneath the sun, as if to underscore it as another source of assistance in the face of danger. In addition to this, YN has used the symbol of a big, bold yellow sun in previous drawings to express strength and health. Furthermore, she says of the sun in this drawing that it stays up during the night, a possible indication that she requires this symbol of strength to be present all the time in the face of the unpredictable danger of the "deep water" of her illness. In reality, YN informs the researcher that she swims in the deep end of the pool when she goes swimming. Thus, she seems to use her real experience of the real potential danger of deep water to express her feelings about the unpredictability of danger in her life and the need to have things in place to rescue her from that danger.

This entire drawing looks uncannily like graphic representations of the Human Immunodeficiency Virus replicating in a human cell. This graphic resemblance merely reinforces the notion that YN's drawing is a depiction of her condition.

The need for affirmation and approval

YN requests that the researcher mark her "work" (her drawing). She has asked for this before, but it was explained to her that the drawing is not about "right" and "wrong." She seems to be asking for approval and affirmation:

YN: I want you to mark it. I want a mark – maybe I'm right or maybe I'm wrong.

When the researcher refuses to mark the drawing, YN draws her own stamp on the page and adds the words "work" and "good" to the stamp. She seems intent on being assessed.

Again, there is a body of water. Water may therefore represent something significant for YN. The water also seems to be the main focus of this drawing. There are no human figures in this drawing. Another notable feature of this drawing are the up-down patterns bordering the top and bottom of the page.

Unlike other drawings where YN has written on them, her writing on this drawing does not form any coherent sentences. She has written single words, as if simply naming the objects she has drawn: "sun", "water" and "pool"; one of the other words denotes an action: "hold", which is an action associated with connecting with something or someone. In the context of a pool, the word "hold" may be associated with the holding onto the side of the pool as a source of security. The word "hold" is also written close to the bold yellow sun she has drawn. The sun seems to be a symbol of health, even caretaking, in her drawings. Is she saying something about holding onto sources of health and strength when confronted with potentially dangerous situations like deep water?

She has also written the word "good" next to boxed off red pencil words saying "work good". In the same box are green crosses. This is an unexpected combination: good work is usually indicated by ticks not crosses. This harks back to a possible active dynamic or conflict for YN: a confusion between her desire for perfection, in the face of imperfect experiences. The other words in the drawing do not make much sense: "pat", "mix" and "ace", while still other words and letters do not make recognisable English words.

Drawing #11, Week 9 (Final session)

Glimmering hope

In her drawing, YN has depicted dark night sky, with stars, a sun and a "flower growing." The juxtaposition of these symbols of light and growth with the looming darkness suggests that YN experiences the presence of hope in the face of potentially overwhelming and occluding situations in her life. This is inferred particularly from the following extract:

R:	…[Which] is your favourite?
YN:	My favourite what?
R:	The sun? Flowers? Sky? The stars?
YN:	The stars… And only the stars.
R:	What makes the stars so special for you?
YN:	This is why: because it twinkles. I like it when, everytime I go to sleep, then it twinkles.

This time, a picture of what appears to be a night sky. No water, no people, no earthly objects and features. There are three yellow stars, and then what looks like an orange and yellow sun, and a green and yellow flower head. Interestingly, the entire page is shaded over in blue crayon. This diminishes the brightness and boldness of the objects she has drawn here. This depiction of a night sky may be a fitting picture drawn in the final session, demoting the end of our time together: there is a transition, just as there is transition from day to night.

In some way, the shading in this drawing seems reminiscent of the shaded black patch in Drawing #8. While in that drawing, the darkness was only a part of the drawing, here it is the entire drawing. Has YN taken the viewer completely into this darker part of herself? In Drawing #8, the sun and flower were outside of the dark patch. Here, they are inside the dark patch. Does this denote some kind of integration or coming together of that which is obvious and visible and light, and that which is dark and dimmer? The 'overseeing' sun of Drawing #8 is now incorporated into the darkness, as is the growth-representing flower. The darker and lighter elements, the elements of day and night, are reconciled in this drawing. This may represent an expression of a coming together of two opposite but complementary parts of herself and her life experience.

It may be possible that, through her drawing sessions, she has become aware of the lighter, healthier, more resilient and resourceful parts of herself, and has come to be able to 'draw'

these aspects of herself and her experiences into the less illuminating, darker, possibly even more desolate and colder (as perhaps indicate through her depiction of black patches and the night-sky) parts of her experience. The latter may be the parts of her life that have to do with the fragmented and occasional contact she has with her mother, her status as an "orphan" and her HIV-positive status.

4.3. Analysis and Discussion: Participant No. 2 – BT

General Comments

Refer to Appendix E for a brief chronological history of significant life events for BT and to Appendix F for his drawing series.

This eight-year old boy used the research process as a way of communicating his feelings, perceptions, fantasies and realities. He used the drawings as a way to enter dialogue with the researcher about the things that mattered to him. Thus, he described his drawings and told stories about his drawings, but also spoke about events and experiences that are not explicitly depicted in what is on the page. He is not markedly verbally articulate, but has managed to use the research context and activities to express himself with profound clarity. At first glance, what he has to say may appear fragmented; what he has drawn, primitive. However, listening attentively, intuitively, skillfully and interpretively to this boy's pictorial and verbal expressions has revealed a rich understanding of him as well as of his context.

The drawings start off with a bright and colourful, somewhat abstract appearance. They become more easily definable and more concrete with each subsequent production. The amount of drawing on the page also increases, perhaps as the child grows more familiar and relaxed with the research situation. In addition, the drawings appear to increase in intensity, giving the appearance of increased activity. This seems to reach a peak in Drawings #4, #5 and #6. The amount of energy plowed into the drawings then appears to wane after Drawing #6; they take on a sparser appearance. Initially, Drawings #7 and #8 carry the appearance of vitality and effort, suggested in the bold use of colour and intensity of the shading. However, from Drawing #9 to #11 (final session), they assume a fainter, less shading-intense appearance, to the point where it is a strain to actually make out what is on the page. In the earlier drawings, this child uses pastel crayons more readily, while he opts for less intense and less bold coloured pencils in the latter drawings. Judd (1989) notes how a chronically ill child's elected use of pencil instead of bolder drawing materials suggests a waning of energy. In her own and others' experiences of working with this group of children (many of whom were diagnosed with cancer), the use of pencil was highly correlated with the child's awareness of their life-threatening diagnosis as well as a poor prognosis within the course of the illness. In the latter drawings, the diminished energy is also suggested through the child's use of mostly the left hand side of the page, leaving the right hand side of the page blank. This

is unlikely to be a problem of organic origin, as he demonstrated his ability to use both sides of the page adequately in other drawings in his series. His final drawing is barely visible.

There are many unusual features of BT's drawings:

> The house on wheels (Drawing #2)
>
> The anthropomorphic house with feet, arms and a face (Drawing #5)
>
> Houses with faces (Drawings #3, #5, #9)
>
> The house with a heart shaped feature attached to it (Drawing #7)
>
> Unusually-shaped houses (Drawing #1 is oval-shaped; drawing #3 is triangular;
>
> Drawing #9 is oval with scalloped edges and looks like a cloud)
>
> The house with the tri-coloured appendage (Drawing #4)
>
> The sky-line below the suns and clouds (Drawing #5)
>
> Multiple suns (Drawings #5 and #8)
>
> Red clouds (Drawings #4, 5, 7 and 10)

There are many abstract features in his drawings:

> Circle (Drawing #1)
>
> Arrow-shaped feature at the feet of the red figure (Drawing #4)
>
> Tri-coloured feature attached to the house (Drawing #4)
>
> Red oblong structure that is transformed into a house with a door (Drawing #4)
>
> Odd-shaped, cloud-like house with face (Drawing #9)

Missing features in his drawings include:

> The human figures are conspicuous by their almost total absence. The only drawings featuring human figures are Drawings #4 and #6.
>
> Base walls or 'bottoms' are absent from the triangular houses, giving these houses an incomplete appearance. BT is capable of producing more complete looking houses, which renders the less complete ones (Drawings #3, #4 and #5) significant.
>
> The ground lines of the houses in Drawings #2, 3, 7, 8, 10 and 11 are absent. Again, he has drawn ground lines below the houses in other drawings in the series, which makes his use of this feature significant.

Repetitions include:

      Smoking chimneys (Drawings #2, 3, 5, 8 and 10).

      Multiple suns (Drawings #5 and 6)

      Multiple, similarly drawn figures (Drawing #6)

      Conflation of house and human features (Drawings #3, 5 and 9)

Other comments:

Many of BT's drawings look as if they are floating or suspended – they lack a ground line. Overall, his drawings have a rather unusual appearance, reflected for example, in their many unusual features and the unusual use of colour. There are also a few inconsistencies, e.g. in his application of colour intensity, shading and the amount of activity or content on the page. The chart below (Figure 1) is a graphic representation of how BT's use of colour, shading and amount of content and activity suggest a fluctuation in the degree of energy, investment and intensity in his drawings across the series. Using an arbitrary scale, the Y-axis reflects the degree of investment from 0% to 1500.00%, while the X-axis reflects each drawing in the series from #1 to #11.
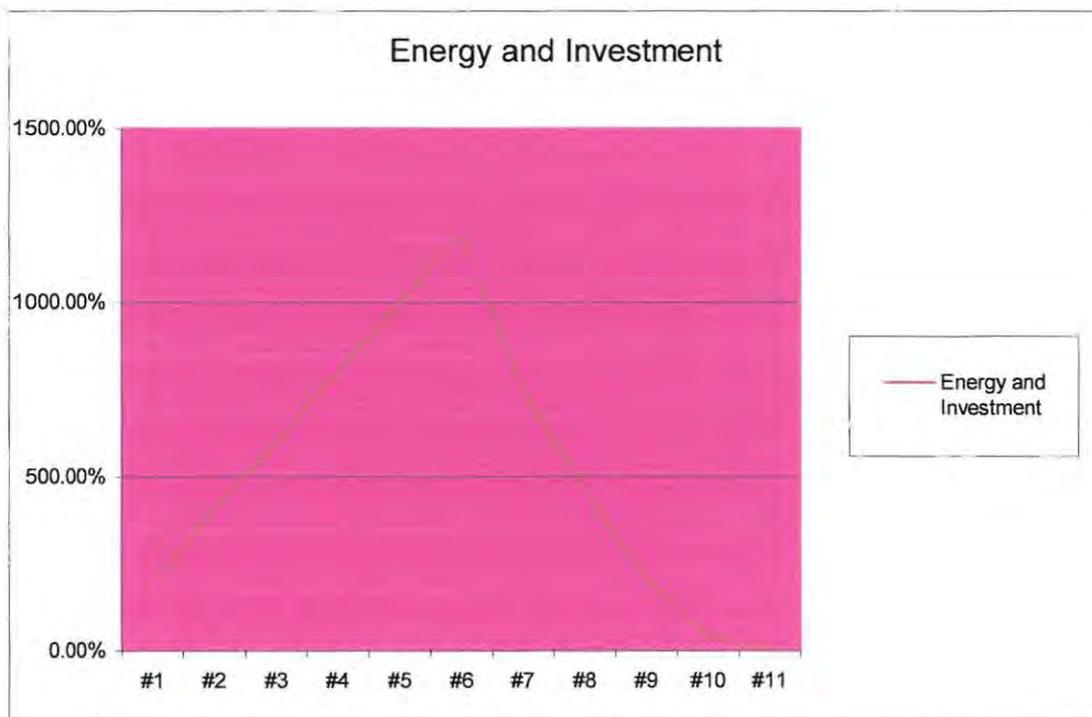

Figure 1

As the graph suggests, there is an almost exponential decline in energy from around Drawing #7. This decline in energy seems to have coincided with the time around which BT was reminded that the research process was going to end a few weeks ahead. It seemed as if he disinvested himself from the research context as well as his relationship with the researcher when he realised that termination was inevitable. This may be a pattern of relating that BT adopts when he is aware that a relationship or process is not sustainable over the longer term for him. It may be viewed as a protective or defence mechanism. Certainly, one of his caregivers at the home has described how it is difficult to find and maintain a volunteer for BT due to his pattern of presenting as sociable and accessible in the beginning, only to become aggressive, uncooperative and rude at some point further down the line. Those who have attempted relationships with him are reported to have grown exhausted with his behaviour and withdrawn their investment from their relationship with him. In a way, BT's attitude towards, and investment in, his drawings mimics the way in which others have responded to him.

Bowlby (1973) postulates that a child who feels insecure about the availability and sustainability of intimate relationships due to formative disruptions in primary relationships, will tend to withdraw from and express anger towards, potential caring relationships (in Weinfeld et al., 1999). This appears to be a feature of BT's relationship pattern.

The manner in which BT interacts with the research process demonstrates some of the value of using this particular methodology and technique that involves collecting a series of impromptu drawings from a child. The process has the potential to unearth insights into the style and pattern of relating that the person has experience of. Within the context of a time-restricted process, this approach therefore has the potential to enhance an understanding of how the child responds to loss or potential loss. This information may be used to assist the child and his/her caregivers to prepare for and cope with the inevitability of loss.

Drawing #1, Week 1

> BT: I'm inside my circle house, and my brother and my sister [are] there. And my
>   brother's name is M, and my mommy's name is [the name of the principle caregiver
>   at the children's home]. And my little big sister's name is T and B.
> R: What is going on inside the house?

BT: I don't know what's going on outside – I'm watching "Dragons". ...It's my play house.

My family home of containment and goodness

This, a drawing of his house may be seen as a visual statement of where he lives. It suggests that he does have a sense of home as well as a sense of family due to his mentioning of his brother, sister and mother. The names he mentions are the names of children and one of the adult caregivers at the children's home. BT has been living at the home since infancy, and, insofar as his experience is concerned, he has not had any other exposure to the realities of "home" or "family." Thus, his opening statement suggests that for him, his family is comprised of the other children and adults at the home.

Due to his use of a closed circle or oval to depict his home, the drawing has a contained feeling about it. The closed circle suggests safety and protection: nothing can penetrate, suggesting a sense that he feels protected and safe in his family home and family "circle." The purple band on the inside of the circle is perhaps another layer of protection. The use of circles in children's drawings has been likened to mandalas (Malchiodi, 1998; Bach, 1990) that are symbols of containment and wholeness. This "house" looks like a capsule suspended somewhere between the heavens and the earth. The sun is shining brightly and the clouds that are present in the sky are not shaded in. They presumably have little or no ability to occlude the bright, warm rays of the sun. There are no sign of danger or vulnerability in this picture, suggesting that this is how BT experiences his home.

Two parts make up the whole

BT's shading of the circle in two different colours, each occupying the area of the inside of the circle in equal parts suggests that BT's experience of his home is comprised of at least two different but equal parts, denoting a sense of balance and harmony.

Play house

Lastly, BT's reference to the home as his "play house" conveys a sense that his home is a place where he is able to relax and enjoy himself. At the same time, his use of the word "play" evokes associations of things that are pretend and not real. This may be an allusion to his awareness that the people he lives with are not his 'real' or biological family. BT has met his biological mother, and is aware of her, even though he refers to his principle caregiver as "mommy."

Drawing #2, Week 2

Relationships of intimacy and affection

> **BT:** There's my girlfriend, whose name is B. And then she does that (he bats his eyelids).

This is BT's opening statement about his drawing. He is referring to the pencil drawn figure alongside the red sun in the top left hand corner of the page. This reference to "girlfriend" denotes an intimate, affectionate relationship. The girl whose name he mentions is, in fact, one of the other participants. His statement at the very least is suggestive of an awakening of his sexuality. It also suggests a desire for intimacy. Contained in what he says is also the idea that an effort – in this instance in the form of flirtation – has to be made in order to achieve the level of intimacy he possibly desires.

According to Jacobvitz and Hazen (n.d.) children will not be able to develop decent peer relationships before they have managed to forge stable bonds with caregivers (in Lyons-Ruth & Jacobvitz, 1999). BT's statements about the "girlfriend" may therefore indicate that he has been able to build adequate relationships with his caregivers, enabling him to develop similar peer bonds.

The unpredictable collision of intimacy

From speaking about the flirtations between the sun and his girlfriend in the picture, BT abruptly shifts to speak about danger:

> **BT:** [The sun] likes B. ... And then the smoke comes out and... ... And then the house collapses on the tree... ...and the clouds make rain.

The house he has drawn is on wheels, and his description suggests that the house collides with the tree. Through this seemingly misplaced allusion to signs of danger and destruction in the form of fire ("smoke"), collision and rain immediately after speaking frivolously about intimate relations and flirtations, BT may be expressing his experience of the outcome of flirting with intimacy: mayhem. This is not far from the reality of some of his relationships, e.g. with his mother who abandoned him after what are described in his records as feeble attempts at intimacy, and with volunteers who have also abandoned him because they have

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been unable to manage his disagreeable and antagonistic behaviour. His use of the word "collapses" thus seems apt, given his circumstances.

This drawing may be seen as a depiction of the formative experiences of relational deprivation as well as life-threatening illness episodes BT endured. This explanation would be consistent with the theories of Bowlby (1973 in Weinfeld *et al.*, 1999) and Gibbs (1989) and Greening and Dollinger (1992 in Stoppelbein & Greening, 2000). These theorists postulate that a child who has had threatening experiences in the formative years of life will carry these experiences with him and express them in some form later in life.

Drawing #3, Week 3
Sadness as a response to the ravages of extraneous forces
In his description of this drawing, BT explains that the house he has drawn is "sad" because of the wind, the fire and the angry sun. BT seems to be saying that sadness is an emotional response he is familiar with when there are potentially dangerous forces around. Depression has been noted as a common response in children living with chronic illnesses (Livneh & Antonak, 1997), HIV/AIDS (Wiener *et al.*, 1999) and facing significant losses (Judd, 1989).

Feelings are important too
He then relays a story of one of the girls at his home who touched the "fire" (he is referring to a flame). This was the last session in which the participants were together as a group, and the other two added to his story about this girl, saying that she cried and was then put into a "dark room just because she was crying." They seem to be saying that the punishment did not fit the crime for the girl, and that attention was paid to her disobedience rather than the fact that she got hurt. They seem to imply that their feelings are not taken into account as much as their oppositional behaviour is at the home.

The sun versus the clouds: An expression of conflict
BT asks of the story he presents: "Can the sun win or the clouds?" He expresses a concern over a conflict between two opposing elements: one hot and fiery, the other cool and with the ability to douse the flames of the fire. Through this query BT expresses a desire to know how the battle will end. Which battle beyond his story and his picture he is referring to, is unknown. However, his illness has resulted in numerous febrile infections and hospital admissions. One of the aims of the management of these infections is to bring his temperature

down; to douse the flames of his illness. Thus, it would not be pure conjecture to suggest that the battle he refers to alludes to the battle with his illness. In the context of this interpretation, his question is extremely pertinent and profound.

Drawing #4, Week 4

This turned out to be quite a dynamic drawing, in that BT changed features in the drawing while he was telling the story about his drawing.

Anger, violence and rage

> BT: ...This boy is angry. He's the naughty one, who hurts people and who hurts somebody. Sometimes he gets angry and he kills the person. Here. I'm gonna show you where's the knife (at this point he adds a knife to the hip of the red figure in the drawing).
>
> R: He's such a violent person. Why is he so angry?
>
> BT: Let me show you where's his gun.
>
> R: Why's he so angry? Why's he so cross?
>
> BT: Here's his gun (BT draws a gun using the same black marker he used to draw the knife).
>
> R: How come he's so cross?
>
> BT: Because he wants some people to kill, some people to eat.
>
> R: Does he just like to get cross?
>
> BT: No. He takes the people and then he takes the skins off, and he puts the people in the fire. And then he... ...that's why I make the rain for them...

This story is riddled with violence and gruesome torture of people. Based on BT's story, the boy's rage is untethered. This kind of free-floating rage is perhaps more potentially dangerous than rage that has an identifiable origin. Rage that is tied to something can perhaps be appeased through addressing its cause. On the other hand, rage that is unlinked may be more difficult to manage and contain, as it simply exists in and for itself. However, it may be that something the "people" in BT's story have done has incited this boy to extreme anger and violent rage. One wonders if these "people" are the same people that may have abandoned BT, whose relationships "collapsed" before him. So enraged is the boy that he acquires weapons to hurt and torture these "people." Bowlby (1973 in Weinfeld *et al.*, 1999) has noted that anger is a common response in children who have experienced insecure bonds with primary caregivers in infancy. Anger has also been noted as an expected emotional reaction to

loss of significant figures (Judd, 1989). It is highly likely that BT's anger is a result of repeated losses throughout his life.

Abating the rage

Almost immediately, BT brings some rain to save the "people" from the wrath of the boy's rage. The rain may have been introduced as a way to suppress the violent rage expressed through the figure of the boy. Yet, this rain, too, is the cause of violent action, this time, against the boy:

> **R:** Who's the rain for?
> **BT:** For him.
> **R:** What does the rain do to him?
> **BT:** Hurting him…

The rain apparently protects the people, but also hurts the boy. This suggests that BT may not be aware of non-violent ways to protect himself or other people.

Drawing on the resources of others

BT scribbles over the yellow sun that he initially drew at the top of the page, and replaces it with a sun that looks very similar in shape to the sun that the researcher had drawn in his own drawing. The first sun was used to hurt the enraged boy in the drawing, while the second sun made the same boy feel "happy." It is possible that in a quest to find an unambiguous source of assistance to overcome the rage and violence, BT was forced to look beyond the domain of his own mind and experience. It is possible that BT is overwhelmed by his own rage, which disallowed him from generating a non-violent response to hurt and anger. Consequently, he 'borrowed' a feature from the drawing of the researcher:

> **BT:** …And here's the other sun (he draws the second sun very close to the head of the red figure)… …And now he's gonna be happy now. He's gonna be happy (he changes the down-turned mouth of the red figure to an upturned mouth).
> **R:** What makes him happy?
> **BT:** Because he likes the sun…

The incorporation of a feature from the researcher's drawing may also be interpreted as an idealisation of the researcher. This dynamic makes a case for initiating and developing

therapeutic relationships for this kind of seemingly emotionally challenged child, with mental health and child care practitioners and professionals. It has been noted that one of the factors that influences the development of resilience and adaptive coping styles in children with life-threatening conditions like HIV/AIDS is the availability of appropriate and adequate supportive figures in their environment (Geballe & Gruendel, 1998)

Transient happiness and overwhelming rage

Even the effect on the emotional well being of the boy in BT's story, of incorporating the sun from the drawing of the researcher is not sustainable: the story rapidly reverts to content with a violent orientation. This suggests that the rage and anger that BT has ostensibly experienced and may still experience is intense and overwhelming. Immediately after explaining that the boy is happy due to the appearance of the second sun, he says, "Then he squash!" At this point, BT crosses out a small green house to the bottom right of the red figure. This house was apparently the boy's house. He continues: "…Then he goes to the other people, and the other people kill him." This boy's happiness is short-lived. BT's story suggests that there is something so large and looming in this boy's life that quashes his happiness, his sense of safety (the crossed out green house) and finally his life. At a later stage in the telling of his story, BT shifts from speaking about the boy in the third person to using the first person as well as explicitly identifying the figure as himself: "That's me." Hence, there is a clear identification with this figure. It may be plausible to consider the possibility that this overwhelming and persistent presence in the boy's life – and in BT's life – is HIV/AIDS and the ramifications of living with this illness. One of the more salient negative consequences of the illness for BT is that he was abandoned by his biological mother and family, and that he seems to have struggled to sustain meaningful relationships with guiding and parental adult figures.

Determination and desire to be good

BT seems to demonstrate an awareness of the undesirable aspects of his behaviour, and a desire to be a "good guy" through the character of the boy in his story:

> **R:** He's got quite a hard life, this boy. Things are quite hard for him. So, he gets angry and then he wants to kill all the other people…
>
> **BT:** And then he wants to be a good guy…

BT shows that he would very much like to overcome his rage and anger. At this point, BT makes a concerted effort to reconstruct a home and less frenetic, more normalised life for the boy in his story. He scratches out the red clouds and red raindrops that were hurting the boy, leaving the boy feeling "happy" again. He also names the light green house to the left of the boy on the page as the boy's home. This boy also has a mother, but she is not at home at the time – she is at work. The absence of the mother from home is consistent with the reality of BT's circumstances. Developing the boy's sense of stability, through the addition of a door BT transforms the red oblong structure to the right of the page into a house belonging to the boy's friend. At this point, he uses a black pen to add a second figure to the drawing. This figure is drawn holding the hand of the red figure. This appearance of this figure in the drawing seems to have a calming effect on the drawing itself, with all its intense red shading and objects of violence. It seems significant that this new figure holds the hand of the red figure; it looks as if the "friend' is guiding the red figure. The following dialogue about the relationship between the boy and his "friend" elucidates the value this relationship has in calming down the boy's rage:

R: Who is his friend?

BT: I don't know, but I need to make a girl (he draws the new figure) …And here she is, happy to see him.

R: Is she his friend? Is she the one who stays here [in the red house]?

BT: Ja. Sometimes, she likes him. And he wants to run to her to tell her there's a letter for her.

R: What does the letter say?

BT: I don't know.

R: Does she have a name?

BT: Her name is Natasha.

R: And this [red figure] is you?

BT: No – his name is Travis.

R: I see Natasha doesn't have arms. Why's that?

BT: (draws arms on the smaller figure)

R: Can Natasha be his friend if he has guns and knives?

BT: No. He doesn't make… He crosses out (BT crosses out the gun and knife of the red figure).

R: And what is this here [at the feet of the red figure]?

BT: The fire! They're having a braai.

R: What are they having a braai for?

BT: Because they're friends.

BT's story suggests that rage, violence and anger can be overcome through intimacy and affection, expressed in the friendship between the boy and girl in the story. This relationship is so potent that it has even been able to transform the once-dangerous fire into a presence that is not just non-threatening: the fire has also become a symbol of more amicable relations between people. Cashdan (1988) and Casement (1985) have both commented on how therapists may provide clients with an experience that redresses past imbalances and relational inadequacies. It is possible that, in this drawing, BT expresses his use of peer relationships as well as his relationship with the researcher/author to assist him to heal some of his past traumas.

Transformation

BT's process in producing this drawing and speaking about it was one of obvious transformation. It started off with intense violence, rage and destructive interactions between people, and ended with a description of a happier, calmer scene and more affectionate interpersonal dynamics. As part of this turnaround, BT incorporated aspects of the drawing of the researcher who was possibly identified by BT as an idealised figure. The transformation continued through a development of symbols of goodness, normalcy and affection (researcher's sun, house, mother, friend) with a concomitant ridding of symbols of destruction. It is deemed important that BT expressed the murderous quality of his rage as a necessary starting point of transforming this into something more manageable and desirable. This dynamic process proves BT's potential for change in a therapeutic context. It also demonstrates the potential for clinically oriented research to have a therapeutic impact on participants and reinforces the idea that therapeutically-framed relationships have the potential to influence positive changes in clients and participants (Malan, 1995; Casement, 1985).

Drawing #5, Week 5
Conflict evokes sadness

The conflict between the sun and rain clouds introduced in Drawing #3 is aired in this drawing again:

> **BT:** (speaks as he draws) I'm drawing a sun. The sun is not happy. He's angry because the clouds are here – the red clouds. Because the cloud is happy, cos it's raining. The sun wants to go to kill..."

Once he has finished his drawing, he approaches the researcher, and continues to describe what he has drawn:

> **BT:** (referring to the house-like structure in the drawing) This is me. I'm feeling sad. I'm crying. Yes, because the sun is trying to hurt the clouds and the rain is coming down.
>
> **R:** The sun wants to hurt the clouds, [yet] the clouds look very happy here.
>
> **BT:** Yes, and the sun is happy because the sun is beating him up.

BT seems unable to move away from talking about conflict and violence. He has placed himself in the drawing not as a human figure, but as a house. Through the house, he expresses sadness about the conflict between the sun and clouds. It seems this is a clue as to BT's emotional response to conflict. In the drawing, BT has used an intense blue sky line to separate the house/himself from the conflict above. This suggests that he feels and would like to feel protected from the conflict, violence and anger represented by the fight between the suns and the cloud. The repeated depiction of stories of conflict and violence suggests that he is consumed by this kind of dynamic, and is perhaps trying to find a way beyond it, as he did with Drawing #4.

The happy sun and the sad sun

There are two suns in this drawing; one drawn with a happy looking face, the other drawn with a sad facial expression. The two suns work together to fight against the rain clouds. They apply violent force to take the cloud away. This leaves the house (and ostensibly BT himself) feeling happy that the sun is shining. Through this scenario, BT seems to be saying that he needs assistance in order to remove the unwanted elements from his world – the elements that evoke sadness. BT also seems to identify with the sun and the strength of the suns in his story to overcome the threat of the angry cloud. He does this by singing while he draws: "*A sunbeam, a sunbeam. Jesus wants me for a sunbeam...*"

Attack, counter-attack and victory

Through his story, BT depicts a scenario of attack, counter-attack and finally, victory: the "bad guy" cloud attacks the sun, the sun responds by launching a counter-attack on the cloud

with the help of a second sun. With force, the suns (the "good guys") vanquish the cloud, an outcome that BT is "happy" with. The suns also manage to set up a barrier of protection for the house/self, in the form of the blue sky-line. The cloud thus represents an unwanted entity; the suns represent the effort to protect the self from this entity, as well as the effort to get rid of the unwanted entity.

This scene may be viewed as an analogy of BT's experience of his illness, particularly when he became symptomatic. The virus may be the aggressive unwanted entity that makes him feel sad. His own efforts to fight back are supplemented by the efforts of medical personnel and his caregivers. These efforts are infused with tones of force, as perhaps, BT's experience is that this virus can only be overcome with aggressive combative methods. Indeed, in the past when he has been severely ill, efforts to treat him have been aggressive to bring his high temperature down, for example. BT has not been severely symptomatic for a few years, but his records and reports from his caregivers indicate that he has had numerous episodes of severe infection in his life to this point. He was hospitalised on many occasions. The efforts to treat him back to health were successful, and for while, the virus was beaten. His story of attack, counter-attack and victory is precisely what he has experienced vis-à-vis his illness. It demonstrates his acute awareness of his illness, even though he does not speak directly about "HIV" and "AIDS."

The dynamics of the story of overcoming the unwanted cloud is also similar to the manner in which BT reacts to other people when he wants to protect himself: he uses aggressive action and words. Thus, his story resonates with the manner in which he deals with his illness as well as interactions with people. It seems to be a guiding narrative for BT.

Relentless onslaught

Much like HIV is never entirely annihilated and has the potential to repeat attacks on the body, the attacks in BT's story persist, even after the cloud was killed by the suns. Subsequent to the death of the cloud, the house/self is only allowed transient relief. Soon, other elements start attacking it:

R: And when the clouds are dead, how does that make you feel?

BT: Happy.

R: (referring to the green shaded area at the bottom of the page) And what's this?

BT: The grass. …It's windy (he takes the page and draws the blue feature to the right of the house/self, ostensibly representing the wind. He sings as he draws). *All the leaves, all the leaves are falling off, falling off, falling off, falling off, falling off. Down comes the rain, splashes on me. Look at the bad wind.*

R: What's going on here?

BT: The leaves are flying. He won't be able to see because the leaves are going to go in his eyes, and that's why he says, "Hah!" That's why he's running.

R: He's running because?

BT: He wants to go to another house.

R: What's going to happen at the other house?

BT: It's going to be hot!

R: And how is that for him?

BT: And then he's gonna be happy.

Here, BT alludes to the kind of experience he endures around circumstances and conditions that he does not like and desire, whether it be his illness, his relationships or anything else in his life. He implies that he faces attack from conditions beyond his control much of the time, and that his reality involves facing these attacks, overcoming them or escaping from them, and facing more attacks. His relief from attack is short-lived.

The second part of his story is different from the first, in that he does not fight back against the wind and rain. Instead, he runs away. This suggests that in the face of relentless attack, BT's defensive structure changes: instead of fighting back, he resorts to escape to a different place altogether. Perhaps the fantasy of "another house" comes with a fantasy of a different set of circumstances with a different pattern of reality. Some months after the data collection in this research process, BT's caregivers reported that his behaviour towards his peers and caregivers had become increasingly aggressive and hostile (protecting himself by fighting back). He was put onto medication to reduce his aggression, which abated to a point. At the same time, he started telling his caregivers that he was going to run away from home. It is possible that BT's aggression at home was an attempt to say that he was unhappy about something, and that he was fighting against what he felt unhappy about. It is also likely that the decision to address his aggressive behaviour with medication translated into his emotional needs and the message behind the behaviour being overlooked. It is plausible to infer that he acted like the house/self in the drawing who ran away to "another house" in response to the onslaught of threatening elements: in the face of his unmet needs and unchanging circumstances, he felt defeated and in the face of not much changing, he resorted to fantasies

of escape. The house/self in the drawing has an exasperated and unrelieved expression, a pictorial representation of the emotional response to persistent frustration that BT seems to be familiar with, both in fantasy and in reality.

Drawing #6, Week 5

The value of external sources of support

BT produced this drawing spontaneously in the same session as Drawing #5. It depicts a continuation on the theme of fighting off the "bad" clouds. In Drawing #5, one of the suns enlisted the help of another sun to overcome the cloud. The idea of acquiring extra help and support to overcome "bad" and unwanted elements is repeated in this drawing: the scene depicted seems to be the final demise of the "bad" cloud at the hands of the nine-strong team of four "friends" and five suns. There is a sense that BT feels strengthened in his fight by the additional helping figures. It may be possible that this is the alternative to running away from his circumstances: getting extra help.

Drawing #7, Week 6

A reminder of the onslaught

Again, BT has drawn a tree to depict wind blowing. Based on the role the wind played in Drawing #5, it is likely that the wind in this drawing is also an attacking element. And once again, what BT tells us is that he faces these kinds of elements continuously and regardless of how much effort went into suppressing and abating them. As in previous drawings, the mood of the sun seems to reflect BT's own emotional response to the persistence of these "bad" elements. In this drawing, the sun, he says, feels "sad." It may be significant that the sun in this drawing is red and has no rays – a sign, perhaps, of the depressed mood of this sun. This is distinctly different from the yellow suns with rays in previous drawings that were depicted in a belligerent mood. BT may be saying something about the defeated and depressed state he finds himself in within a context of persistent negative circumstances.

Attachment, separation and loneliness

While BT draws this picture, he sings, *"Bye-bye, baby. Bye-bye,"* followed by asking me whether I have "other children" that I work with. This evokes a sense that BT has grown attached to the researcher and is trying to determine his place in the relational world of the researcher. He may also be thinking about the inevitable termination of the sessions. The words he sings allude to some kind of separation. Further into speaking about his drawing, he

points out that the red feature hovering above the house to the left is a "lonely" cloud. Then, "Everybody's inside and they say the clouds are rude." BT seems to be referring to a situation where people have rejected someone due to his/her rudeness. This has left the person feeling lonely. He uses the "bad" cloud to express this.

At the children's home, BT has been reported to be hostile and rude. Many of the children are said to dislike and even fear his behaviour. As a result, a number of the children avoid meaningful contact with BT. In many ways, the predicament of the "bad" cloud mimics BT's own predicament. Through this apparent identification with the clouds, he seems to express his feelings about this situation through the character of the cloud: he feels lonely.

As previously discussed, hostility in relationships may be BT's way of expressing his fears and feelings of being threatened in relationships, due to failed attachments in his formative years (Bowlby, 1973 in Weinfeld *et al.*, 1999).

Limitations
In his description of this drawing, BT says that the clouds and wind prevent the children in the home from going to the beach where they would be able to play and enjoy themselves. He adds, "...[A]nd their mommies said when it's hot you can come to the beach..." This suggests that the suppression of the bad elements (wind and clouds) is associated with sunshine, outdoor play, fun as well as the children's mothers. These bad elements may be seen as a generic obstacle and limitation to, access to fun, enjoyment and freedom of movement. At the same time, because of the association with "mommies", it is plausible to consider that the bed elements also limit access to free interaction between children and their mothers. In this sense, the bad elements may be a metaphor for the children's illness. HIV/AIDS has placed restrictions on the lives of the children at the home: they have been placed in a children's home, separated from their mothers and families; their mothers have died due to AIDS; those whose mothers are still alive have restricted access to their mothers; they are not always able to access fun and enjoyment when they are symptomatic. Generally, their illness limits the children at the home in terms of the unpredictability of the illness and in terms of their relationships, especially parent-child relationships. The clouds and the wind in this drawing may thus be a symbol of the limitations associated with being HIV-positive:

> **BT:** ...[T]hey don't like the wind. They want to play outside, and want to go to the beach.
> And their mommies said, "When it's hot you can come to the beach, and you can...

you can play on the jumping castles. And that's why they all say the clouds are rude. And they think the sun is good.

Orphanhood, death, loss and mourning

Through his story, BT demonstrates an awareness that the children living at the home – himself included – are orphaned, as the following extract indicates:

R: Whose house [is this]?

BT: Uhm... [The children's] house! They don't have mommies, that's why they don't wanna go in the house. And they don't wanna go to the beach.

R: Why?

BT: They – they all babies, and their mommies are die.

R: What did their mommies die from?

BT: Was the wind, and they all got choked... and...

R: Their mommies got choked from what?

BT: Was something what come! And choke them! ...And their mommies fall down the sand.

R: The mommies?

BT: Yes, and the daddies fall down the sand.

R: The daddies as well. And the children – what happened to them?

BT: They – they not happy, because they... they miss their mommies, and that's why some friends come and keep the babies...

Here, BT displays a profound awareness of the circumstances of the children living at the home. His version of events told through this story, is highly consistent with reality. It is reasonable to consider that he is included as part of this group of children. He does not name the cause of the parents' death as "HIV" or "AIDS." However, he does express an awareness that something unwanted killed off the parents. This reinforces the foregoing interpretation that the unwanted elements (wind and clouds) are symbols of HIV/AIDS in BT's drawings and stories, since it is true that the parents of the children at the home have died of AIDS. It is also true that the children were placed under the care of "friends": caregivers and volunteers at the home. Through this account above, BT also communicates that the children grieve the loss of their mothers. The children at the home do not usually speak openly about their parental loss. An assessment of BT's neuropsychological functioning revealed that his verbal abilities are significantly compromised. This research process has shown that he is able to use the tool of drawing and story-telling to articulate his understanding of his life circumstances

as well as his feelings. It is recommended that this technique be applied to assist BT (and also other children like him) to speak about what he knows, understands and feels. This will also assist his caregivers to gain greater insight into his inner world of feelings, thoughts, perception and understanding.

Time to listen to children (1999) is an edited book by Pat Milner and Birgit Carolin that advocates for developing the time, space and skills for listening to and hearing, the voices of children from their perspective, to assist and enhance understanding their experiences, concerns and needs. Person-centred art is specifically discussed as a means of communicating with children (Giles & Mendelson, 1999 in Milner & Carolin, 1999). Judd (1989) and Bertoia (1993), based on their work with children diagnosed with cancer, also advocate for the use of non-verbal techniques – drawings particularly – as a way to gain access to the core concerns and consciousness of children. Judd (1989) particularly espouses the value of gaining insight into a child's awareness of the processes of death, dying and bereavement. She also presents an argument against the suppression and repression of the more emotionally painful and uncomfortable aspects of dying and bereavement processes. She cites a study that demonstrated the benefits for a child's self-esteem and level of intimacy with those close to them in the context of an ethos of more open communication in families over the course of the illness (Spinetta & Moloney, 1978 in Judd, 1989). BT has demonstrated the value for him of being provided with the appropriate space and opportunity to express his feelings and concerns. His 'acting out' at the home may in part be due to the frustration he experiences in not being able to express himself verbally. The drawings and the stories appear to have given him the medium through which he can safely communicate.

Vulnerability and protection

In addition to the "friends" that have come to take care of the babies, BT's story involves "…[D]ogs [that] are looking after the children." These dogs protect the babies and children against the clouds. At the time of the data collection, the children's home was preparing to get a dog. This had been a topic of interest for many of the children. It appears that BT has used the reality of this prospect to inform his fantasy of being protected against "bad" elements. BT's experience is that the children at the home have indeed been taken care of and protected.

"Strangers": a perception of harm

BT introduces talking about "strangers." He incorporates this notion into subsequent stories. Here, he mentions it for the first time:

> **R:**   ...[T]ell me about the strangers.
> **BT:**   They cross because... they like the rain.
> **R:**   Who?
> **BT:**   The bad guys... They only like the wind and the rain.

The significance of "strangers" becomes clearer in later drawings. Here, he associates them with the "bad" elements. It will be elucidated later how this is significant, and how BT's use of the idea of "strangers" is a way in which he talks about HIV/AIDS – itself "strange" in that it is a foreign organism that occupies the human body.

Love in the home

Loving, affectionate relationships must be a part of BT's home life, as he clarifies that the heart-shaped feature attached to the house is "smoke" in the shape of a heart. The children inside the house were "cold" and "crying", hence they made a fire. The fire generated smoke which billowed up in a heart shape, signifying the children's "love" for each other. Not only does BT imply that he resides amongst loving peer relationships, but also that the relationships develop partly as a response to the desolateness experienced by the children at the home: their hardship has partly moulded their intimacy.

Emotional fluctuation

BT has a tendency to abruptly shift from a more uplifting content and tone to a more disheartening tone. He did a similar thing in Drawing #2, commented on under the heading *The Collision of Intimacy*. Here, once again, affection and intimacy seem to precipitate this abrupt shift. This suggests that BT's experience of intimate relationships is that they are not comprised only of 'goodness':

> **BT:**   [The children] love each other.
> **R:**   [They] love each other? And who else loves each other?
> **BT:**   But then, now, the children is cross!
> **R:**   Why?

BT:	Because it's cold and they cry. Some children... (He fades away as he becomes distracted by something).
R:	The children are cross because? We were speaking about the heart and you said the children are cross. Why?
BT:	Because it rained...

BT seems to express a constant awareness of the "bad" elements that have the potential to destroy or undermine anything that is good, leaving the children feeling sad and angry. In many ways, the constant presence of the "bad" elements in BT's drawings is like the constant presence of the virus and the illness in the lives of the children. The course and impact of the illness on the lives of the children and its potential for devastation, he appears to be saying, is unpredictable.

Drawing #8, Week 7

Before the session started, I reminded BT again that the research process would end in three weeks' time. He went very quiet upon hearing this news, and then said that his "tummy" was sore.

Loss, despair, loneliness and fear

Almost every week since he has been attending the sessions, BT would enquire about the researcher's mother and family. Mostly, his concern is about the fact that the researcher does not live with his own mother and family. "Shame. Shame for you," he would say. On the way to the research room, BT cut his finger on a twig. He was bleeding slightly and the researcher took him to get a plaster. BT and the researcher returned to the research room and commenced the session. As he drew, BT initiated the following dialogue:

BT:	(singing) *It's a sun-day; it's a sun-day, the sun is happy...*
R:	What makes it happy?
BT:	Because the clouds is gone.
R:	The clouds are gone...
BT:	What's wrong?
R:	Do you think something is wrong?
BT:	Yes.
R:	Why?
BT:	What's wrong about you?
R:	About me?

BT:	Ja.
R:	What makes you think something is wrong with me?
BT:	I think you're crying.
R:	You think I'm crying?
BT:	Yes, because you miss your mommy… Did your mommy die?
R:	No. My mommy didn't die.
BT:	Now where's she?
R:	Did *your* mommy die?
BT:	Ja… She's still co- (He and the researcher talk over each other at this point) …Where's your mommy?
R:	She lives in… I don't live with her.
BT:	Can I go there?
R:	You want to visit her? What about your mommy? Where is she?
BT:	Hmm? She comes on Christmas only. And when she dies, neh, I stay alone and I can't go home. Ja, when she dies. That's why I'm afraid to go there. When she dies then I can't go home, and then I'm gone get lost in…

BT has been told before that the researcher's mother is still alive. Thus, his line of questioning her seems to be based on his own concerns about his own mother and her whereabouts. Speaking about the researcher's situation may be a way in which BT feels safer to speak about his own situation, which he gladly talks about once he gets going. In this session, he specifically used the researcher to introduce his own feelings related to the loss of his own mother. It is unknown whether BT's mother is still alive or not. She has rarely and irregularly visited him in the past. He seems to be expressing his despair and sorrow about the absence and loss of his mother. He also expresses fear and loneliness associated with her death. Bowlby (1973) has recommended that persons who have experienced significant losses in infancy, must be given the opportunity to express their feelings about these losses (in Weinfeld *et al.*, 1999). It seems that BT has managed to utilise the research space to express his feelings about his own losses.

Family, fantasy and desire

When asked how the situation of losing his mother and being on his own may be resolved, BT states that his father will walk from a far away city (Johannesburg). He continues to say that his father will stay with him. He speaks about being afraid of the dark and not being able to sleep. He also says that his "sister" will stay with him. Further into the session, he informs the researcher that he will stay with his "big brother" who is "the monitor." In reality, BT has no

knowledge of his father. He has also never met any siblings or half-siblings. Thus, his idea that his family will come to look after him now that his mother has died, is a fantasy-based idea, and a likely wish or desire he has for the safety, containment and stability of family contact. He seems to seek some kind of reassurance and allaying of his fears through these fantasised ideas of being looked after by his family. He expresses anxiety about losing his mother, for example in the following comment: "I'm not going to bed when my mommy die." This suggests that the loss of his mother has caused him considerable anxiety. Another statement he made indicates that he is afraid of the dark: "…then it's darktime. I'm scared and I don't sleep. I don't go to bed." Thus, not wanting to go to bed when his mother dies, implies that he is anxious.

The "strangers" (a continuation)

In this session, BT develops the idea of "strangers" that he introduced in Drawing #7. According to his description, the "strangers" killed his mother by smothering her. This suggests that BT's framework for understanding his mother's absence in his life is that she was murdered. His school teachers have reported that the school conducts educational talks on "stranger-danger". BT has been exposed to these talks. It is possible that this information has given BT some tools to explain his mother's absence, possibly even her death. Perhaps at another point in his life, as he learns new things, his explanation may change. As Piper (1999 in Milner & Carolin, 1999) points out, a child's explanations are largely influenced by what s/he has been exposed to in their limited lives. Thus, their explanations for events may not be the objective truth, but it is valid in terms of what the child knows up to that stage in life.

Strangers are "bad" and must be avoided. In the absence of understanding the actual reasons he has no contact with his mother, her death at the hands of "bad" people must seem plausible. At the same time, his choice of explanation is somewhat significant within the context of HIV/AIDS. He could have chosen some other explanation for the loss of his mother. Opting for the stranger option may be influenced by what he was exposed to at school at the time, yet it also has a metaphoric resonance with HIV/AIDS. The virus that causes AIDS may be viewed as a "stranger" attacking the human body. Hence there appears to be some relevance in BT's choice.

Reinforcing the strength and value of the sun

In this drawing, BT has used bright oranges: the colours of the sun. Again, he speaks about the positive value of the sun for the children at the home where he stays. He contrasts this with the undesirable clouds. Almost as a way of underscoring the desirability of the sun and the heat, he has drawn some scribbled orange lines between the sun and the house. These represent heat and fire. In the presence of such intense sunlight and heat, the clouds have no chance: "When the clouds come back, and then all the suns is gonna fight with the clouds, and the clouds is gonna be dead." In this context, fire is not dangerous; it is necessary to overcome the "bad" clouds.

The sun and heat are so intense in this drawing that they appear to have eradicated all the "bad" elements. The strength of the sun has enabled him to entertain the idea of living with his family (mother, father and siblings) and being cared for by his mother. The sun obviously plays an important positive role in his life. When the sun is shining, BT can play outside, go to the beach and generally have fun. He imagines that if the sun is strong enough, it will bring him what he deeply desires: a caring relationship with a living mother and family.

Drawing #9, Week 8

A happy sun

BT has moved on from depicting a sun that fights off the bad elements to a sun that is simply "happy." It is also drawn in green pencil, rather than the usual bold orange and yellow. This may denote that, for the time being, he has managed to express all he has needed to about the need to combat the things that cause harm and unhappiness.

The value of kinship: Protection

The rather unusual looking green structure with the red outline in the centre of the page is a house. In his story about this drawing, BT lives in this house with a male friend. This friend is "big and strong" and will grow up to be a "strong daddy" who will look after him. This suggests a wish to be protected and taken care of. The friend he names has the same name as a boy who attends the same school as BT. According to BT's teachers, this boy is physically bigger than most of the other the children at the school. This boy and his family are homeless. He is admired by many of the children at the school, and seems to have been idealised by BT. It is possible that BT has selected this boy to live with him in this house, as he perceives this boy to be strong and resilient, given his size and the fact that he survives on the street.

This boy will help to protect BT against "stranger" attacks. In his story, BT tells of how the strangers may manage to penetrate the house and tie him up. However, he will overcome them and call the "police" who will take the strangers "to jail for twenty hundred years!" As in Drawings #5 and #6, it is with the help and support of others that the bad elements are overcome.

Friendship as a response to parental loss

BT says that the boy has come to live with him in this house because BT's mother died. After being "burnt in a fire", his mother was taken to hospital in an "ambulance." She died there. BT felt "sad" about this loss, and asked the boy's mother whether he could live with BT. BT seems to express that friendship may help to alleviate some of the sadness associated with parental loss.

It is also significant that he has not depicted his mother as alive, as he did in the previous drawing. Here, he acknowledges the loss of his mother, and attempts to manage it.

Emotional vulnerability

It is noteworthy that BT indicates a need for protection, as he is one of the bigger children at the home. By 'importing' a figure that is even bigger than he to live with him, it may be interpreted that the vulnerability he refers to here is not physical. The suggestion that refers to his emotional vulnerability is reinforced by his reference to his "sad" state at the loss of his mother, and the fact that he wanted the boy to live with him "because" his mother died. This also suggests that the "strangers" are symbolic for attacks on his physical and emotional self.

Drawing #10, Week 9

This drawing is an almost exact replica of Drawing #8. The only difference is the colours that are used. This suggests that he applies less effort in this drawing. His use of coloured pencils rather than pastel crayons also implies reduced energy invested in the drawing process. His attitude to the session on the whole is consistent with these interpretations based on his use of drawing materials and the repetition of images: he was reluctant to draw, which is unusual for him. He also repeatedly asked when the session was going to end.

The need for friendship reiterated

BT reinforces the need for friendship in his life. He asks the researcher to write the name of a friend of his on the page. This girl, he said, lives with him in the house he has drawn. Immediately after speaking about this friend, he tells the researcher that his mother has died in the hospital. There is, once more, an association between the death of his mother and the presence of a friend in his life.

Terror

BT tells of a scene of terror, where a bomb exploded in a restaurant and killed one of the children from the home. This did not happen in reality, and it seems therefore, that BT has used what he knows to explain the death of one of the children at the home. He also demonstrates an awareness of the emotional reaction to death at the home: sadness.

The fact that BT chooses an act of terror to explain the child's death is significant as it suggests that this is a terrifying and catastrophic event for him.

Assessing the merits of his symbols of strength and protection

BT engages the researcher in a dialogue about the merits of the sun, Jesus and wolves (wild dogs). He seems intent on determining the power of these symbols. He has used and alluded to these figures as symbols of power, might and protection in his life experience and perceptual universe. This may be interpreted as a need to ascertain the real, objective value of these symbols, almost as if assessing their worth in the real world. He may want to secure support and protection for himself.

The value of clinical research

The aforementioned question-and-answer dialogue may be relevant in this penultimate session with the researcher. He may have experienced the research space as a place to gain clarity on things for himself. This highlights the benefits of the researcher-participant relationship, as well as responsibly designed clinical research.

Drawing #11, Week 10 (Final session)

BT appeared pensive and reflective during this session. He was also more subdued than before. When the researcher asked him whether he was aware this was the last session, he replied, "Yes," whereas before, he always asked, "Why?" This suggests a tacit acceptance of

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the termination. He acknowledges that sadness is expressed at the termination of the research process, but is unable to own these feelings for himself. Instead, he informs the researcher that one of the other participants said she would feel sad. This is accepted as his way of expressing his own sadness.

This final drawing is extremely faint, and Judd (1989) is recalled as commenting that fainter drawings imply reduced investment. BT's withdrawal would be an appropriate indication of the termination of the sessions.

In some way, this drawing harks back to the drawing #1, in that it has a squiggly line drawn around the house giving the appearance of something that is enclosed or encapsulated. This is a similar visual concept to the "circle house" of Drawing #1, and may denote that things have come 'full circle' as it were in this process.

Separation, loss, illness and death

Unlike Drawing #1 that seemed to symbolise containment and harmony, the house in this final drawing is under attack. The squiggly circle around the house is a ring of fire. A bomb has fallen on the house, destroying it and the children inside. Like the terror of the bomb blast that he spoke about in the penultimate session, BT signifies that there is terror associated with the final session, and thus, with separation and loss, for him. It is not just separation from the researcher and research context that has evoked feelings of terror and mayhem, but separation of children from their mothers, between BT and his mother. Separation from their mothers has seemingly rendered the children vulnerable:

> **BT:** There were a bomb come, and then the children… And their mommy went away, and then the children was left – these big children. And when the bomb come, they look down, and the bomb went in the door, and then they die. And their mommy was crying…

In previous stories BT has told, the mother or his mother died. Here, the tables are turned and the children have died. In the previous week's session he mentioned for the first time the death of a child from the home. Here, more than one child living in this house has died. This is strongly suggestive of BT's awareness of the AIDS-related deaths at the home where he lives. It is possible that he has linked the children's separation from their mothers with their deaths. The devastation is caused by separation and loss, not necessarily by illness. However,

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the "bomb" in his story is indicative of an event that is unexpected and terrifying that leads to the children's demise: something is not entirely predictable. This would be more consistent with the course of HIV infection. Therefore, this child expresses an awareness of the terror of separation and loss as well as the terror of HIV/AIDS illness. Congruent with his and others' reality, he has tied together the events of parental loss, HIV/AIDS and the (premature) deaths of the children at the home.

Survival

Despite the bomb, one of the children survived. This child had gone away "in the taxi" with the mother. All the other children died in hospital. This may allude to the reality that when the children who have AIDS become severely ill, they may be taken to hospital where some have died. The child that survived is most likely an allusion to the HIV-positive children at the home who are still alive after many years, and many illness episodes or 'attacks.' BT is one of these children. The child in his story that survived did so because that child went away with the mother. This may signify BT's perception that the children that survive living with HIV/AIDS are appropriately and adequately cared for.

Hospitals and death

In one of the preceding weeks, BT mentioned that his own mother died when she was taken to the hospital. Here, he mentions that the children who were in bomb-blast die when they go to the hospital. He then speaks about the "dirty apples" and "dirty food" in the hospital." Perhaps due to fact that some of the children from the home have died when they went to hospital, BT has come to associate hospital admission with death.

The irony of HIV/AIDS

BT reveals that the reason the children could not get out of the bombed house was that their mother had placed a "rock" in front of the door. She had placed the rock there to protect the children from the "strangers." It is ironic that her very efforts to protect the lives of her children contributed to their demise. This scenario seems to demonstrate BT's awareness of the irony that children living with HIV/AIDS face: regardless of how much they are cared for, they are still vulnerable to the ravages of their disease. Ultimately, they will not be protected from death.

Appropriate grieving

BT: [The sun is s]ad because the children die. And the mommy was crying.

Through his story, BT expresses an appropriate emotional response to death: sadness. His final statement is one that reflects the reality of living with HIV/AIDS: that death is ultimately unavoidable, but also that survival is possible.

4.4. Analysis and Discussion: Participant No. 3 – CU

General Comments

Refer to Appendix G for A brief chronological history of significant life events for CU and to Appendix H for her drawing series.

Initially, this child was reluctant to participate. She participated more spontaneously and enthusiastically when the children were seen as a group in the first few sessions. She appeared shy and hesitant when on her own, but soon warmed to the space and activities. She was eventually able to use the sessions in a way that suited her.

If there is one word that summarises this child's process across the ten weeks of data collection, it is "transformation." She used the space to express and work through an issue that was reported to have been bothering her for a few years. This issue had to do with her anxiety. As the ensuing discussion will reveal, her anxiety is interpreted through the lens of the different dimensions of her life. After having presented and explored the fantasy that seemed to contain her anxiety, CU spontaneously decided one week that she did not need or want to depict this matter any longer. At the same time, one of the caregivers from her home reported a shift in CU's behaviour, indicating that some of her anxiety was alleviated.

One of the more seminal experiences of this child's life is that in the year prior to the commencement of the research process, she very nearly died due to becoming severely ill while away on a holiday with her maternal uncle. Those looking after her at the home expected her to die and prepared accordingly. Thus, no preparations were made for CU to return to school that year. Contrary to everyone's expectations, CU woke up one morning after a number of weeks in bed, asking for her school shoes. She wanted to go to school. From that day, she gradually and almost miraculously recovered. It appeared that this child was not ready to die just yet. Something pulled her back into life.

The other main theme depicted in CU's drawing series is the relationship between the sun and the clouds. This relationship will be mapped throughout the ensuing discussion.

CU's drawings are as much an honest and sincere expression of her experiences, both in her fantasy life and in her external reality.

Drawing #1, Week 1

Opening statement: Containment, security and belonging

CU depicts a scenario of activity and interaction amongst members of a family living in a house. She includes herself as part of the family she talks about, which denotes a sense of belonging to a family. This family may refer to all the adults and children living at the children's home; it may also refer to a maternal uncle, aunt and cousins she recently made contact with. In addition to the sense of belonging conveyed through the scenario she depicts, there are also suggestions of domestic security and protection from potentially harmful external elements: the "cold" outside.

Ascension

Visually, the dark blue sky appears as if it is overwhelming the house; it occludes the top of the roof of the house. The house looks as if it is ascending into, or being swallowed up, by this dark blue sky. This is visually suggestive of two things: (1) CU's experience of the extraneous factors and circumstances of her life is that it is sometimes overwhelming, and that it occasionally occludes or darkens the more positive experiences of home and family life; and (2) an ascension into heaven. The latter interpretation is valid in the context of the fact that CU was very close to dying approximately eight months prior to participation in this study.

Malchiodi (1998) has commented on references made by Bach (1966) and Perkins (1977) to the "transpersonal aspects" (p. 213) of the experiences of dying children as expressed through their drawings. The two authors cited by Malchiodi (1998) have identified that children on the brink of death or living with a life-threatening condition tend to draw windows in the eaves of their drawings of houses. Bach (1966) has called these "'soul windows'" (in Malchiodi, 1998, p. 213). Bach's usage of this term alludes to Swiss mythology which says that the "soul window" of a house is the window through which a dead person leaves the house. While CU and the researcher did not speak about the two orange shapes on the roof of the house in this drawing, there is a resonance in this aspect of her drawing with the notion of the "soul window" as spoken about by Bach (1966) and Perkins (1977) (in Malchiodi, 1998) and CU's real, lived through experience of almost dying at the end of 2001/ beginning of 2002. In the next drawing (#2), the roof of the house drawn also exhibits two darker red features that, symbolically, may be construed as "soul windows."

Drawing #2, Week 2

Visually, this drawing appears much lighter than the previous drawing. CU used coloured in this drawing, whereas she used pastel crayons in the first drawing, which created a more intense and looming appearance.

Visibility versus Invisibility

As in Drawing #1, CU speaks about the presence of people inside the house she has drawn, in the absence of actually having drawn any human figures. The phenomenon of living with HIV/AIDS means that the disease is always present but not always visible. In some way, the juxtaposition of the absence of human figures from CU's drawings with the presence of these figures in her descriptions of her drawings is similar to the reality of the disease in the lives of many of those affected and infected, including CU and the children residing at the children's home where she stays.

Connection and belonging

Consistent with drawing #1, CU conveys a sense of belonging in this drawing through her references to "family" and "friends" who live in the house. This is developed further in this drawing when CU describes herself riding a bicycle belonging to one of the other children at the home. She seems to convey her connectedness or relationship with this child, and possibly other children, through using something that belongs to him: "I am riding B's blue bike."

Sun and Clouds, Part I: Neither here nor there

Here, the sun and clouds are introduced for the first time. As mentioned under "General Comments" above the trajectory of the relationship between these two features in CU's drawing series will be mapped henceforth. Here, the manner in which both these features are presented in the drawings versus the way in which she speaks about them in her description of the drawing is suggestive of ambivalence about something. The sun is placed at the top of the page, yet she intimates that it is "going down"; the clouds are still visible on the left hand side of the page, yet she says that she has "rubbed them out." It is postulated that this ambivalence relates to her survival and the role and position of potentially occluding and threatening elements in her life, respectively.

From ascent to descent

Drawing #1 gave the impression of the house ascending into the heavens. The possible transpersonal meaning of this has been discussed above. In this drawing, CU has the following to say about the sun she has drawn:

CU: The sun is going down and down and down and down! ...

Bach (1990) and Malchiodi (1998) have commented on the motif of the sun in the drawings of chronically ill children. The movement of the sun across the sky is used as a metaphor for movement of a person across the lifespan. Accordingly, the setting of the sun is likened to the final years of life and the descent into death. Furthermore, the term "twilight years" is used by many people in a way that refers to people who are in the latter years of their lives. Thus, a setting sun or a sun that is "going down" evokes ideas of death and ending, or nearing the end of a life. Within the context of CU's near death experience, the descending sun in this drawing may be a reference to this very part of her life. This idea of a transpersonal reference to death is reinforced by the ascending house and orange features on the roof of the house in the preceding drawing as well as the darker red features on the roof in Drawing #2. As mentioned under the foregoing heading *"Sun and Clouds: Part I"* the descending movement of the sun in CU's description is significant as it contradicts the positioning of the sun at the top of the page in this drawing. This suggests a possible ambivalence about CU's perception of her own position in life, given that she is alive, despite having come very close to death.

Death averted

As discussed, drawing #1 has a looming appearance and is visually suggestive of an ascension. By contrast, Drawing #2 is visually less suspended and there are more features that evoke a sense of groundedness (the house stands on a groundline) and vitality (the rooted flower) being represented. Again, this cannot be ignored as it can be read as a metaphor for the fact that CU is still alive and has averted death.

Drawing #3, Week 3

It's possible to love even monsters and pigs

CU's focus in this drawing are the two figures on the right side of the page. The one she calls a "monster", the other "a big fat pig." In this session where the other two participants are still present, CU is helped by them to describe the relationship between the two figures. It is a relationship of affection and romance: "...[T]hey love each other," she says. By the end of her

verbal description, the monster has transformed into one of the other participants, YN. There is a playful and frivolous banter amongst the three children about the relationship between these two figures. It may be safer for CU to address her perceptions and ideas about human relating through less-threatening, non-human figures. This approach is not unusual for a seven-year-old child (Malchiodi, 1998).

At the same time, it may be that CU perceives herself and others like her as "monsters", due to being infected with HIV. There are times when the children who are infected break out in sores and rashes, develop hoarse coughs, become radically emaciated, do not grow as fast or as tall as their healthier, non-infected peers. In short, they can look different as well as are different from other children, even when they are asymptomatic. Beyond the surface, their difference lies in the fact that they do not have parents, do not live with their parents, live in a children's home, are looked after by nuns, have to take medication and are HIV-positive. They are also sufficiently different to have elicited interest – albeit with good intentions – from external agencies, international sponsors, volunteers, entertainers and researchers. CU may be expressing her experience and perception of her difference through the figures of the "monster" and the "big fat pig." She speaks about them endearingly and playfully, evoking a sense that, even though they are different, they are lovable and capable of love. It is in the capacity to love and be loved that the children who are infected with HIV are not different, but the same as other non-infected children and individuals.

Malchiodi (1998, p. 201) has commented that younger children (three to eight year olds) tend to articulate their perception of illness in their drawings as shapes and figures that they refer to as "monsters", and that have "animal-like" features and "nonhuman" aspects. Of children's depictions of illness, she says: "…[C]hildren's concepts of illness go from external (monsters) to internal (actual disease-causing cells in the body), and their images of these external and internal causes changes with age and exposure to information on how one becomes sick (Malchiodi, 1998, p. 202)." This reinforces the notion that the "monster" and the "pig" in CU's drawing may indeed be her current perception and understanding of her illness. Furthermore, the juxtaposition of the tall and thin figure (the "monster") and the shorter, fatter figure (the "big fat pig") may be CU's way of expressing some of the changes her own body went through when she became severely ill over 2001/2002: she lost a substantial amount of weight. This, to her, may have been a change that rendered her "monstrous." Through the

relationship between these two faces or symbols of her illness, she seems to be saying that it is possible to love and be loved as a person living with HIV/AIDS.

Splitting: Protecting vulnerability

In this drawing, visually speaking, there are many signs of halving, splitting or two-ness: the two figures; the abstract-looking oval feature (which CU calls a "cat") above the two figures is split vertically in two; the house on the left side of the page is also split vertically in two; the body of the purple figure is split vertically in half; the cloud at the top of the page is split vertically in half by a wavy line; the sun and the cloud are separated or 'split' from each other by equidistant positioning relative to the "cat"; the mouth of the sun is split both vertically and horizontally; and when the page is folded exactly along its vertical centre line, the entire drawing is 'split' in two, with the house occupying the left side of the page and all the other features occupying the right side of the page.

In the context of psychoanalysis and object relations theory, the word "splitting" has a very specific meaning that may have relevance for an understanding of CU's use of halving or splitting in this and later drawings. A very basic understanding of this concept is extracted from Ogden's (1990, p. 44) description of this aspect of Kleinian theory: in order to protect the "endangering" from the "endangered" parts of experience, the infant will split life-enhancing (endangered) from destructive (endangering) elements and experiences. Ogden (1990, p. 44) likens the biological instinct of the young of certain animal species to "separate" themselves from danger in the form of predators to the instinct that a human infant, child or adult has to separate itself from biological and psychological (life-threatening) danger. Various mechanisms or "defensive activities" (Ogden, 1990, p. 45) are deployed to this end.

While CU does not explicate the symbolism or significance of the sun or the cloud in this drawing, her fellow participants have: in BT's drawings, the clouds are symbols of danger and destruction, while the sun is a symbol of strength and resourcefulness. YN also uses the sun as a symbol of wellness. In this session where the three participants still share the space and time, and where they contribute to one another's descriptions of the drawings, it is not unlikely that they also share symbolic meanings. This, and the fact that the meaning of the sun as a good element and clouds as a bad element becomes clearer in later drawings, suggests that this is the symbolic meaning these features hold in this drawing. In this drawing of CU, the sun is separated or 'split' from the cloud, suggesting a separation of something that may

be dangerous from something that is endangered or a source of health. The other 'splits' in the drawing support the idea that this drawing is, on some level, an expression or analogy of the psychoanalytic notion of "splitting" as explicated above. The implication is that this drawing also depicts CU's protection of herself from the more destructive or endangering aspects of her circumstances and her experience. In the context of her life, one of the more obvious "endangering" or life-threatening elements is her illness. Indeed, she has experienced the potential of her illness to obstruct life. It has already been ascertained above in under the heading "*It is possible to even love monsters and pigs*" that CU has depicted images of her illness in this drawing. The many 'splits' in this drawing may thus be an expression of CU's need to protect herself from the biological and psychological dangers of living with HIV/AIDS.

Change and growth from illness and adversity

On the dress of the taller figure in the drawing, is an image of a butterfly. In the subsequent session, CU verifies that this is in fact a butterfly. She explains that the butterfly is trying to chase and scare the "monster" (which she later refers to as "The Ticklish Lady") away. Dorothy Judd (1989) in her book on working with bereaved and terminally ill children, *Give sorrow words: working with a dying child*, explores the idea that for some children, living with a life-threatening condition facilitates emotional and psychological growth and maturity. The notion of developing resilience and adaptive responsiveness to adverse conditions like chronic illnesses has also been addressed in the **Literature Review** section of this thesis. Judd (1989) draws upon the work of Elizabeth Kubler-Ross (1975) to clarify how children with chronic illnesses use their illness experiences to grow and to change: "Kubler-Ross used the imagery of a cocoon and a butterfly: the child's ill body is like a cocoon, or chrysalis, and soon [s/]he will leave it behind, becoming the butterfly [s/]he always was, and go on."

If this monster in CU's drawing is indeed a symbol of her illness as suggested in the opening paragraphs of the analysis of this drawing above, then what Kubler-Ross had to say about chronic illness being a conduit of change for some children, may indeed be true for CU. The butterfly in her drawing may be a symbol of the change and growth she has undergone as a result of her illness and as a result of surviving the ravages of her illness. This is reinforced by the fact that the butterfly, as small as it is, has the ability to scare the monster away. This is a likely indication of CU's resilience.

In addition to this, the oval-shaped feature above the two figures in the drawing that CU has called a "cat" has a cocoon-like appearance. Given CU's ability to draw figures with faces and smaller features and details, it is surprising that this oval feature is not more distinguishable as a cat. Furth (1988) comments that abstract features in children's drawings are suggestive of unformed ideas, feelings or perceptions. The abstract quality of this oval feature in CU's drawing is therefore suggestive of something she has not yet clearly defined or understood for herself. It stands as a symbol of something that is in the process of developing and taking shape or form, much like the process that occurs inside a cocoon or chrysalis when a caterpillar metamorphoses into a butterfly.

Under the section on **General Comments** in the introduction to this analysis and discussion of CU's drawings, it was highlighted that one of the central themes of CU's drawings and drawing process, is transformation or change. While this theme will become clearer in the analysis that follows, her image of the butterfly in this drawing is already a harbinger of what is to come.

Drawing #4, Week 4
The Ticklish Lady
In Drawing #3, the tall, thin figure was referred to as a "monster." Here, in drawing #4, a similar looking figure is depicted and is given a gender and an identity. Also, confirming the interpretation of this figure as a symbol of her illness – the result of which CU lost much weight – CU draws attention to the body image of this as well as the other figure in the drawing:

> **CU:** Once upon a time, there was a skinny lady… And there's a tree and a sun, and there's a skinny and a fat!
> **R:** And who is the skinny?
> **YN:** (answers for CU) The Ticklish Lady.
> **CU:** Yes.
> **R:** Who?
> **CU:** The Ticklish Lady.

Further along, in a discussion that reveals that the Ticklish Lady is not just CU's property, but has been freely shared with the other children at the home, CU and YN tell the story of The Ticklish Lady. What follows is an edited version of this excitable discussion:

R: ...And what are these things on [her] head?

CU: It's brown and black and brown and black! ... ...It's long hair!

R: And I see this Ticklish Lady has no arms...

YN: She does have!

R: Does that mean she can't tickle you?

CU: She can. She goes like this (CU shows how the Ticklish Lady would put her arms under her sweater.)

R: So, she hides her arms away. And when does she pull them out?

CU: No, she doesn't pull them out. And when she's thins, she walks like this (CU demonstrates how the Ticklish Lady walks with her arms under her clothing).

R: And so she tickles you from under the jersey?

YN: Yes, she does.

CU: She doesn't even have a jersey.

R: And how does she make you feel?

CU: She makes me sad... And cross – for crying. And I can't get to sleep.

YN: And very scared. [The Ticklish Lady] loves [the] dark.

CU: Cos she doesn't want you to see her... She's too scared.

R: Who else saw her?

CU: (she mentions the names of about five other children who live with her at the home)

It was a challenge to figure out what the Ticklish Lady represents for CU. This figure seems not to have any obvious counterpart in her waking reality. The matter was thoroughly investigated at the home, and it was concluded that this figure was imaginary, and possibly an image emerging from CU's fears of the dark. In the current investigation and analysis, this and other possible explanations have been considered. Once again, no single explanation is more correct or more complete than any other. The complex and multidimensional nature of the children's lives implies that the different perspectives offered here are treated as components of a larger whole.

Ultimately, whichever explanation is preferred, the emotions associated with this figure cannot be disputed, since CU openly names them: sadness, anger and fear or anxiety. Thus, the Ticklish Lady, at the very least, is a figure that manifests when these feelings predominate.

Most authors of bereavement, mourning and loss across the lifespan (e.g.Judd, 1989; Kubler-Ross, 1975) agree that there are generally four or five stages that a person goes through in response to a significant loss. Regardless of what the stages are called, there seems to be agreement that at some point, a grieving person will experience depression, sadness despair, anger, resentment and anxiety. People who are faced with the certainty of a premature mortality, such as those diagnosed with terminal illnesses, may also go through a mourning process while still alive (Bertoia, 1993). These people may exhibit fear and anxiety related to their impending death. These are all feelings that are expressed by CU in relation to the Ticklish Lady. Therefore, it is possible that this figure is a manifestation of CU's grieving process over the AIDS-related death of her mother when she was a year and a half old, the loss through AIDS-related deaths of some of the other children at the home where she stays and her own impending death.

Malchiodi (1998) recommends that the art of children who have experienced significant losses such as those of parents or siblings, be approached with a willingness to understand their art from what she calls a "spiritual" (p. 193) perspective. She defines these aspects of children's drawings as "...content or characteristics that reflect children's experience of God or intangible entities such as angels, religious figures, or ghosts and the supernatural, and experiences associated with church or religion (Malchiodi, 1998, p. 193)." Of course, there are many other definitions of spirituality, but this lies beyond the domain of this study. The part of Malchiodi's discussion on spirituality in children's drawings that may have value for understanding CU's Ticklish Lady, is where she comments that children may depict deceased relatives as angels or fears that the "ghost" of this person will return and materialise in their bedrooms. It is this latter aspect that evokes an association with CU's Ticklish Lady who comes at night and of whom she is afraid. It may be possible, then, that the Ticklish Lady is the imaginary manifestation of some of the emotional components of CU's grieving, as discussed. This figure may simultaneously represent the kind of fear that Malchiodi (1998) refers to: CU's fears that her dead mother may come back to her as a ghost.

Perhaps a less esoteric explanation may be that CU has fears and anxieties specifically related to the death of her mother that have inspired the configuration of her Ticklish Lady fantasy. This figure may be about her wish that her mother were still alive as well as about her anxieties connected to her mother's death. These anxieties may be part of her grieving process, but may also be part of the fears she has about being in the world without a mother to

look after and guide her. It may also be about the anxiety and fear she has already experienced as motherless child living with HIV/AIDS. She may have experienced pain – both physical and emotional – as an OCWA. This may help to explain why the Ticklish Lady's tickling hurts and why there is such a strong reaction against her, not just from CU, but from many of the other children at the home, who all have fears about being OCWA's. Further validation for the idea that the Ticklish Lady may also be a manifestation of CU's fears about her illness, is that her arms and hands are hidden under her clothes. The implication is that what she uses to inflict pain is invisible and hence, her attacks are unpredictable. This may leave CU in a hyper-vigilant state – a state of heightened anxiety. In many respects, as was discussed in the **Literature Review** section of this thesis, it is the unpredictability of the illness that many people infected with and affected by HIV and other chronic illnesses, find most devastating (Duggan, 1994; Koocher, 1984 in Midence, 1994). The nature of HIV infection is that it is not apparent that someone is infected with HIV, until they are symptomatic. In this way, the virus is like the Ticklish Lady: its ability to harm is hidden and its attacks are unanticipated as a result.

The "fat mama": A possible fantasy of health

The identity of the second figure in the drawing changes through CU's description from initially being the Ticklish Lady's boyfriend, to being her father, to being described as "a fat mama." This figure looks very similar to "the big fat pig" in the previous drawing. Once again, CU has juxtaposed a thin figure with a fat figure. In the previous drawing, it was suggested that this was, partly, a metaphor for the juxtaposition of illness and health, respectively, within the context of HIV infection. The naming of this figure in the current drawing as a "fat mama" reinforces this notion that the thinner figure represents illness and the fatter figure, health. There are indications, as discussed under the previous heading, that the Ticklish Lady may be symbolic of CU's deceased mother. By calling the fatter figure a "boyfriend", then "father", then "mama" (mother), CU identifies this figure with familial relationships. Consequently, this figure may represent that which is healthy and desirable and stands in contrast with the absence of these kinds of relationships from her life. Within the context of weight loss as a symptom of HIV infection in general as well as in CU's own experience of the illness, she may perceive a fat mother to be healthier than a thin mother. Hence the foregoing hypothesis that the two figures in this drawing are a repeat expression of the juxtaposition of health and illness in CU's drawings.

Health is not absolute

In CU's experience, health is not an absolute. Through her depiction of the fatter figure in the drawing, she displays an awareness that even no one is ever in perfect health. This would be very true for her experience of her own health and illness and that of other children around her. Having interpreted the fatter figure as a representation of healthier parts of her experience and desires, it is important to note that this figure is not in perfect health. Indeed, just in appearance, this figure looks somewhat disfigured. When asked about the appearance of this figure, CU informs the researcher that "[h]e hurt himself on his eye." The signs of imperfection are prevalent and apparent. This is suggests that pain – at least of the physical variety – is a very real and unrelenting aspect of CU's experience.

Vulnerability and resilience

CU presents a similar process to one of the other participants, BT. In drawing #5 (Week 5), BT expressed a story of attack, counter-attack and victory. This was discussed earlier under the analysis of his drawings. Here, CU speaks of a similar process vis-à-vis the Ticklish Lady. In CU's story, the attack by this figure is countered by one of the other children from the children's home. The end result is that the Ticklish Lady is beaten. The use of different metaphors to express a similar process or dynamic in the two participants' drawings, is highly suggestive of a shared experience in relation to their HIV illness: through the use of drugs, caring and the children's intrinsic fighting spirit, they have survived many mild to severe illness episodes in their lives thus far. As mentioned, CU's most recent episode has been her worst to date. This survival experience is no doubt expressed in her story of the Ticklish Lady. It is a story of resilience being generated from adversity and vulnerability. CU's process of fighting back against the 'enemy' and achieving victory is reflected in the following extract of her description of the current drawing:

> R: …[T]ell me about when [the Ticklish Lady] comes.
>
> CU: [This other girl at the home] comes behind her, and smack her on her bum, and then [that girl] runs to her room, and we're fast asleep, and then [the girl] says, "What's that?" And then [the Ticklish Lady] went like this (CU demonstrates with her hands what the Ticklish Lady does). And she almost tickled me, and so [that girl] smacked her and …almost bit her… … [That girl] is not scared of [the Ticklish Lady].
>
> R: …[This child] sounds quite brave.
>
> CU: She sometimes gets a knife in the kitchen and she sometimes [threatens the Ticklish Lady with the knife].

YN: [This girl] did that before and that's why [the Ticklish Lady] is not coming in again!

CU: Because she thinks [that girl] is here…

Protectiveness

CU displays a tendency for protecting that which is hurt, as she explains that the tree in the drawing is there for the rotund figure with the sore eye to sit under. She also explains that if the Ticklish Lady goes under the tree, bees will emerge to sting her.

Drawing #5, Week 5

A time for healing?

For the first time, CU introduces distinctly human figures into her drawings. This suggests that the time for monsters, pigs, Ticklish Ladies and other creatures that evoke fear, sadness, anger and pain, has passed and that CU has moved into a different phase of her drawing process. This may very well be a phase of healing, resolution and transformation, as is suggested by the appearance of what is described as a yellow "plaster" on the head of the figure in the picture.

There may be an implicit identification with the figure in the drawing on CU's part, and it may be less intimidating for CU to speak about her own experiences through the character of someone like her. This identification is extrapolated from the green dress the figure is wearing. On the day of the session, CU herself was wearing a green dress, and intimated to the researcher that green is her favourite colour.

Seeking help for bleeding wounds

According to CU, one of the people living in the house is one of the main caregivers linked to the children's home. The girl in the picture is one of the children who, in reality, lives with this caregiver. In reality, this pair along with four other children were selected to live in a specially created home that is meant to approximate a 'normal' family home in the sense that it is a typical suburban house, there are only six – as opposed to twenty-six – people living in the house, and a caregiver lives with the children in the house. The caregiver also remains the same person over time. This is unlike the set-up at the larger children's home where caregivers may come and go periodically and unexpectedly.

In her story about this drawing, the girl has hurt herself; she is bleeding:

R: What happened [to the girl]?

CU: She had blood (as she says this, CU picks up a red pencil, and shades darker red on the forehead of the figure in the drawing).

The shading is interpreted as a kind of underscoring of the fact that the wound is bleeding. This suggests an awareness on some level of the significance of blood in the context of HIV infection and transmission, as the girl in her story is HIV-positive in reality. The girl's wound may be seen as a generic wounding that needs adult attention. The blood conjures up impressions that the wounding is blood-related, as emotional and physical wounding with HIV/AIDS is. The fact that the girl in CU's story is finally helped suggests that CU has observed and experienced the children at the home receiving appropriate help from their adult caregivers.

A depiction of lived reality

In her story, CU describes that the girl hurt herself and sought help from the caregiver inside the house. When the girl arrived at the door of the house, it was locked. This led her to cry. When the caregiver saw her through the window, she opened the door and was let inside. She ultimately felt safe inside the house.

In many ways, this story mimics a real event in the lives of the children at the home. As mentioned, a handful of the children were selected to live with a caregiver in a family-sized home in a suburban area. Many of the adult workers and the children at the home saw this as a positive, healthy step for these children. (YN also alluded to this event in her drawings, as was previously discussed). Here, CU almost undoubtedly represents this event or her perception of this event. This is gleaned from the fact that the children and caregiver she names in her story are exactly the same children and caregiver who went to live in this house. CU implies that her perception of this event is that there are children who are hurting and wounded. These children have sought help from the caregivers at the home and were responded to in a positive manner. The clouds in this drawing may thus be unhappy as there has been a very real triumph for the children.

Sun and Clouds, Part II: A dissonant relationship

CU clearly expresses that the relationship between the sun and clouds is devoid of love: "[The clouds] don't love the sun." She explains that the clouds are "too sad" about the presence of the sun. If the yellow sun is a symbol of health and goodness, as in the drawings of the other

two participants, this reinforces the notion that this drawing is about the triumph of health and resilience over danger.

In terms of the drawing being a depiction of the real event of the departure of some of the children from the home as discussed above, it is postulated that the sad cloud is also an expression of CU's own sadness at the loss of these children from the home, as well as her sadness about not having been selected for residence in this desirable domestic set up.

Putting on a brave face
Even though the girl in the story has hurt herself and is bleeding, CU explains that she is "laughing... cos it wasn't so sore." This suggests that in CU's experience, some of the children respond to their wounding with courage.

Separation and reunion
Apart from the depiction of helping the wounded child, CU's story also highlights a process of separation or alienation and subsequent reunion. Initially, the girl in the story is alienated from the rest of the people in the story: she is outside the house, while the others are inside. Through the "crying" of the girl locked out of the house, CU expresses that sadness and despair are associated with separation. It is likely that CU herself has experienced these feelings as a result of the separations and losses in her life.

When those inside the house realise that the girl is outside, they unlock the door and let her inside; she is reunited with them. A dynamic of disconnection and connection is a feature of CU's lived reality, in that she was separated from her mother when her mother died; she has been separated from some of the children at the home through death and other circumstances; she has been separated and reunited with some of the caregivers working at the children's home who have come and gone intermittently. Perhaps due to these experiences, CU is ambivalent about connections with other people. This is suggested through the absence of arms from the figure of the girl in the drawing when CU first presents it. While she talks about her drawing, she suddenly realises that she has omitted the arms and quickly adds them to the figure. She tells the researcher that without arms, the girl would not be able to hug the others. The act of hugging is suggestive of affectionate reaching out and connection between people. As soon as CU has drawn arms on the figure of the girl in the picture, the story takes a

turn and the girl is united with the others inside the house. Thus, CU emphasises the value of having the resources in facilitating interpersonal connections.

Drawing #6, Week 6

An expression of loss and pain

The pain of separation introduced through the previous drawing is magnified in this drawing, as her opening statement indicates: "It's a sad sun and sad children." The story behind the sadness is that the two figures in the drawing are being separated. The taller figure is the mother and the shorter one, the child of this mother. The child is going away to a camp. This is the reason the two of them are in such a desperate state of despair. This story and drawing are a likely analogy of CU's lived experience of separation from her own mother when her mother died. The age of the child in the drawing (five years) is the same age that CU was at when efforts to place her with a foster family came to nought, and it was decided to keep her in residence at the children's home. It is thus possible that the drawing is a frank representation of CU's despair around that time at the deprivation and loss of what could have been.

Separation is also associated with anger for CU, as the following abridged extract of dialogue demonstrates. This strongly implies that CU is expressing a process of grieving, as discussed earlier regarding Drawing #4 (Week 4):

R:	…Tell me why the cloud is happy.
CU:	Because it's going over the sun.
R:	… … How does that make the sun feel?
CU:	Angry.
R:	…What is the sun going to do with that anger?
CU:	Burn [the cloud].

Apart from the sadness of the separation, CU also implies that for her, separation is associated with danger, fear and death: there are "bad guys" at the camp the child is going to who have the capacity to "kill you." This may be an expression of CU's own experience of separation from her mother through death. The "bad guys" may be her fantasy of death and thus another way in which she understands her illness.

This drawing is possibly the starkest in appearance. The only colour in the drawing is the yellow of the sun. This relative absence of colour suggests a withdrawn stance. This is consistent with the depressive affective content of the story and drawing.

Sun and Clouds, Part III: Taking sides

The symbolism of the sun and clouds is refined in this drawing, as it is clear that the sun reflects the feelings of the human figures, and very likely, CU's own feelings. The cloud is happy amidst this picture of separation and loss. This adds credibility to the idea that the clouds in CU's drawings are symbols of the unwanted or undesirable (as in BT's drawings).

Discarded protection

On the reverse side of the page, CU had started a drawing of what she said was an umbrella which is used "when it's cold." In the previous week's drawing the child figure was "cold" due to having been locked outside of the house, denoting a discomfort regarding separation. It is possible that the umbrella was an attempt to symbolise protection against the "cold" and thus the discomfort of separation. Bach (1990) and Furth (1988) both recommend holding drawings up to the light when the child has used the reverse sides of the same page to draw, as this may reveal a relationship between features on one side and the other, elucidating some of the meaning of the drawing. When the current drawing is held up to the light, the umbrella rests just above the heads of the two crying figures. This reinforces the interpretation of the umbrella as a symbol of protection against the discomfort of separation.

It is perhaps then significant that CU doe not complete and discards the drawing of the umbrella. This suggests that the separation depicted in the current drawing was not prevented, or that her sense is that there is very little that can guard against the reality and pain of separation. Further ahead in this discussion, CU's experience of being unable to prevent separation or the pain of separation is reiterated in the final drawing she produces in the series.

Drawing #7, Week 7
Redressing loss through the provision of care

According to CU, the figure in this drawing is a likeness of any one of the many openly maternal caregivers looking after the children at the home. She and the sun are depicted as "happy", while the cloud is "cross… [b]ecause the sun is here." In CU's lived experience,

after the loss of her mother and the loss of the potential foster home, she was taken into permanent residence at the children's home. There, she has been adequately cared for by the many capable, maternal women working there. The home attempts to provide a loving, nurturing, caring, stimulating, secure and materially adequate environment for the children. Immediately following her drawing of the despair of separation and loss, it is possible that in this drawing, CU affirms that the environment of the home and staff looking after her have helped to restore some of what she lost emotionally through the death of her mother.

Transformation: Letting go of fear

It is this session that reflects some kind of transformation for CU. Since Drawing #3, she has depicted scenes and stories of fear, loss and mourning, with a momentary allusion to healing in Drawing #5. In this session, CU makes a firm decision not to express any of these negative emotions and experiences. She starts off drawing a figure on the reverse side of the page that looks very similar to the "monster" and 'Ticklish Lady" of previous drawings, but then discards it. In fact, CU tells the researcher that this was the Ticklish Lady and that she expressly did not want to draw this image any longer. The researcher makes an interpretation about this that is shared with CU. Her tacit agreement with this interpretation suggests that something has shifted for her. An interview with one of the caregivers from the home that week revealed that the shift was not confined to the research room; it was paralleled in lived reality: reports indicated that CU had been anxious at night, and had difficulty falling asleep. This resonates with her story about the Ticklish Lady who loves the dark. The night before this session, CU is reported to have gone to sleep without any hassles. This suggests that CU overcame one of her significant anxieties. It is likely that the research activities and space had some part to play in this. Practitioners and authors of art therapy agree that the process of producing and reflecting on art with a trained therapist has the capacity to facilitate transformation and resolution of inner conflicts and concerns for clients (Nicholas & Lister, 1999; Malchiodi, 1998; Furth, 1988; Dalley *et al.*, 1987). One of the ways in which this may be achieved is based on the understanding that the client expresses significant experiences and concerns through their art. Through reflection, dialogue and interpretation of the psychological and emotional aspects of their art, the client is able to work through, resolve and move past significant conflicts and concerns. This appears to have occurred with CU. Note the following dialogue:

R: Who was that lady [you started drawing on the reverse side of the page]?
CU: I didn't want to draw about Ticklish.

R: Was that the Ticklish Lady? So you didn't want to draw about [her]. How come?

CU: Cos I done that all the time.

R: You did that all the time. So, now you wanted to draw a different lady. Was the Ticklish Lady cross that you didn't want to draw her?

CU: (nods, "Yes.")

R: So you scratched her out. And when you scratched her out, how did it make you feel?

CU: Happy.

R: Well, it's good that you are drawing other ladies and not just the Ticklish Lady. But it was also very important for you to draw the Ticklish Lady. …I think you wanted to tell somebody about [her] and that you were so sacred of her. And all the time you were drawing her and telling me how scared you were of her, and how you fought her and [got rid of her]. And now, she's even gone from your drawings, and that's a good sign. That means you have really won the battle against [her]. Do you think?

CU: (nods, "Yes.")

R: How does it make you feel that she's gone?

CU: Happy.

The researcher reflects on and validates CU's process of repeatedly depicting the same kind of imagery and emotional content. He affirms her need to have expressed this fantasy and its emotional and psychological dimensions. He then highlights for CU how this empowered her to overcome some of the uncomfortable aspects of both her inner and lived experiences. As with BT, CU"s drawing process demonstrates the capacity for appropriately designed clinical research to not merely gather information, but also to facilitate therapeutic change for participants.

Drawing #8, Week 8

Sun and Clouds, Part IV: Fighting back

The sun seems to have grown in strength relative to the clouds since the previous drawing. In this drawing, she describes how the sun has captured the cloud, hence the unhappy face of the cloud. This may be indicative of a process of growing resilience in CU herself. This process of increasing strength is like the physical process CU has lived through in the context of her illness: she went from being close to death to recovery to an asymptomatic state. Thus, the relationship between the sun and clouds may be a depiction of the relationship between health and illness, respectively, in CU's body.

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Consolidated change

While the previous drawing demonstrated a transformation in CU, this drawing demonstrates a consolidation of that shift. She announces that the current drawing is "different", that she has used "different" colours. Indeed, she has introduced more colour into her drawings again, suggestive of a sign of increased vitality. Furthermore, this is the first drawing in her series where she has used the entire page. She has left no blank/white spaces. Again, this suggests increased vitality as there is more energy to cover the entire page. With the danger in the form of the cloud trapped by the sun, it is possible that her vitality is released.

Normalcy and health

The standing figure in the drawing is not in despair; she is "happy." She is also not monstrous, animal-like, disfigured or hurt in any way. Neither is this figure a woman. This appears to be a depiction of a normal, healthy girl. This may be how CU sees herself in the absence of symptomatic illness episodes and emotional trauma. Having represented and worked through some of her more unsettling and upsetting experiences and feelings, it seems that CU expresses that she has reached a state of health and normalcy. The other figure in the drawing is a boy child who is swimming in the water. There are no signs of impending danger, just of contentment and enjoyment. This picture suggests that CU does carry experiences of calmness and contentment, or else she may not have been able to produce this drawing.

Drawing #9, Week 9

Desire for a normal family

In this drawing, CU depicts a family comprised of a father, mother and two children, a boy and a girl. While she has not had this kind of experience of family in her life, she has met up and spent time with a maternal uncle, his wife and their two children. Thus, this picture may not just be a fantasy about having a normal family; it may also be a depiction of the family that she has met.

Impending danger and death

Despite the security of the normal family, the protection afforded the children by their parents and the barrier "line" separating the blue area from the purple area, the threat of danger and death is still apparent. This threat takes the form of a shark – the figure hovering above the purple shaded area. The family in the drawing is at the beach in the "big pool." On the other

side of the "line" is a shark in the bigger ocean. This shark kills children and eats them. The children are protected by the "line" and by their parents.

The reality of CU's condition is that even in asymptomatic periods, the threat of death and illness are still looming. There is the sense that not even a normal family can ultimately get rid of the danger altogether. In CU's real lived experience, she went away with her maternal uncle and his family on a holiday at the end of 2001. It was during this holiday that she became severely ill and had to return home. She was close to death, but recovered. Therefore, it is possible that this drawing is also a depiction of her lived experience that not even having a family can annihilate the reality of her illness.

Current containment of danger

As the previous drawing suggested, CU expressed being contented and "happy" after weeks of despair and turmoil expressed in her drawings. This drawing conveys a similar sentiment. In addition, it also conveys a sense that whatever is potentially dangerous and life-threatening in her life is contained at least at the time that she produced this picture. Similar to Drawing #3 (Week 3), there is a protection of the "endangered" from the "endangering" through what in this drawing is more obvious as "splitting."

Perceptions of normality

CU mentions in her description of this drawing, that the family will go home to the suburb that the children who were selected to live like a 'normal' family, live in. From this, it may be inferred that she sees that group of children and their caregiver as a normal family, protected from harm and danger.

Drawings #10 and #11, Week 10 (Final Session)
Markers of health and growth

The first two drawings CU produces in this final session were outline tracings of her foot and her hand. On the foot, she wrote the number "13" which is her shoe size, and on the hand she write the number "10" to represent the number of fingers she has. She spoke about functions and uses of her feet and her hands. Her feet are important for "moving" and "walking." Her hands are used for "washing… eating… [and] touching people – if you like them." These tracings impress as statements of her normal health, growth and development. In the context

of living with HIV/AIDS it is not surprising that she may feel normal health and growth are achievements worth noting. These are literally, pictures of her normal development.

Drawing #12, Week 10 (Final Session)

The researcher told CU that he would like to take a photograph of her drawing. This was after she had already produced the foot and hand tracings. She enthusiastically and hastily produced her final drawing (#12). Having depicted pictures of health, containment and normal growth, this drawing was somewhat unexpected. It depicts a dark and sombre scene of despair and vulnerability. It is postulated that this is a reality that CU cannot get away from and that she wanted to leave the researcher with a realistic picture of herself and her experience. It is also postulated that the termination of the research process and separation from the researcher was experienced as devastating for CU, and that she chose to express this in her final drawing. Indeed, it has been shown that loss and separation are difficult experiences for her.

Sun and Clouds, Part V: Symbolic confirmation

She initially drew the faces of both the sun and the human figure with upturned, "happy" mouths. After she added the seven clouds and falling rain to the drawing, she drew a down-turned, "cross" mouth on the sun and a down-turned "sad" face on the figure of the man. This confirms that the sun and clouds in her drawings represent a conflict between health and goodness, and ill-health and badness, respectively.

"Unprotection"

Like the incomplete and discarded umbrella drawn in Week 6, the umbrella in this drawing fails to protect the man against the rain. This is a sign that CU feels that she is vulnerable to an onslaught of undesirable and harmful elements, and that there is nothing that can protect her against this. In terms of her illness, this is and has been her reality. The metaphor of failed protection may also be interpreted as an allusion to the manner in which CU contracted the virus: through vertical transmission, i.e. her mother contacted the virus through unprotected sexual intercourse.

In terms of her relational losses, a lack of protection has also been a reality for her. It is possible that the inevitable termination of the research process reinforced CU's notion that she will always be vulnerable to loss and separation.

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4.5. Beyond the data collection process...

BT had mentioned in his final session that CU had expressed sadness about the end of the sessions with the researcher. It was partly due to this information and CU's final drawing and the researcher's interpretation of the drawing that highlights CU's vulnerability around loss, that the researcher decided to pursue a process of similar activities with the children beyond the data gathering phase. After discussions with the children, their caregivers and the consulting team, a collaborative decision was reached for the researcher to start a separate yet similar process of drawing with the children who were involved in the research as well as five other children from the home. This took the form of fortnightly free play and drawing sessions with the researcher (who then assumed the role of facilitator) for approximately six months. Extraneous circumstances impacting on the lives of the researcher and the children resulted in a termination of these sessions after the six-month period at a meeting where this was explained to, and discussed with, the children. At the same time, the researcher continued to participate in monthly consultation meetings about the mental health of the children at the home. To date, this level of participation in the lives of the children at the home, particularly in the lives of the three research participants has not been terminated, only transformed.

CHAPTER 5: CONCLUSION

It is impossible to be neutral. You always have some opinions about what is going on and your opinions are going to have an influence. The big challenge is to the belief in reality: looking for scientific truth and what is really going on. What is the real story...? What is the real diagnosis? ... What is the real reason behind what is going on? You think that what you observe is there. But we find what we look for. The recent change in the past five or 10 years is the realisation that there is no reality to discover. You are not discovering the reality, you are inventing the reality.

- **Gianfranco Cecchin** (1999)

What children know and what children tell, is not often what we hear. Listening to children, particularly those children who are relatively more vulnerable – biologically, socially and psychologically – demands listening to the language that they speak. It has been highlighted throughout the preceding sections that children do not generally communicate their experiences and their understanding of their experiences in a manner that is immediately understood by adults. It has been shown that the "inner world of children" is best accessed through non-verbal and what this author would like to term "metaphoric media." By this it is meant that children communicate by using metaphors. These metaphors may take various forms, each representing the lived reality of the child. Some of these forms include art, play and story. This is how children may communicate their clear and profound knowledge of things. It is also how knowledge may be passed on to many children. We only have to think, for example, about the visual metaphors on television screens that attract and capture the attention of children and that influence children's behaviour, to know how powerful metaphoric language is when setting up communication channels with children.

Before the communication, comes the experience. Children and adults learn through their lived experiences. We learn, for instance, what is harmful and what is dangerous through our own and others' experiences of things. Thus, in order to be able to communicate with someone – whether child or adult – about their experiences, we need to be able to understand what their experience is. In the context of a helping profession such as clinical psychology, understanding the experience and manner of experience of those we as service providers wish to serve and whose lives we aim to relieve of stress and distress, is invaluable. An existential-phenomenological and intersubjective approach to our clients provides us with the means to develop an empathic understanding of our clients' experiences. It also enables us to determine the meaning of these experiences for our clients and for ourselves.

Of the diversity of experiences we have in life, psychological experience – the "inner world" or "inner experience" – is perhaps the most challenging to access, simply because, as Romanyshyn (1982, p. 174) succinctly states, "[I]t reveals itself only by concealing itself…" By the same token, a metaphor is something that simultaneously reveals and conceals reality (Combs & Freedman, 1990). It is due to the paradoxical "visibility" and "invisibility" (a theme alluded to by at least one of the participants in this study) of psychological experience that "psychological life is always in need of being *recovered* (Romanyshyn, 1982, p. 174).

The Chambers Concise 20th Century Dictionary (Davidson, Seaton & Simpson, 1985) offers the following definitions: A "psychologist" is "one who has studied and qualified in psychology (p. 798)"; "psychology" is a "science of the mind: study of mind and behaviour: attitudes, etc. (p. 798); and "psyche" refers to "the soul, spirit, mind: the principle of mental and emotional life, conscious and unconscious (p. 797)." Having underscored the metaphoric quality of psychological experience, Romanyshyn (1982, p. 174) posits the following understanding of psychological life and the role of the psychologist:

> Psychological life tends to cover itself in the habitual tasks of daily life, in those taken-for-granted, literalizing attitudes and perceptions of everyday living. As such, therefore, we may say that psychological craft consists in bearing witness for what lies forgotten beneath the literalizing attitudes of daily and scientific life. In this regard, the psychologist is not so much a discoverer in search of new truths or stories, or a creator of fresh ideas or tales, but, on the contrary, a witness whose work embodies the unheard (of) stories of an age in the sense of that which an age most desires to forget.

The current study established a space to facilitate a witnessing of the stories lying 'beneath" that which is observed at first glance, of the lives of the three participants. This was established as a means of furthering an understanding of the emotional, cognitive, fantastical, conscious and unconscious experiences of these children. Through the framework of research, this author/researcher/psychologist-in-training not only served as a witness, but also functioned as a documenter and reporter of these children's stories, and of the psychological, metaphorical threads of their experiences.

This researcher/author adopted a position and attitude in relation to the participants and to working with the data that incorporated a few main theoretical and philosophical

underpinnings. The first is that of existential phenomenology or phenomenology, which recognises that experience is subjective and that we should not presuppose knowledge of things before we have sought to discover them. Therefore, the position of the phenomenological researcher is not to know: to "bracket" previous theories and understandings of phenomena and to seek the knowledge of those who have lived experiences of the phenomena being investigated. The knowledge and understanding of phenomena is generated through a process of gathering information and making meaning that constantly returns to peoples' or participants' lived experiences and own associated meanings. This stance, as Brooke (1991) points out, does not preclude interpretation. However, interpretations constantly return to, and incorporate the lived, subjective realities of those who experience the phenomena being investigated. What phenomenological research aims for is an interpretive description of the lived, in-the-world experiences of reality (Brooke, 1991).

The second idea that informed the position of the current researcher is that meaning and understanding is a collaborative process. This is epitomised by the notion of "intersubjectivity" (Natterson & Friedman, 1995) and the co-construction of meaning (Sluzki, 1992). This idea was alluded to in previous sections. It refers to the process of interacting with clients or participants in a collaborative fashion in order to achieve a new, but common and shared understanding of an event, relationship, thought, feeling, dream, etc. From this perspective, the understanding that is generated emerges from, and is informed by, the active participation and inclusion of the experiences, worldviews, feelings and associations of both the participant and researcher. This enlivened interaction has meaning and value for both, as long as both parties agree to the understanding it produces. Not only does this approach produce shared knowledge, but it also deepens rapport and empathy (Schwaber, 1981 in Natterson & Friedman, 1995) and has the capacity to facilitate transformation for the client/participant (Sluzki, 1992). This is achieved as new words, phrases and perspectives based on the clinical training of the therapist/researcher aimed at helping the client/participant, are introduced by the therapist/researcher to describe the experiences of the client/participant. As discussed in the previous **Analysis and Discussion** section, positive transformation took place, in some way, for each of the three research participants.

In a way, this is similar to Bion's (1962) explanation of psychological growth and development in an infant (in Ogden, 1990). From a psychoanalytic and Object Relations theory perspective, an infant will place unformed, meaningless parts of itself and its

experience into its mother; she will process these elements and return them, transformed, to the infant and in a form that now has meaning for the infant, and this is less overwhelming (Bion, 1962 in Ogden, 1990). This aids the psychological growth of the infant. Bion (1962) claims that this is a process that occurs in most interactions between one individual and another, where one is more contained and developed than the other. It is felt that the participants in this study brought unformed or ill-understood parts of themselves and their experiences to the research space. With reference to Bion's formulation, it is likely that the training and experience of the researcher enabled meaning to be made of these elements and for them to be given back to the participants in a more contained form. This resulted in growth and transformation for the participants. Whatever theoretical framework is used to understand the process of transformation in a clinical context, what the current research experience underscores, is the value of a meaningful interpersonal relationship between researcher and participants. It also serves to highlight the value and need for the continuation of this kind of work with children living with HIV/AIDS in the future. Insofar as future clinical research goes, there may be value in investigating the process, dynamics and variables of therapeutic change within a research context with AIDS orphans. This has potential benefits for future child participants as well as expanding the knowledge of working with children facing similar circumstances.

The intersubjective approach is consistent with a phenomenological approach in that it also does not promote a strict adherence to established theories (Natterson & Friedman, 1995). Instead, it promotes interpreting clients' material from a relatively uncontaminated position that allows for new meanings, theories and understandings to emerge. Previous theory is not abandoned, but incorporated where appropriate. As the **Analysis and Discussion** sections reveal, the current researcher/author used this very approach in developing an understanding of the participants' material.

In the current study, the intersubjective process between researcher and researched began long before data collection commenced. As the introduction to this thesis indicates, a relationship between the researcher and participants was initiated when the researcher in the role of intern clinical psychologist conducted a neuropsychological assessment with one of the children from the children's home that the participants were drawn from. This interaction was to become the inspiration for the current study. A relationship was established between the researcher, the children and their caregivers, held together by the subjective life experiences,

interests and needs of all three parties. This research process was partly about making the experiences and stories of the three research participants known, with an emphasis on the psychological aspects. Having recognised the marginalisation and invisibility of the lived experiences of children living with HIV/AIDS, as told by these children – both in South Africa and globally – this researcher felt the need to make a concerted effort to change that. The recognition of the emotional and psychological aspects of experience resonated deeply with the researcher's own lived experience of his own childhood.

Thus, it may be seen that the research process – and possibly all clinically-framed relationships – incorporates the dynamic of intersubjectivity, or what Sigmund Freud and subsequent psychoanalytically-framed authors and practitioners may have referred to as "counter-transference." Natterson and Friedman (1995) highlight the necessity and value of this approach in clinical work. It transforms not just the client/participant, but the therapist/researcher as well. This is consistent with the current researcher's experience of the research and thesis writing process.

Following on this notion of intersubjectivity, is the third idea contained in the design and approach of this study: story-telling. In a review of an essay about the Dobe !Kung people of Botswana by anthropologist Marjorie Shostak (2000), Morelli and Baldwin (2002, p. 381) comment extensively on the role of the "researcher" and the "researched." Morelli and Baldwin (2002) note that the stories told about those that are researched (the participants), are not just a revelation and clarification of their lives, but also a story about the researcher, in this sense that it is a story about the researcher's motivation for pursuing a particular topic as well as that researcher's process through the research endeavour. This may be explicitly or implicitly told. As alluded to above, the life story of the current researcher and motivation behind the research is embedded in the design of the study as well as in the interpretations of the stories of the three participants.

The fourth idea is also congruent with the phenomenological approach. This is the idea that psychological life and experience is embedded in the real world and contained in real objects like books, walls, significant others (Romanyshyn, 1982). Psychological understanding, says Romanyshyn (1982) is one way of perceiving and understanding lived reality and experience. What he seems to be saying is that psychological interpretation and understanding are metaphors for life. Through psychological formulations of experience, it is therefore possible

to achieve a clearer understanding of experience, but at the same time, to hide aspects of that experience. The psychological interpreter can thus only ever make tentative comments and provide tentative formulations.

The tentativeness of the interpretations made in this study is also informed by the reality that "[s]tories told sometimes change with time" (Morelli & Baldwin, 2002, p. 385) at the very least due to changing circumstances and increased life experience. Within a qualitative research paradigm, this underscores the need to return to research data again and again, as it will reveal different aspects and nuances each time (Brooke, 1991). This process of repeatedly returning to something in order to deepen an understanding of it was implemented by the current researcher/author who worked with the material for over one year. He returned not only to the data that was collected, but also to the children who participated in the study both directly through interactions with them and indirectly through interactions with their caregivers. Subsequent to data gathering, each interaction with the children and their caregivers, combined with further interactions with relevant literature and the researcher's own changing circumstances, deepened the interpretation of the material and the understanding of the three participants' experiences. This process of repeated return is consistent with the concept and practice of circularity within a family therapy context, where the therapist – like the phenomenologist – puts aside preconceived ideas and theories when approaching the family and develops a formulation of the presentation of the family through "regular feedback from the family" (Palazzoli Selvini, Boscolo, Cecchin & Prata, 1980). Redefining and reformulating are features of most post-modern, qualitative approaches to psychological research and practice, and is referred to as "reflexivity (Parker, 1994, p. 13)."

What this study has strived to do, is make the experiences of these participants clearer by decoding the pictorial and verbal metaphors they presented. At the same time, psychological discourse is used as a clarifying instrument. As yet another metaphor, the interpretations offered in this study are only tentative. Their value lies in drawing attention to a thread of experience that is not immediately visible, and that adds an extra dimension to the understanding of phenomena and the understanding of the three research participants. Hopefully this knowledge will enable those looking after these three specific children, as well as those looking after children faced with similar circumstances, to empathise with and manage them, with enhanced attunement to their needs.

It is the opinion of this researcher/author that the current study has achieved what it set out to: to describe the complex experiences of three orphaned children from a children's home who are living with HIV/AIDS. The intention was to use the perspectives and understanding of the children, and this was successfully carried out through the use of age-appropriate research tools: drawing and story-telling. The study also succeeded in maintaining high ethical standards throughout, as the children's well being was always a top priority. Due to information gleaned from the literature, the researcher was well aware of the therapeutic potential of the process for the children. Despite this, it was never expected that the children would actually benefit therapeutically from the process. Thus, when this was observed by the researcher, it was assessed as an unintentional success of the study. It also emphasised the value and need for clinical research to be ethically conducted. Part of what this means for the current researcher is that clinically-oriented researchers need to consider the imperative of research designs that do not merely produce more information, but that add value to the lives of participants as well.

While the study took a while to initiate and complete – two years from inception to report – there has been great value in this for the researcher and for the participants. As discussed earlier in this section, things change over time; the nuances of things tend to be revealed with time. This has meant that the analysis of the data has deepened to a point where it is closer to the lives of the children than it perhaps would have been if less time was spent returning and re-returning to the material. The extended time spent on the analysis has also meant that the researcher has had further and ongoing contact with the children's home. This has enriched the analysis, but has also meant that the caregivers at the home were exposed to more discussion about the three participants, as well as discussion about how to work with and manage other children in similar predicaments at the home. It is the experience of this researcher/author that this has enhanced the psychological-mindedness of the caregivers at the home, and has improved their ability to attune to, and empathise with the emotional and psychological facets of the children. Regular meetings have been held to speak about emotional and behavioural matters. Feedback from the staff has indicated the value of these brief consultations for them.

On this basis, it is recommended that working with children living with HIV/AIDS requires a multidisciplinary approach. What teams, service providers and families should recognise is that children who are vulnerable need to be listened to and heard on emotional and

psychological levels as well as having their physiological and material needs provided for. One of the ways that this may achieved is to use methods such as creative artistic expression and story-telling. Preferably, this should be conducted or supervised by a trained mental health professional. Furthermore, it is imperative that children's needs and understanding be heard from their perspective, in order to avoid assumptions, but also to inform more appropriate management.

This study was limited by the time constraints of academic deadlines and requirements, as well as funding. With adequate funding, research of this nature cold be repeated with larger groups of children, over longer periods of time, and even be converted into a sustainable action research programme for orphaned children living with HIV/AIDS. It would be useful to continue to provide this kind of space and opportunity for emotional and psychological expression and reflection for such children. Those living in large children's homes often miss out on being attuned to on this level, as caregivers have to attend to the many practical tasks of childrearing. It would be thus be beneficial for future researchers as well as programme developers to consider funding a longitudinal study of this nature.

This study was limited to working with children from just one of the children's homes in South Africa. There are many more homes that are not as well resourced and family homes where AIDS orphans reside. It is recommended that this kind of research be conducted with those children as well. There are many more voices that need to be heard.

One of the more outstanding findings of this study is that the three children display and express their ability to survive and thrive in the face of difficult life circumstances. This underscores the need for children living with HIV/AIDS to be perceived not just as vulnerable, but as capable and resilient as well. With appropriate and adequate care and the advent of antiretroviral treatment, infected children are surviving into the pre-pubertal and pubescent years. They need to be seen as growing, developing and legitimate citizens with future lives. If the three participants in this study are representatives of their group, those HIV-positive children that have survived numerous illness episodes, hospitalisations, parental deaths and peer deaths are adaptive and resilient. These aspects of their personalities need to be attended to and reinforced. It has the potential to be radically empowering for them. It is recommended that the development of resilience and competence in South African AIDS orphans (affected and infected by HIV) be further investigated.

Milner and Carolin (1999) advocate for the following of the wisdom of the children in their edited book, *Time to listen to children: Personal and professional communication.* This time certainly has come. The National HIV and Syphilis Antenatal Sero-Prevalence Survey in South Africa 2002 (Department of Health, 2003) estimated that 91 271 babies had become infected through mother-to-child transmission in 2002. 26.5% of women who are pregnant in South Africa today are HIV-positive. Antiretroviral therapy will not prevent all mother-to-child transmissions and infant infections. The figures are staggering, and even if there are no new infant infections, there are at least one million HIV positive infants, children and youth currently living in South Africa. These are the children who are likely to lose their mothers to AIDS. Many of them will be orphaned children who are going to require care and support. These are the children who will need to be listened to, who will need to be heard. May we learn to listen closely…

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Rhodes University, Grahamstown

Consent to allow a child under your legal guardianship to participate in a psychological research study

Title:
An interpretive use of drawings to explore the lived experiences of orphans living with HIV/AIDS

Study Purpose

You are invited to allow your child to participate in a study conducted by a researcher from Rhodes University Psychology Department. The aim of the study is to explore and describe the experiences of orphaned and/or abandoned children living with HIV/AIDS. It is hoped that the findings will mobilise the voices of the children in the context of the pandemic, and that what they express will enhance our understanding of them and their needs. This information may be valuable for designing various programmes for the children and developing empathic relationships with them that are more reflective of their lived experiences.

Study Procedures

Should you decide to allow the child to participate in this study, the child will be required to attend six to eight sessions with the researcher, at the Red Cross Children's Hospital Child and Family Unit, 46 Sawkins Road, Rondebosch. Sessions will take place once a week after school hours, and will involve the child producing drawings and telling stories about the drawings. The child will draw on his/her own, and discussions will take place in a group format with two other children from your home, as well as the researcher. If the child is resistant to sharing the drawings, s/he will be given the option of discussing it alone with the researcher. Sessions will be recorded onto audiocassette for the purposes of subsequent analysis. Drawings will also be used for analysis. Duration of sessions will be up to one hour. All information obtained during these session will remain strictly confidential and be treated with utmost respect.

Furthermore, your consent will grant permission for the researcher to approach your institution and the child's school for documentation and information pertaining to the aims of study. If any copies are to be made of documents or interviews of relevant parties are needed, you will be duly informed and consulted.

Possible Risks

The sessions may bring up sensitive issues and information that may not have been in the child's awareness before. As a result, some emotional discomfort may be experienced by the child. To ensure the safety of the child, the researcher will apply his expertise and experience to the situation. In addition to this, the use of drawings and the group format have the potential to be fun and non-threatening. The child will always be consulted as to whether s/he is comfortable, as will you yourself. You will be informed of appropriate procedure and referred to appropriate professionals should any emergencies arise.

Possible Benefits
Through the drawing process, the child may develop a clearer sense of self and feel empowered and heard. The child may also have certain questions answered about his/her condition, and develop a sense of not being the only one with certain experiences, feelings and thoughts. It is also hoped that the child and others like him/her will benefit from the findings, as noted above.

Alternatives
No detrimental action will be taken if you decide for the child not to participate.

Voluntary Participation
Participation in the study is entirely voluntary. The child has the right to refuse to participate in any way, to any degree. You and the child's needs will remain paramount throughout. If either of you feels the need to withdraw, this will not impact negatively on either of you in any way. You and the child's right to withdraw may be exercised at any point in the research process.

Confidentiality
All information obtained from the child and other sources will remain strictly confidential. Recordings of the sessions will be transcribed for analysis purposes. The cassettes, transcripts and drawings will not reveal the child's identity, the identity of the home or that of the child's school. All records will be secured. You will be consulted as to how and where the records will be stored, both during and on completion of the project. Any reports and publications about the study will not identify the child, any other participant or his/her living and learning environment in any way.

Questions/Queries
Any study-related questions, concerns and emergencies should be directed to:

1. Mr Clint Steenveld, Principal Student Researcher, Department of Psychology, Rhodes University, Grahamstown, 6139, Tel: 083 3333 327.

Questions, concerns and comments about the child's rights as a study participant, your rights as the child's legal guardian and the research itself should be directed to:
1. Mr Jan Knoetze, Principal Academic Supervisor, Department of Psychology, Rhodes University, Grahamstown, 6139, Tel: (046) 603 8505.
2. Ethical Standards Committee, Rhodes University, Grahamstown, 6139, Tel: (046) 603 8500.

****

I have read the above and am satisfied with my understanding of the nature of the study, the nature of the child's participation and its potential risks, benefits and alternatives. My questions about the research have been answered. I agree for the child to participate in sessions where s/he will be involved in drawing and interviewed. I agree for audiocassette recordings to be made of interviews. I also agree that these recordings may be transcribed by a research associate selected by the researcher, and understand that all procedures will adhere strictly to principles of confidentiality. I have been informed that I shall be consulted regarding the decisions about records on completion of the project and its associated report. I have been offered copies of this consent form for perusal by other relevant parties.

_____
Child's name (printed)

_____   _____   _____
Name of the child's legal   Signature of the   Date
Guardian (printed)   legal guardian

_____   _____
Witnessed by Clint   Date
Steenveld (Researcher)

Rhodes University, Grahamstown

Information Sheet and Assent Form for Child Participants

****

What if I agree to take part in a Study about HIV/AIDS…?

What is a researcher?
A researcher is someone who is like a detective who likes to find things out.

In this study, the detective-researcher wants to find things out, and would like you to help him.

He would like to find out about you – what you do, what you feel, what ideas or questions you have in your head.

****

What is this thing called a "study" all about?
A study is a bit like a detective's investigation.

The detective has to speak to people and do different things to find out what he wants to know.

So, in a study, the detective-researcher has to speak to people and do different things to find out what he wants to know.

In this study, the researcher wants to know about YOU.

The adults at your home were asked if it's OK for you to be part of this study about HIV/AIDS.

The reason that they were asked, is because you are not old enough to sign things just yet.

But, this does not mean that you will be forced to do anything you really don't want to do.
Even if the adults at your home said "Yes" for you, you can still say "No! I don't want to!"

In this study, you can help the researcher to find things out about you.
He will give you a chance to draw and speak about some of the things that you think, and some of the things that you feel and some of the thins that you do.

If the detective-researcher understands you really well, then he can help other people to understand you, too.

He can help other people who have children like you to understand them better!

****

What do I have to do if I say "Yes"?
If you say, "Yes! I want to be a part of this investigation!", then you will have to come to a playroom the Red Cross Children's Hospital Child and Family Unit in Rondebosch.

You will come once a week, and will stay for about an hour.

You will come about 6 to 8 times.

In the playroom, you will draw and talk about the things that you draw.

There will be two other children from your home there, too.

We will try to chat with one another in the room. the researcher will also be in the room, and will also draw and talk.

The researcher will record the talking onto a cassette.

Later on, someone will listen to the cassette recording, and type what you and the others have said.

The researcher will also look at the drawings afterwards, and see if he can understand what the drawings are about.

The researcher will also ask you and let you know if he needs to speak to any of the adults at your home, and at your school.

He will also let you know if he wants to look at reports and files about you.

****

What if something happens that I don't like?

The researcher will try to make things fun and safe for you.

Sometimes, things don't always go as planned, and we feel unhappy.

If you feel very unhappy about something, then you must tell the researcher, and he will see if he can help you.

If you say or draw things that you don't really want others to hear, then you must tell the researcher about those things.

He will speak to you about it, and try to help you.

****

Is there anything in it for me?

Lots of children like to draw and like to tell stories.

It can make them feel good inside.

Maybe you'll feel good after drawing pictures and speaking about them.

If you do this, then adults might be able to understand you better and help you out a little better, too.

It can also be good to learn that other children think or feel the same things you do.

You may have questions that you want an answer to – perhaps you'll get the answers to some of your questions.

****

Can I say "No!"?

Of course you can say "No!" If you don't want to draw and tell stories one a week, then you must tell an adult or the researcher, and you won't have to do anything you don't want to do.

If you say "yes", but later you feel that you want to change your mind, then that 's OK, too – just let an adult know about it. Nothing bad will happen to you if you say "No!".

****

What if other people find out?

The researcher will make sure that no one else finds out your name, where you live, or where you go to school.

So, no one else will know that you did the drawing, or that you said something in the room.

If you want to show your drawings to someone else, then you can speak to the researcher about it.

****

What happens to my drawings and to the recordings?

The researcher will keep your drawings and the cassettes safely locked away.

When the study is over, the researcher will write a report about what happened.

At the end, you will help the researcher decide what to do with the drawings and the cassettes.

If you want your drawings before the end, then the researcher will make a copy for you to keep.

****

Who do I speak to if I have any questions?

If you have any questions, speak to the adults at your home, who will contact the researcher.

The researcher's name is **Clint Steenveld**.

****

If I write my name on the line at the bottom, then it means that I understand the things that will happen in the study, and that I will try to help the researcher to find out more about me.

I will draw pictures and tell stories about the things I draw.

If I don't understand, or I feel unhappy, I will tell an adult or I will tell the researcher.

If I don't want to do something, I don't have to.

My name is: _____

Date: _____

Name:	YN
Sex:	Girl
DOB:	1994
Admitted to children's home:	1996-07 (1yr 10mths)
Committed to children's home:	1996-10 (2yrs 2mths)
Mother:	DN
Father:	Unknown

Notes by the Social Worker

Both YN and her mother are HIV+. YN was badly neglected by her mother, and had been in and out of hospital many times.

Since the age of 5 years, YN has been much better physically, "lively" and "loveable". She can be "bossy", and throws tantrums when she does not get her own way, but she is learning to share.

1996-07-03

At 23 months (just after arrival at the home), YN was brought in by a Social Worker (S/W) and Mother (Mo) on detention orders from Wynberg Children's Court. YN was discharged from Victoria Hospital, where she'd received treatment for Pneumonia and Diarrhoea. The hospital requested placement, because of signs of neglect by Mo and a query of "psychiatric problems" in Mo. Mo was living in squalid conditions. YN has had 6 admissions to hospital since March 1995.

YN can walk, and is quite healthy looking, despite her condition. YN was quite upset when Mo left, but she soon settled in happily. Mo was told to call/visit often.

1996-07-22

No further contact from Mo. YN is setting in well. She has herpes at present (oral), but it's healing and doesn't really affect her eating.

1996-12-04

Mo "suddenly appeared" for a visit today. She said she was staying in a township in Cape Town. She said she had no money to make contact earlier. Mo had no further contact with the S/W at Victoria Hospital.

1996: Medical problems:

April –	swollen glands
May/June –	Discharge from ears
July –	Diarrhoea
August –	Right ear pain
September -	Coughing

1997-04-07

Mo visited again since Dec 1996. She appeared "calmer" and did not demand to take YN with her. Said she can't take YN home.

YN is doing well, though can be quite oppositional. She gets into "power struggles" with CU, who is 2mths older than she.

1997-07-14
Mo visited briefly last week. YN was happy to see her, but "not unduly concerned when she left again." Mo has clamed down, and no longer demands to take YN away with her.

YN's potty training is progressing, and she is talking in short sentences now.

1997-08-20
In hospital with Chicken Pox for a few days. She responded well to treatment, and was soon home. Admitted to Somerset Hospital (SH) on 15/08/1997; discharged on 1997-08-19.

Now fully potty trained and making good progress.

No further contact from Mo.

1997-12-15
Progressing well in all areas. Becoming independent. Still has a few tantrums and becomes easily frustrated, but seems to be growing out of it.

Mo visited her briefly last month.

1998-02-23
Mo came to visit, though she did not seem interested and did not look well. She wanted to stay at the home; she was given fare to go home. YN seems "ok" with her Mo.

1998-03-18
YN is fine and enjoying Nursery School. She seems happy. Mo did not come again.

1998-08-11
Mo visited YN at NH and asked for money to go back home. Mo seemed "ok'. She did not give her telephone number or address, and said that she is not working.

1999-08: Progress Report by the home –

Medical: Keeping well. Not hospitalised for some time. Happy.
School: Relates well to peers, but can be stubborn. Loves painting and music.
General: Adapts well to the home.
Family: No contact with Mo since Aug 1998. No contact from other family members.

2001-07: Progress Report by the home –

Medical: Well, and no major illnesses over past year. HIV status rechecked; diagnosis:
                HIV+. Minor ailments managed. Prognosis is fairly good, but difficult to
                assess…
School: "Sister N is concerned about the children at one of the schools, and this needs
                to be explored further."
Family: YN's Mo has visited her once in the past year. Mo always promises to visit
                more often, but does not follow through.
General: YN is happy and lively. She tends to be quiet. Loves lots of attention.

**APPENDIX D: YN'S DRAWING SERIES**

YN, Drawing # 1, Week 1
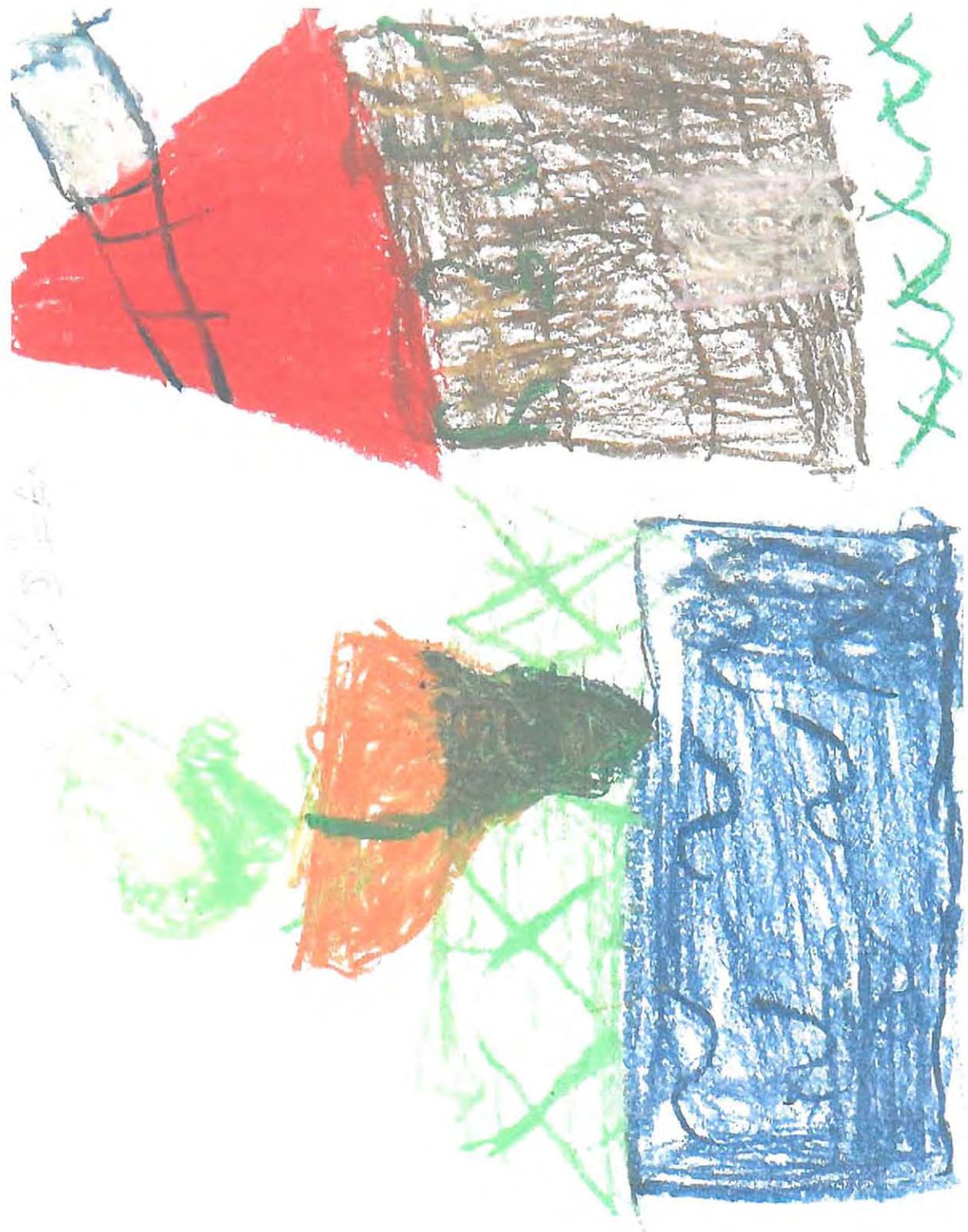
YN, Drawing # 2, Week 2

YN, Drawing # 3, Week 3
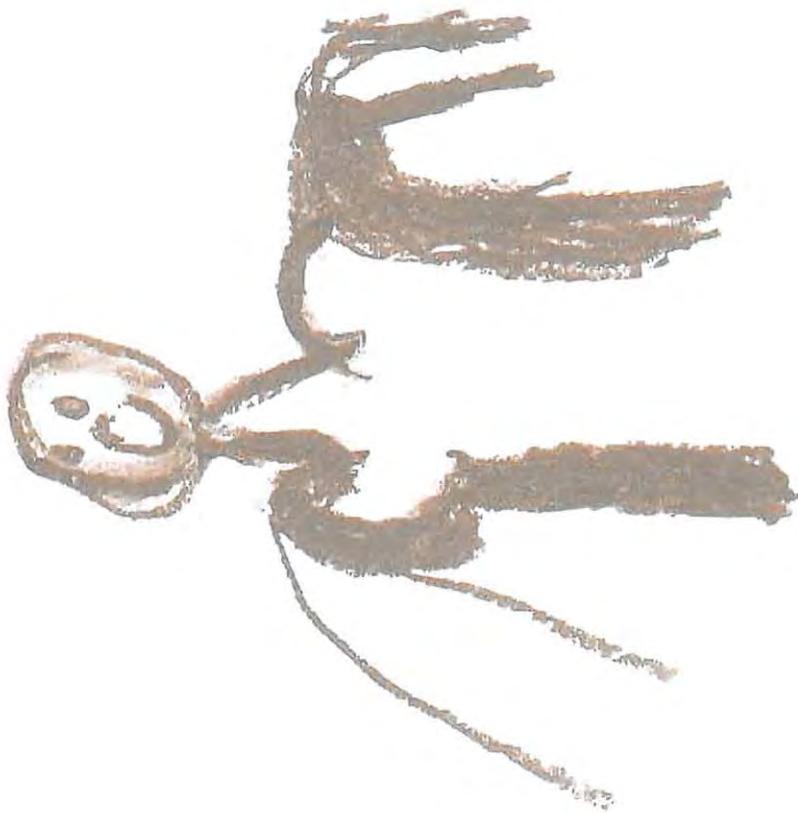
YN, Drawing # 4, Week 4 (discarded picture)

YN, Drawing # 5, Week 4 (second attempt)

YN, Drawing # 6, Week 5
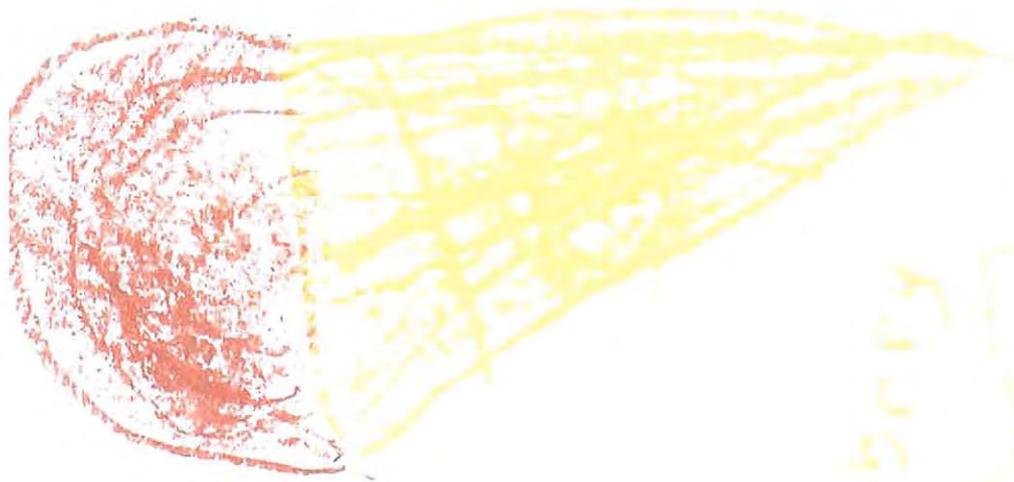
YN, Drawing # 7, Week 5

YN, Drawing # 8, Week 6
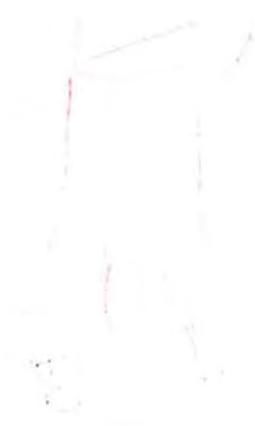
YN, Drawing # 9, Week 7

YN, Drawing # 10, Week 8

YN, Drawing # 11, Week 9

APPENDIX E: BT'S BRIEF HISTORY

Name:	BT
DOB:	1993
Admitted to children's home:	1994-06
Committed to children's home:	1994-12

Mother:	NT; whereabouts unknown.
Father:	Apparently unknown to Mo. Mo was allegedly raped. She could not identify the man (BT's father).
Maternal Aunt:	DT; lives in Cape Town

Mother (Mo) has three children other and older than BT. They are looked after by Mo's sister, and stay in Cape Town. All of them are healthy (not HIV-positive). Their father does not pay maintenance for them.

Mo promised to visit BT regularly. Red Cross Children's Hospital (RXH) said they would call once BT was ready to be discharged.

1993-12
Born at Mowbray Maternity Hospital, Cape Town. Premature at 36 weeks. Good Apgar scores (8; 10).

Mother HIV+ at birth of child. Mother was 27 years old when she gave birth to BT.
She had a history of epilepsy. Mother lived at home with 4 adults and 5 children. Maternal Aunt worked as a char (only breadwinner).

1994-06-16
BT brought to home by hospital transport from Red Cross Children's Hospital, where he was abandoned after being discharged. 6 months old. HIV+. Has recurrent chest infections, diarrhoea and skin lesions.

Mo was allegedly raped. She attempted an abortion, but was unsuccessful. She blamed the rape for her HIV+ status. However, doctors felt she was already in an advanced stage of the disease when tested and diagnosed at RXH. They concluded she must have been HIV+ before the rape.

Mo totally rejected BT. The social worker was unable to help Mo form a bond with baby. No family members were willing or in a suitable position to care for him. Thus he was paced permanently at the children's home.

1994-07-13
BT has been well, apart from a wheezing chest and skin lesions. Intermittent diarrhoea. Has been given Hibtiter vaccine and VitA capsules, as part of research at Somerset Hospital.

1994-09-22
Growing well. Wheeze under control. Except, he developed a temperature over 40 deg Celsius on Tuesday, and his breathing was very distressed. He was admitted to Somerset Hospital. There was a slight improvement, but he had to stay in hospital for a few days.

1994-09-26

Much improvement and he is responding to treatment. Discharged on 30/09/1994. Seems very "serious" at home.

1994-10-05
Fine, except that he's "chesty" and has lost weight.

1994-10-08
Admitted suddenly to Somerset Hospital with rising temperature, poor breathing and much distress. Receiving appropriate treatment (oxygen and antibiotics).

1994-10-16
In hospital. Much improvement. Developed kidney infection.

1994-10-26
Still in hospital. Severe diarrhoea.

1994-11-07
Discharged "at last!". On full TB treatment; even though tests for TB were negative, there may be underlying TB.

1994-11-19
Admitted back to Som Hosp (SH), in great distress with high temperature. Discharged 1994-11-25 and happy to be home.

1994-12-06
Fairly stable. Trying to crawl, but slow in moving himself. Not vomiting as much; reflux seems under control.

1995-01-23
Doing well. Nebulised regularly. Still on TB treatment. Demeanour not so "serious" anymore.

1995-02-14
Admitted to SH with pneumonia.

1995-02-18
In hospital and much better. No further contact from mother, or any other family members.

1995-02-21
Discharged. Much improved. Large boil on cheek. Very happy to be home.

1995-03-10
Fairly sable. "Quite a little chatterbox." "Loves to hear his own voice." Far less "serious" than before. Still afraid to pull himself into standing position. No contact from family.

1995-03-14
S/W from RXH called to say Mo has contacted her to say that she did not want to see BT or to take him home.

1995-06-06
No further contact from family – no visits, even though Aunt called twice to say they would come. Family still won't take BT due to his HIV+ status.

BT is fairly stable, growing well and trying hard to talk. Climbing and crawling but can't stand alone.

1995-07-01
Admitted to SH after few days of respiratory distress. BT is very miserable and cried bitterly when left in hospital.

1995-07-03
Still very distressed and upset in hospital. No family contact

1995-09-01
Was discharged a few days after admission, but he contracted Herpes last week, and had to be admitted to SH again – unable to swallow due to Herpes in throat.

1995-09-05
Still in hospital for herpes. Improving. Mo came to see him unexpectedly today. She said she'd been in the Eastern Cape again and could not get treatment for herself, as she was staying far from the clinic there. Mo was taken to SH to see BT, who was very unfriendly and refused to be held by her. She had last seen him when he was 4 months old, "so his reaction is understandable."

Mo was surprised to see how BT had grown, but understands he is sick and will not recover (from his HIV+ status). On the way to drop her off at the train station, she asked, "Who will pay for the coffin?" She tends to wander and her mental status is questionable.

1995-12-19
Never saw Mo again after this visit. Family members who had called and said they'd come, never did.

BT's health has declined, and he is back in hospital with severe pneumonia, molluscum contagiosum and weight loss. He is becoming quieter and less energetic.

1996-04-21
Still no further contact from the family.

BT is doing well. The doctor is "amazed" at him. He is walking well. He is more alert and interested in his environment than before. He enjoys dancing and clapping. He is till "clingy" when tired, but is improving. The molluscum is clearing up.

1996-07-02
Improved self-confidence. BT is happier and more sociable. Chest is problematic, but under control.

Mo visited the S/W at RXH, and asked for a place to stay; her family cannot accommodate her. RXH suggested the Sisters of Charity in Khayelitsha for her (home for care of HIV+ adults). She did not ask about BT, nor mention that she had visited him.

1997-04-07
No further contact from the family. BT is growing well and becoming quite a "giant". Enjoys Nursery school. Talks well. Tends to be quite a "bully" with the younger children. Is health is good. Is active and enjoys swimming.

1998-03-23
Coping well. Enjoys school. Physically well.

1998-04-21
Still coping well.

1998-11-05
Seen at the RXH Developmental Clinic, and Ritalin was prescribed and commenced.

1999-12
Mo called; she wants to take BT out fro Christmas, as they'd not seen each other for a year. Staff members felt it was important that Mo visit BT at the home first. No further contact from Mo.

2000-04-18
Assessment at the Red Cross Hospital Developmental Clinic. Age 6yrs, 4mths. Diagnosed with Hyperactivity.

2000-05-05
Ritalin commenced.

2000-12-06
Mo called and arranged to visit on 11/12/00. Mo said she was "cross" with the home. The staff explained that BT does not know Mo and needs to see her again. Hope she comes…

2000-12-19
Called family to encourage Mo to come and visit.

January 2001
Transferred to the LSEN class at school.

2001-02-27
CT Brain – no signs of atrophy; normal brain.

Sep 2001 (3rd term):
School report indicates: "…becoming enthusiastic about his work, especially Maths."

2001-11-28
Cognitive Assessment at the Red Cross Hospital Child and Family Unit – visual functioning better than verbal functioning. Poor potential for good intellectual functioning. Recommended that BT continue in the "Special" (LSEN) class at school.

APPENDIX F: BT'S DRAWING SERIES

BT, Drawing # 1, Week 1

**BT, Drawing # 2, Week 2**

BT, Drawing # 3, Week 3

BT, Drawing # 4, Week 4
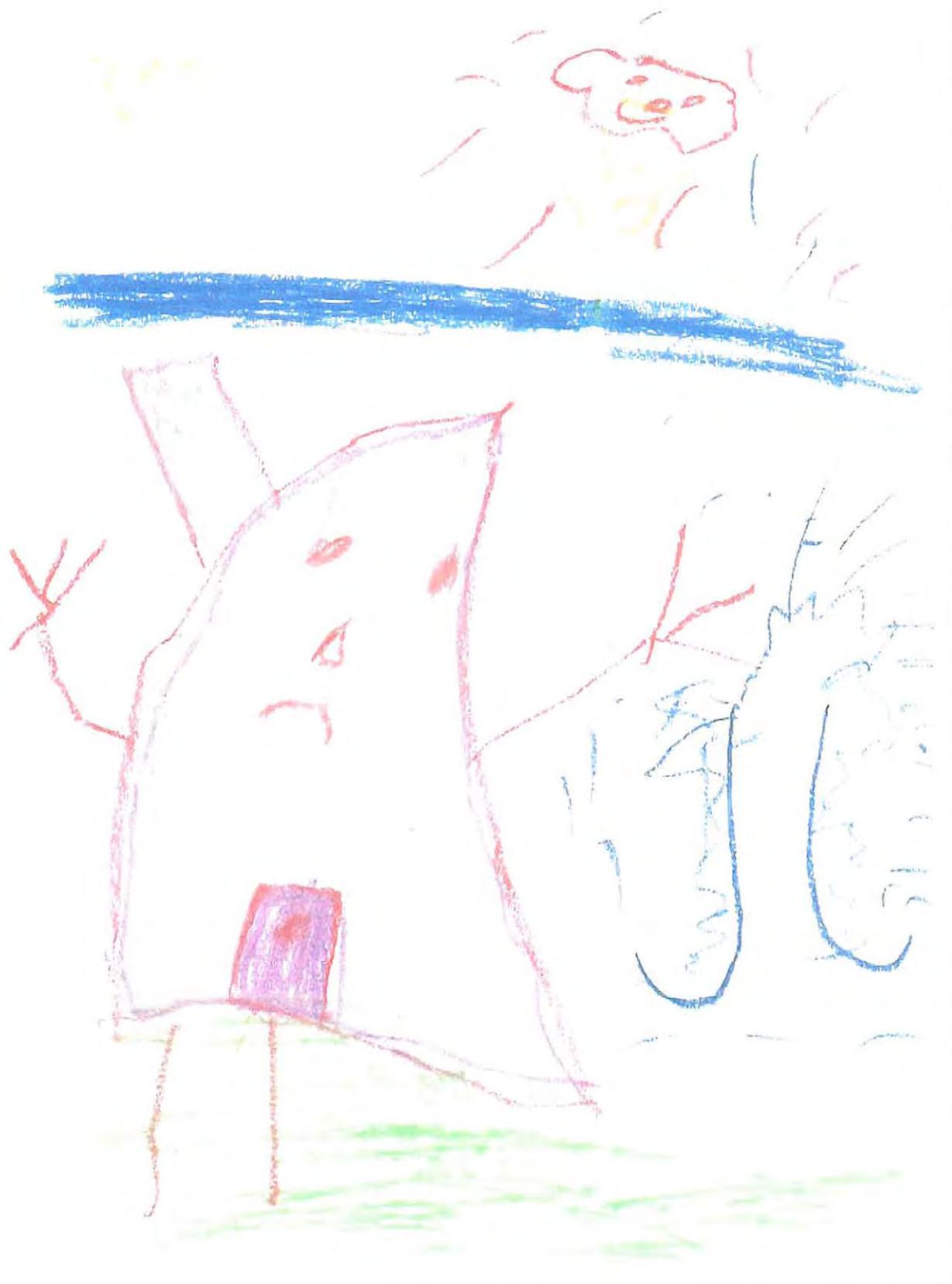
BT, Drawing # 5, Week 5

BT, Drawing # 6, Week 5
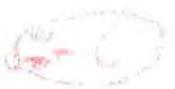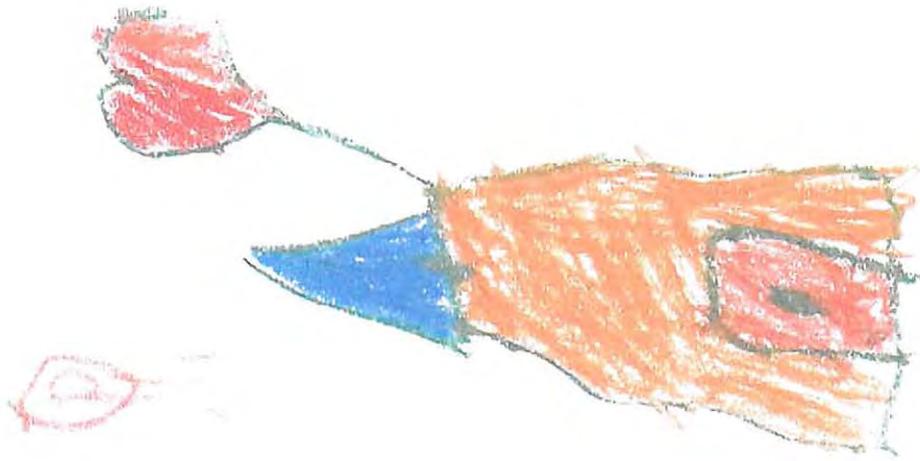
BT, Drawing # 7, Week 6
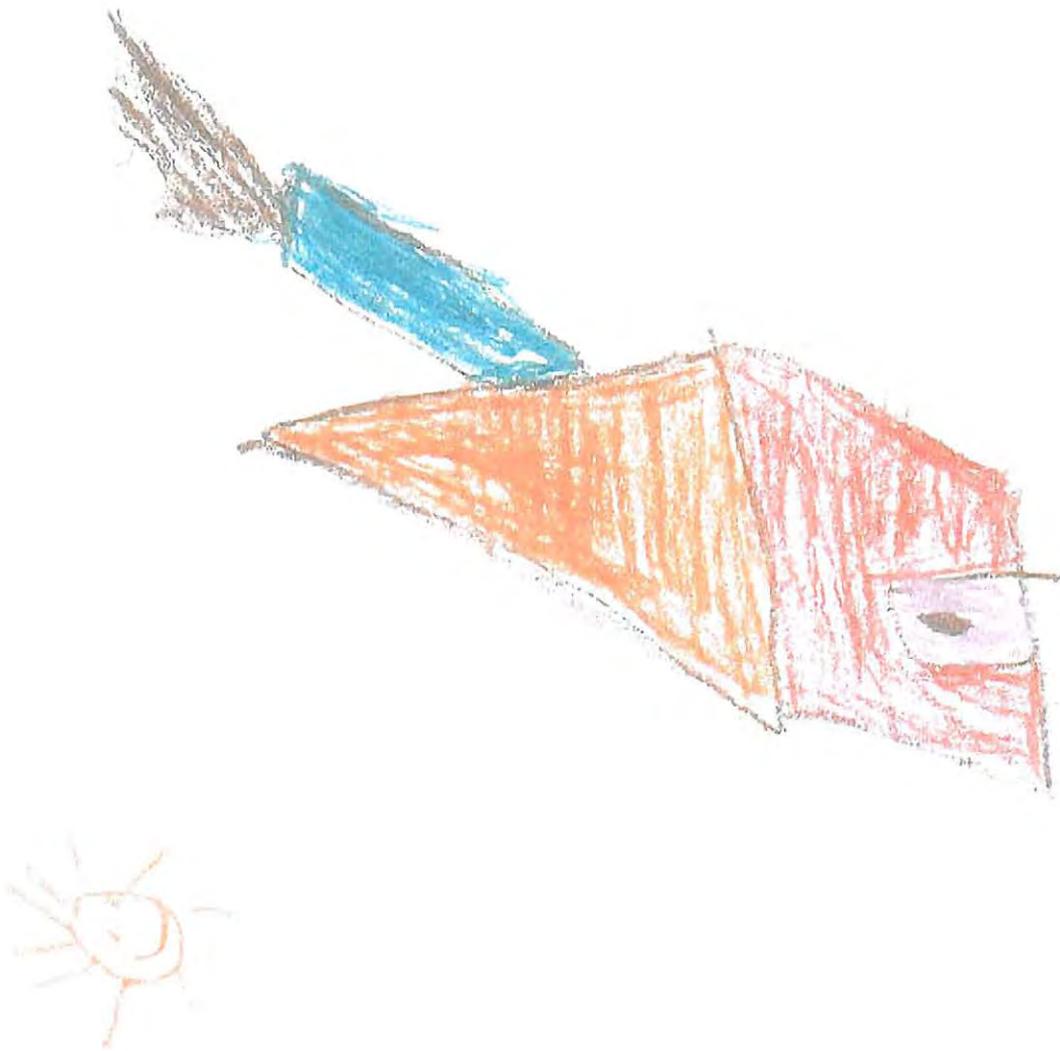
BT, Drawing # 8, Week 7

BT, Drawing # 9, Week 8

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BT, Drawing # 10, Week 9

BT, Drawing # 11, Week 10

Name:	CU
DOB:	1994
Date admitted to NH:	1995-08
Date Committed to NH:	1996-02
Mother:	QU, died December 1995 at age 18 years.

Background (from Child Welfare Society report):
The case was reported to Child Welfare Society by Mrs U from Groote Schuur Hospital (GSH) in Feb 1995. The biological Mo was staying at the Sisters of Mercy residence in Khayelitsha. Mrs U requested placement for the child, but fortunately the Sisters of Mercy were willing to take Mo and child. They stayed there for 5 months, then Mo took ill, and could not even hold the child. Mo was admitted to Somerset Hospital, and later, Brooklyn Chest Hospital for TB treatment.

Family:
Mo and Fa reported to have met at boarding school. Mo said Fa left her after he heard she was pregnant. They have had no communication since.

Mo and child were close; the only thing that separated them was Mo's illness. Mo would love to care for child, but can't due to poor health.

Socio-cultural:
Family were "staunch" members of the Roman Catholic Church. Mo was a strong believer in God. She believed that whatever happens to her and her family, is always through God's will. She believed in prayer.

Housing and Environment:
Family used to stay in a two-bedroomed shack in Khayelitsha before Mo diagnosed with AIDS in Feb 1995. After diagnosis, Mo was admitted to GSH. Went to stay at Sisters of Mercy after discharge.

Financial:
Mo was unemployed, but supported by a Maternal Aunt before she became ill.

Other:
Fa has never been supportive. Mo only knew that he was from "Natal."

Mo did not have a good support system, as her family had not visited her at all in the places she'd stayed.

Notes from folder at children's hoe

1995-08-18
Red Cross Society nurses brought baby to the children's home today, on their way to Eleanor Murray Hospice, where Mo was admitted for respite care of terminal AIDS. Mo is happy that

CU will be staying at the home, although she was initially "negative and anxious" about her baby leaving her.

Mo and baby had been staying at the Missionaries of Charity Home, Khayelitsha. Mo was very unhappy there.

CU also HIV+, but is currently stable. She is "sweet and friendly" and socialises well with the other toddlers.

1995-08-20
CU visited Mo, who is very sick, but much more comfortable at the hospice. Mo was delighted to see CU.

1995-08-23
Mo transferred to Brooklyn Chest Hospital – severe TB. Took CU to see her today.

1995-12-14
CU has visited Mo regularly. Mo's condition deteriorated. She died on Monday. CU has been keeping fairly well, and is a "very happy and playful little girl".

1995, Feb-Aug
CU presented with, and was treated for, various ailments: sore mouth, tummy pain, vomiting, diarrhoea, raised temperature, shingles, coughing, pneumonia, body rash.

1996-04-21
CU is developing appropriately. Loves to sing and dance, and socialises well. Maternal Grandmother (MGM)has called, but not visited. She informed the home that CU's Fa had died of AIDS the previous August (1995); he was a cousin of the Mo.

1996-07-02
No visits from MGM, despite concern expressed over the phone. MGM made no contact with CU's birthday in June.

1997-04-07
Generally CU is doing well. Greatest problem: skin – she breaks out in severe nappy rashes and skin lesions. Has frequent diarrhoea. Talks and socialises well, although much friction with YN (same-aged peer at the home). No contact with MGM for months.

1997-12-09:
CU has been treated for TB. Has AIDS. No family contact.

1997-12-15
Becoming "independent" and "fluent" in language. Potty-trained by day, which has helped clear the nappy rash. Loves nursery school, and sings rhymes. Plays well with peers. Still cries a lot and complains of aches and pains, even "when not really necessary." Still needs lots of attention and "extra cuddles". No family contact still.

1998-03-15
Admitted to Somerset Hospital with diarrhoea and vomiting. Not at all well. Stayed in hospital for one week. Seems fairly happy since discharge on 1998-03-24.

1998-07-06
Admitted to Somerset Hospital. Diagnosed and treated for pneumonia. Discharged: 1998-07-08.

1999-08-23
Unable to find foster care for her, due to her illness. The home will care for her "as long as she likes. We do not expect her to live for many more years." CU has not been well. Has diarrhoea and losing weight. Not in bed, but often does not look well.

2000-Feb
Relates well to all. Withdrawn at times and needs lots of attention. Could be forgotten and has to be sought out to give her special attention. Still losing weight, but stabilised since Aug 1999. Frail, but no need to hospitalise. Has spent days in bed, but always up when she feels better. "Her prognosis is not good". No family contact since Oct 1998.

2000-04-14
If all goes well, CU will start school in 2001.

2000-11-07
Developmental Assessment with the Developmental Clinic, Child Health Unit, Red Cross Hospital (aged 6yrs 4mths). "On developmental assessment she has borderline to mild fine motor and receptive language delays. She may require some assistance in class with learning."

2000-11-22
Admitted to Somerset Hospital. Diagnosed with, and treated for Pneumonia. Discharged: 2000-11-25.

2001-Jan
Enrolled for Grade 1.

2001-03-02
Admitted to Somerset Hospital. Treated for Pneumonia. Diagnosed with Chronic Lung Disease.

2001-06-25 (School Report)
CU has settled down, socially. She plays, looks at books, and is generally happy doing her own thing.

2001-10-25 (Letter to Provincial Administration of the Western Cape from children's home)
CU is generally happy but longs to be part of a family. She has an uncle (maternal) in Cape Town, and has visited him on several occasions, which she loves. We are hoping this develops into a lasting relationship and that she'll be able to stay overnight with her uncle's family. The uncle lives in very cramped conditions and would not be able to care for her on a long-term basis.

CU attends "Brownies" which she enjoys. She also went on a school camp during the July school holidays, which was very exciting for her.

2001-12-07 (School Report)

More time is needed in Grd 1.

2002-07-22 (School Report)
"At the beginning of the year, CU showed very little interest in school work. This has changed dramatically. She has made very promising progress..."

2002-10-07 (School Report)
Grade LSEN. "...a very happy child... enjoys doing things... has a most charming and disarming smile..."

2001-Dec to 2002-beginning of year
CU went away to the Eastern.Cape with her uncle and his family. She took ill on the trip. The family was hugely anxious and concerned when they got back, as CU was very ill and had lost a lot of weight. The staff at the home thought she was going to die. No preparations were made for her to go to school. She was eventually put on Morphine. Somehow, she pulled through, and though she lost so much weight, and is not back to normal weight, she has put some of it back on. She has not been seriously ill this entire year since.

APPENDIX H: CU'S DRAWING SERIES

CU, Drawing # 1, Week 1

205
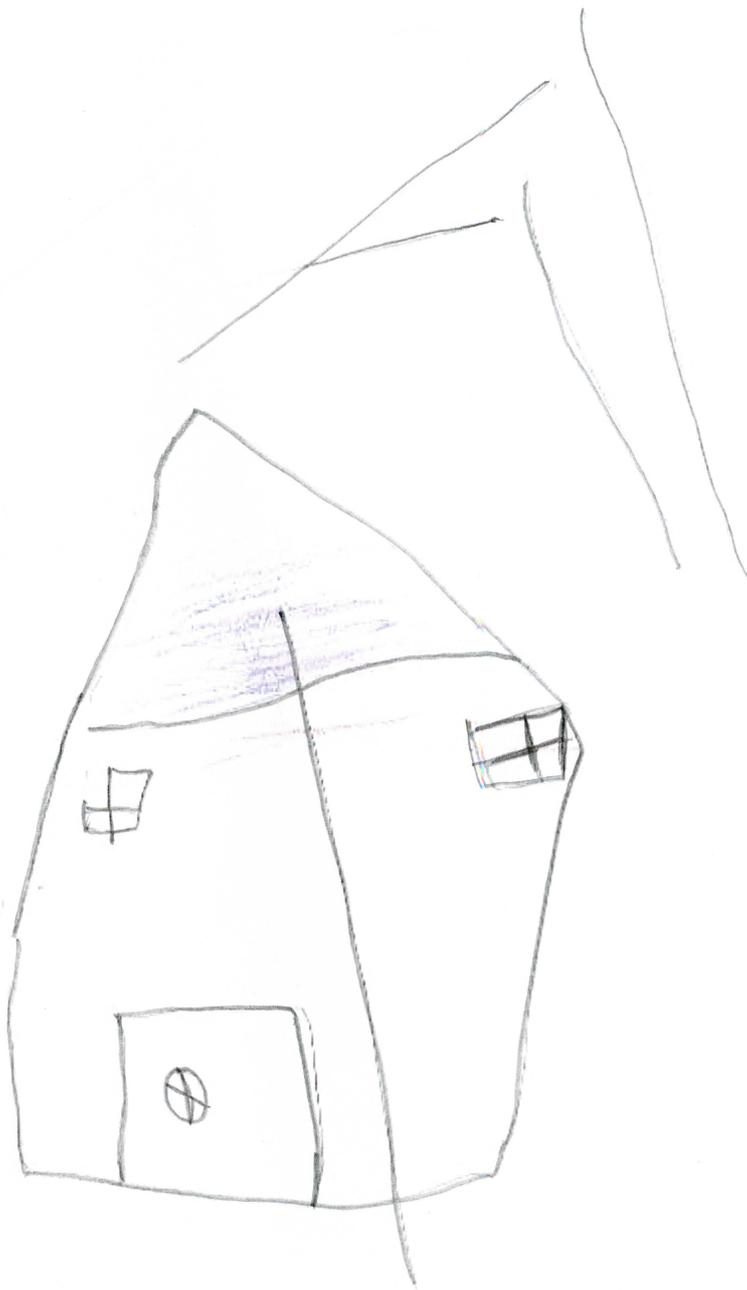
CU, Drawing # 2, Week 2

CU, Drawing # 3, Week 3 (left)
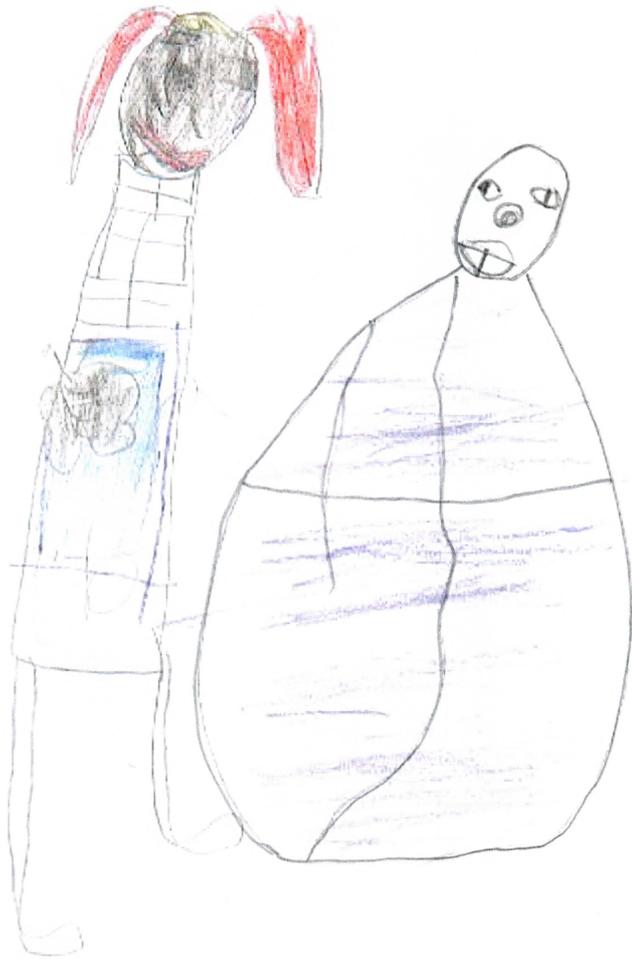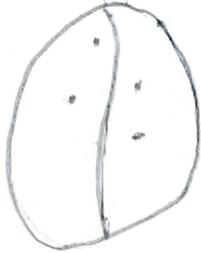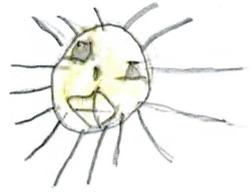
CU, Drawing # 3, Week 3 (right)
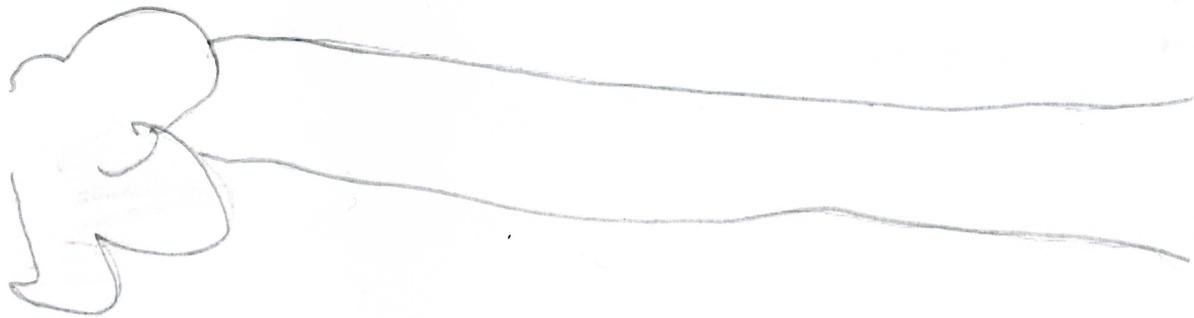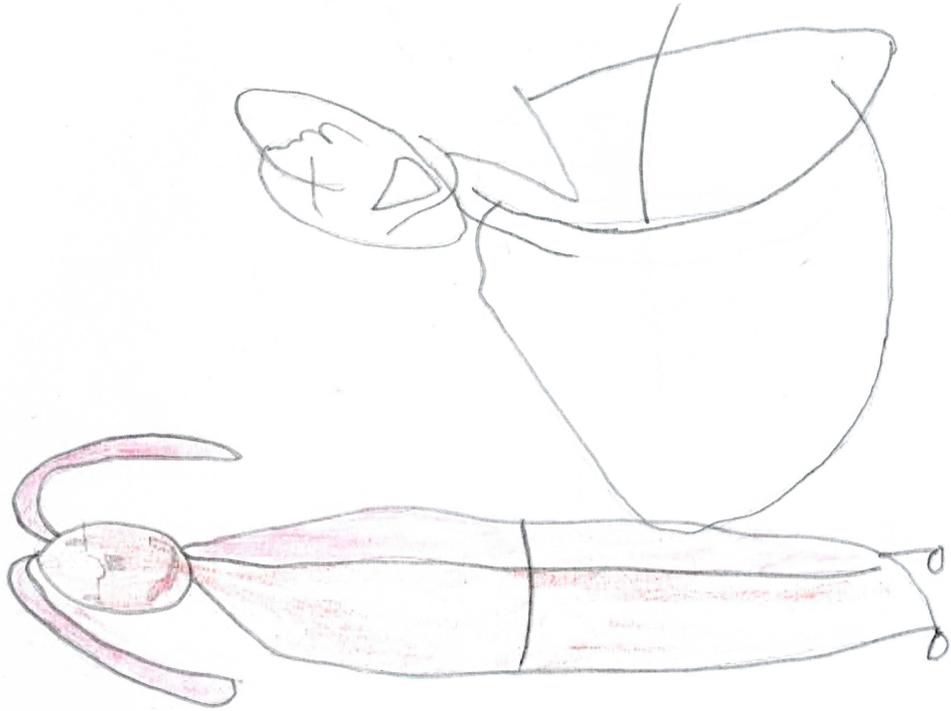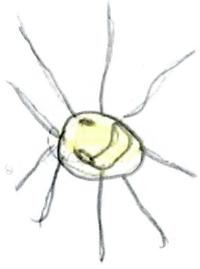
CU, Drawing # 4, Week 4

CU, Drawing # 5, Week 5
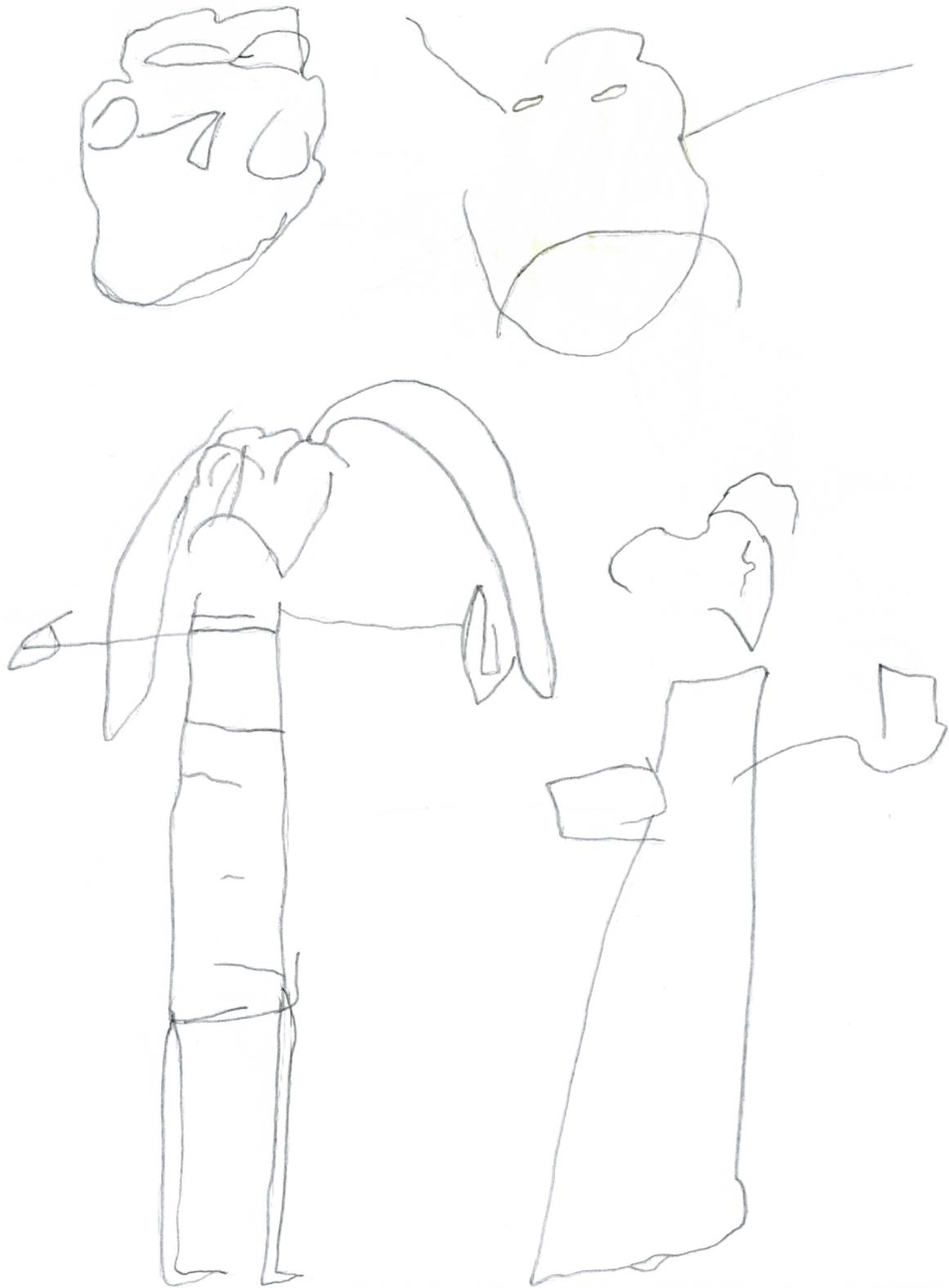
CU, Drawing # 6, Week 6

8 October 2002
(Week 7)

CU, Drawing # 7, Week 7

**CU, Drawing # 7, Week 7 (discard)**
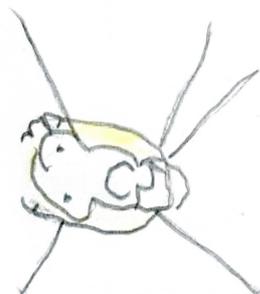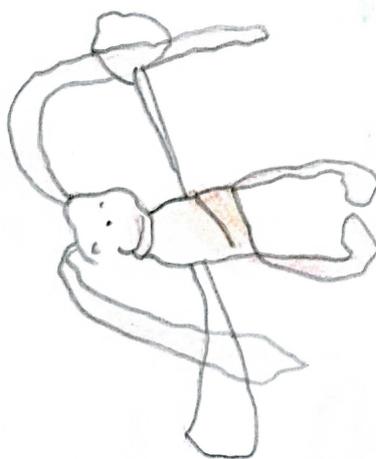
CU, Drawing # 8, Week 8
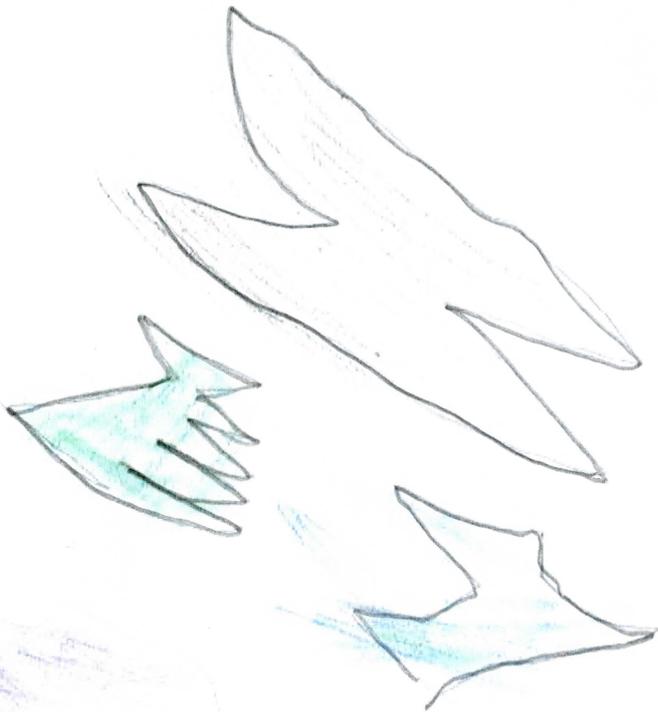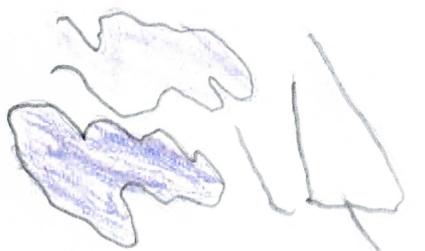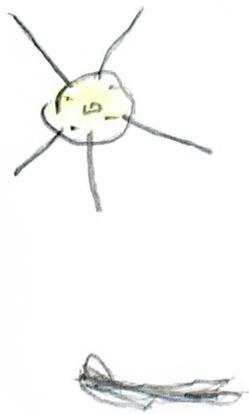
CU, Drawing # 9. Week 9
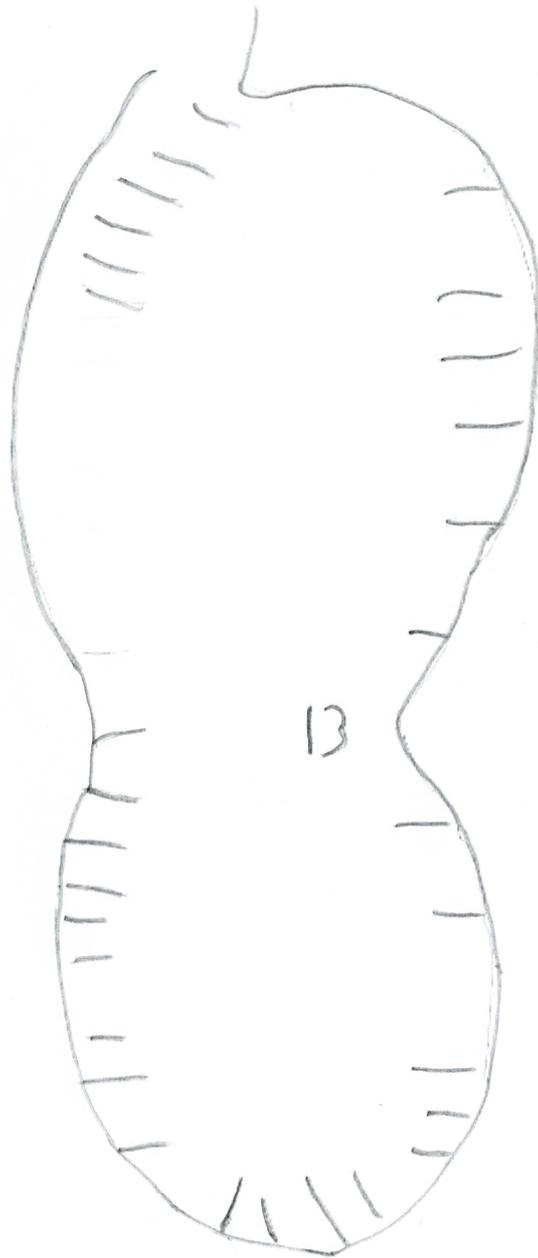
CU, Drawing # 10, Week 10

29 OCTOBER 2002
ATHULE

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CU, Drawing # 10, Week 10

CU, Drawing # 12, Week 10