A PSYCHOSOCIAL DESCRIPTION OF YOUNG ORPHANS LIVING IN CHILD-HEADED HOMES

by

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submitted in partial fulfillment of the requirements
for the degree
MASTER OF ARTS IN COUNSELLING PSYCHOLOGY

DEPARTMENT OF PSYCHOLOGY

FACULTY OF HUMANITIES
at the
UNIVERSITY OF PRETORIA

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AUGUST 2009

DECLARATION

Student Number: 27464033

I declare that A PSYCHOSOCIAL DESCRIPTION OF YOUNG ORPHANS LIVING IN CHILD-HEADED HOMES, which I hereby submit for the degree Master of Arts in Counselling Psychology at the University of Pretoria, is my own work and has not previously been submitted by me for a degree at another university. Where secondary material is used, this has been carefully acknowledged and referenced in accordance with university requirements. I am aware of university policy and implications regarding plagiarism.

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ACKNOWLEDGEMENTS

ABSTRACT

By 2010, it is projected that there will be 25 million orphans worldwide. It is anticipated that 2.3 million children will be orphaned due to AIDS in South Africa by 2020. Traditionally, the extended family has absorbed most people affected by the disease but there is a growing concern that families are finding it increasingly difficult to cope, perhaps reaching saturation point. In the absence of alternatives, some children end up living alone in child-headed households (CHHs), the numbers of which are rising at an alarming rate. Despite the increase in this living arrangement research is scarce on the psychosocial consequences of AIDS related orphanhood. This is more evident concerning very young orphans living in CHHs. This qualitative study explores psychosocial issues pertaining to young orphans living in CHHs from an ecosystemic perspective. Four participants, who worked in various capacities for two non-governmental organisations, were interviewed in-depth about their experiences of working with young orphans. The conversations were subjected to an interpretive analysis where, in collaboration with the participants, central themes and sub-themes were identified. Eleven main themes emerged from the analysis: *why children live in child-headed households; issues surrounding the death of a parent; experiences of a young child living in a child-headed household; the experience of living in a child-headed household; stigma; relationships with relatives; relationships with peers; relationships with crèches and teachers; relationships with the community; relationships with non-governmental organisations; and relationship to government and essential services.* Based on an integration of the findings, a model was presented depicting the ecosytemic factors affecting the very young child living in a CHH.

Key Words: *HIV/AIDS, orphans, early childhood development, child-headed household, psychosocial, ecosystemic epistemology, poverty, South Africa, orphans and vulnerable children, non-governmental organisation.*

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ACRONYMS AND ABBREVIATIONS

ADHD	Attention Deficit Hyperactivity Disorder
AHH	Adult-headed Household/Home
AIDS	Acquired Immune Deficiency Syndrome
ARV	Antiretroviral Drugs
CHH	Child-headed Household/ Home
Heartbeat	Heartbeat: Centre for Community Development
HIV	Human Immuno-deficiency Virus
ID	Identity Document
Ikageng	Ikageng Itireleng AIDS Ministry
NGO	Non-governmental Organisation
OVC	Orphans and Vulnerable Children
RDP	Reconstruction and Development Program
STI	Sexually Transmitted Infection
UJ	University of Johannesburg
U.S.	United States

CHAPTER 1

THE JOURNEY

*'Begin at the beginning,' the King said, very gravely, 'and go
on till you come to the end: then stop.'*
- *Lewis Carroll, (1865/1994) Alice's Adventures in
Wonderland (p.142)*

INTRODUCTION

The aim of this research is to offer a psychosocial description of very young orphans (between 2 and 5 years of age) living in child-headed households (CHHs) as result of HIV/AIDS. Although research exists on the impact of HIV/AIDS on affected children, very little research focuses specifically on the psychosocial repercussions for very young children, particularly those living in CHHs. The rapid spread of HIV/AIDS throughout the world has resulted in a global crisis, with the worst affected region being sub-Saharan Africa, "the epicentre of the pandemic" (Earls, Raviola & Carlson, 2008, p. 298), where 24% of the world's children aged 0 to 4 years are anticipated to live by 2020 (Dunn, 2005; Richter & Rama, 2006). Children have become the most acutely afflicted age group (Earls et al., 2008). It is projected that by 2010 there will be 25 million orphans worldwide (Tindyebwa et al., 2006), with 2.3 million children orphaned by AIDS in South Africa by 2020 (Actuarial Society of South Africa, 2005). *The National Household HIV Prevalence and Risk Survey of South African Children* established a prevalence rate of 5.4% in children between the ages of 2 and 18 years and a maternal orphan rate of 3.3% for this age group (Brookes, Shisana & Richter, 2004). Overall, 0.5% of South African households claimed to be headed by a child between 14 and 18 years of age. Authors (for example, Brookes et al., 2004; Meintjies, Budlender, Giese & Johnson, 2003) agree that the full impact of orphanhood in South Africa has not yet been experienced but argue that there is still time to prepare for its increase. It is anticipated that by 2015, 15% of all South African children will be orphans (Brouard et al., 2006).

Most people affected by the disease are absorbed into the extended family but it is evident that the extended family has become overloaded, bringing into question the very notion of what comprises a family (Dunn, 2005; Freeman, 2004; Hlatshwayo, 2003; Li et al., 2008; Ross & Deverell, 2004; Swift & Maher, 2008; Townsend & Dawes, 2004, 2007; United Nations Children's Fund [UNAIDS], 2006). In the absence of healthier options, the numbers of CHHs are rising at an alarming rate (Donald &

Clacherty, 2005; Donald, Lazarus & Lolwana, 2006; Louw & Louw, 2007; Richter & Desmond, 2008; Ross & Deverell, 2004; Swift & Maher, 2008). Several authors (for example, Louw & Louw, 2007; Tolfree, 2006) propose that CHHs should not be summarily dismissed as, with adequate support, they may be a viable option for child care. CHHs are being proposed as a model of care as it is recognised that, in some situations, it may be better for a child to live without adult caregivers. Some children argue that this living arrangement can better cater to their needs than certain alternatives (Goldblatt & Liebenberg, 2003; Louw & Louw, 2007; Rosa & Lehnert, 2003). However, little research is available on the effects that living in a CHH has on a child, especially on very young children.

JUSTIFICATION, AIM AND OBJECTIVES

A bulletin issued by the national Department of Health (cited in Van Vuuren, 2004) announced: "Every responsible adult should realise that the enormity of the HIV/AIDS disaster calls loudly and clearly for all possible available structures and people to be mobilised to nurture children, who are the future of this country" (p. 207).

Despite this call there is a gap in research pertaining to young children living in CHHs. This is disturbing because, as mentioned earlier, this living arrangement is increasing in South Africa and is even being considered as a model of child care. The gap in research filters down to the evident failure of programming and policy to address issues surrounding very young children affected by HIV/AIDS at local, national and international levels, even though they are probably more severely affected by the crisis (Dunn, 2005; Richter & Rama, 2006; Swift & Maher, 2008). Although younger orphans make up a smaller percentage of all orphans (16%), UNAIDS (2006) argues that they are "the least resilient and have the greatest need for physical care and nurturing" (p. 6). Despite this, programmes do not seem to be engaging with specific content for this age group (Dunn, 2005; Lusk, Huffman & O'Gara, 2000) and the concern for young children "remains striking in it's invisibility" (Swift & Maher, 2008, p. xi). Tindyebwa et al. (2006) believe that this is due to a poor understanding of the spiritual, mental, social and emotional issues of young children.

These orphans are affected at a critical formative stage in their development. This has lasting developmental consequences and affects their quality of life (Dunn, 2005; Richter & Rama, 2006). As a result of their specific health, nutrition and psychosocial needs, young children represent a group that requires special attention and yet their unique experiences have by and large been ignored (Dunn, 2005; Lusk et al., 2000; Swift & Maher, 2008). Tindyebwa et al. (2006) point out that

although there are many books on HIV/AIDS in Africa, "they contain little in the way of practical experiences, insights or guidelines about the care of children" (p.13). While the impact of HIV/AIDS research targeted at other audiences does trickle down and profit young children, a specialised focus on the very young is absent or poorly documented (Dunn, 2005; Tindyebwa et al., 2006). In launching *The State of the World's Children 2001,* Carol Bellamy stated: "Unless under-fives are cared for in the present, no amount of later intervention is likely to be effective or efficient" (cited in Dunn, 2005, p. 5).

Research suggests that the 0 to 8 age range is a critical developmental stage as emotional, cognitive, physical and spiritual development is at its most rapid (Dunn, 2005). Because of this rapid development, children do not all have the same needs. For example, the needs of a baby are different to those of a 5-year-old. For this reason, and in order to provide meaningful and focused data, I decided to restrict the research to the 2- to 5-year-old age group. Similarly, although there is a growing trend to focus on orphaned and vulnerable children (OVC) as opposed to only children orphaned by AIDS (Tindyebwa et al., 2006), the scope of this study was limited to orphans living in CHHs as a result of HIV/AIDS.

In addition to the apparent gap in knowledge concerning this population group, I was motivated to investigate this field further because of my own participation in the research, development and implementation of a programme aimed to offer emotional enrichment to OVC in the preschool setting. This constituted part of my training as a counselling psychologist. In interviewing teachers and caregivers it became evident that attention needed to be focused on this specific population group. Their knowledge about the particular needs of these young children in the context of HIV/AIDS was limited and they felt ill equipped to offer effective support. Working in the field with very young OVC touched me emotionally and I felt compelled to contribute to their cause. I felt moved to contribute to this neglected body of research so as to raise awareness of the individual suffering and social disorder that the orphan crisis creates.

Consequently, the gaps in research specifically targeting young children living in CHHs because of HIV/AIDS and my own personal involvement in this field served as my motivation for conducting this study. As the orphan crisis has not yet reached its peak, I hope that this research will contribute, in some small way, toward alleviating the plight of these children. My main objectives included:

- To describe the psychosocial issues surrounding young children living in child-headed homes.
- To describe the psychosocial climate within the child-headed household.
- To explore the relationships that very young children living in child-headed homes have with wider systemic levels, such as their siblings, extended family, neighbours, peers, crèches, the wider community and the wider society.
- To discuss the findings within the context of the reviewed literature and research.
- To provide an ecosystemic understanding of the research problem.

OVERVIEW OF CHAPTERS

Chapter 2

Chapter 2 reviews current literature and research surrounding the research problem. Key concepts are defined and, in order to place the plight of young orphaned children in context, the developmental period of early childhood is briefly described. Discussions ensue as to the relationship between poverty and HIV/AIDS, the historical context of the African family and how this has been disrupted by the spread of the disease and possible placement options for affected children. Research and literature surrounding parental illness and death are discussed as well as psychosocial issues associated with living in a CHH.

Chapter 3

In this chapter, the theoretical perspective from which the research was conducted is explicated. The relevant tenets of an ecosystemic approach are discussed.

Chapter 4

This chapter provides a detailed description of the research methodology. A qualitative research design was adopted and data was collected by means of in-depth, semi-structured interviews with 4 participants. Participants were selected by means of a snowball sampling technique. An interpretive analysis was performed on the data. Techniques to ensure the soundness of the study are discussed and the chapter concludes by addressing various ethical concerns.

Chapter 5

Chapter 5 commences by briefly introducing the reader to the participants in the study and the organisations for which they work. The remainder of the chapter discusses the themes and sub-themes that were induced from an interpretive analysis of the interviews. Themes were emergent and were based on the ecology of ideas that evolved between the participants, my research supervisor and myself during the research process. Thus, the final themes were constructed collaboratively. As far as possible, I have tried to narrate the chapter through the words and experiences of the participants. Eleven central themes are discussed and some of these themes are further broken down into sub-themes. The 11 main themes are:

Theme 1:   Why children live in child-headed households
Theme 2:   Issues surrounding the death of a parent
Theme 3:   Experience of a young child living in a child-headed household
Theme 4:   The experience of living in a child-headed household
Theme 5:   Stigma
Theme 6:   Relationships with relatives
Theme 7:   Relationships with peers
Theme 8:   Relationships with crèches and teachers
Theme 9:   Relationships with the community
Theme 10:   Relationships with non-governmental organisations
Theme 11:   Relationship to government and essential services

Chapter 6

In Chapter 6, the qualitative enquiry as laid out in Chapter 5 is elaborated. A model based on the central themes that emerged from the research serves as a guide for the discussion. An attempt is made to discuss the research findings in the context of other literature and research related to this research problem and to offer an ecosystemic understanding of the material.

Chapter 7

This chapter documents the final step of an interpretive analysis, that of self-reflection. The ecosystemic approach makes certain demands on the researcher, and these are addressed in Chapter 7. My personal experiences while conducting this research are presented in this chapter.

Chapter 8

The final chapter of this dissertation offers an evaluation of the research and makes some recommendations for future research related to this research topic.

CONCLUSION

This chapter introduced the reader to the research problem and highlighted the need for research that focuses on young children living in CHHs. It was argued that very young children are at a critical stage in their development and yet research concentrated on their specific issues has been scant. As the number of orphans and CHHs are expected to increase in sub-Saharan Africa, it was argued that attention must be dedicated to young children's specific needs. Further, this chapter presented the aims and objectives of the research and provided an overview of the chapters contained in this dissertation.

CHAPTER 2

LITERATURE REVIEW

Curiouser and curiouser!

- *Lewis Carroll, (1865/1994) Alice's Adventures in*
Wonderland (p.21)

INTRODUCTION

Very young children are profoundly impacted by the HIV/AIDS pandemic as it influences their personal and social development as well as their quality of life (Donald et al., 2006; Dunn, 2005). The term children is used in most of the literature on HIV/AIDS as "a catch-all term that masks a myriad of differences among young children from birth to 18 years of age" (Richter, Foster & Sherr, 2006, p. 23), which can be misleading. Different needs and experiences according to, for example, age, gender and location (rural or urban) are often overlooked (Richter et al., 2006). Children of different developmental levels have specific needs yet literature and research pertaining specifically to the 2- to 5-year-old age group, especially those living in CHHs, is scarce. Much of the material reviewed here is guilty of reporting on children generally. Where possible, I have pointed out when content relates specifically to the very young child. As literature on early development in this context is limited, the normative development of this age group is briefly described so that comparisons can be made. In South Africa, it is children of African descent, those in poor households and those living in urban informal settlements that are most affected (Brookes et al., 2004; Shisana & Simbayi, 2002). Thus, this chapter contextualises the research problem by relating it to the effects of poverty, the disintegration of the family and alternative child care strategies. Psychosocial issues surrounding parental illness and death are discussed before focusing on CHHs. The chapter commences by defining some key concepts.

CONCEPTS

Orphan

The concept of an 'AIDS orphan' is relatively new (Sherr et al., 2008). Earlier definitions of the term orphan referred to a child who was under 15 years of age whose mother, father or both parents had died (Andrews, Skinner & Zuma, 2006; Donald et al., 2006; Ghosh & Kalipeni, 2004; Richter, 2004;

Sherr et al., 2008). However, it has been increasingly acknowledged that orphans do not cease to need parenting at the age of 15 and thus children up to the age of 18, the customary definition of childhood, are now often incorporated in the definition (Andrews et al., 2006; Donald et al., 2006). UNAIDS (2006) defines an orphan as "a child under 18 years of age whose mother, father or both parents have died from any cause" (p. 4). Richter and Desmond (2008) argue that the term is a technical one and most children identified as orphans in the scientific programming and advocacy literature do actually have a living biological parent. Thus, studies often include different groups of orphans that can be classed into single, double, maternal or paternal orphans (Ghosh & Kalipeni, 2004; Richter & Desmond, 2008). A single orphan has lost one parent, a double orphan has lost both parents; a maternal orphan's mother has passed away, whereas a paternal orphan has lost his or her father (UNAIDS, 2006).

These definitions, which have been widely adopted by governments and aid agencies, have been challenged. It is argued that adults other than biological parents are frequently the main carers of children and therefore the definition should be broadened to include "those whose care is compromised by either the terminal illness of an adult who contributes to their care and/or financial support, or by the death of such an adult" (Swift & Maher, 2008, p. 43). The phrase orphaned and vulnerable children (OVC) is preferred (Swift & Maher, 2008).

Orphans and Vulnerable Children

The phrase orphans and vulnerable children was introduced from a policy perspective to make sure that all vulnerable children, regardless of involvement with AIDS, were included in programmes and to highlight the children's various requirements over time before parental death (Sherr et al., 2008). A vulnerable child can be defined as one who experiences "multiple and/or serious risks to development such as poverty (including adequate housing, water, sanitation, food and clothing); access to social services; disease; disability; neglect; exploitation; or abuse" (Donald et al., 2006, p. 191). Hence, the expression orphaned and vulnerable children includes both orphans and those who are jeopardised in other areas, such as other household factors or parental illness prior to a parent's death (Donald et al., 2006; Schenk et al., 2008; Sherr et al., 2008). However, Schenk et al. (2008) point out that, "while the term is a useful theoretical construct, its practical use is beset by difficulties, both methodological (e.g. defining vulnerability; assuming homogeneity of support needs) and ethical (e.g. danger of stigmatising children by labelling them)" (p. 895).

Child-headed Household

No formal definition of a CHH exists and the precise definition is controversial (Louw & Louw, 2007). A CHH is usually regarded as one where children or orphans live without a resident adult guardian and the head of the household is 18 years or younger (Shisana & Simbayi, 2002).

Psychosocial

The term psychosocial contains an emotional and a social component. Psycho is an abbreviation for psychological and includes feelings (emotions) and thoughts, as well as how children behave because of those feelings and thoughts (Regional Psychosocial Support Initiative [REPSSI], 2007). The social component refers to the child's relationships with others (REPSSI, 2007). De Witt and Lessing (2005) define psychosocial as "individual psychological characteristics that are in continual interaction with the social context" (p. 15). Richter et al. (2006) claim that there is some confusion around the term. Psychosocial interventions, consisting of formalised tools, programmes and processes, differ from psychosocial care and support, which is experienced through interpersonal interactions at home, the community and at school. This care and support allows children to experience a sense of self-worth and belonging, which is essential for learning and the development of skills to participate in society. Psychosocial well-being, on the other hand, is the "age- and stage-appropriate outcome of children's physical, social and psychological development" (Richter et al., 2006, p.15) and is attained through a blend of individual capacities as well as through the material and social environment. In very young children, psychosocial well-being is dependent on the holistic, positive and suitable development of the child, within a supportive family, household and community environment (REPSSI, 2007). Richter et al. (2006) argue that psychosocial well-being "is essential for children's survival and development, especially in chronically difficult circumstances" (p. 15).

EARLY CHILDHOOD

In order to accentuate the plight of very young children in the context of HIV/AIDS, I decided to present a brief introduction to normative child development. Although each child is unique, it is generally believed that they progress through certain predictable stages as they grow. Early childhood, or the preschool period, lasts from about the age of 2 to 6 years (Louw & Louw, 2007). Physical development slows down, allowing for various body parts to develop proportionally (Louw & Louw, 2007). The brain develops most rapidly in the first three years of life and it is here where

children learn most quickly from their opportunities and experiences, laying the mental foundation for life-long strengths or problems (REPSSI, 2007). Language development, organising and planning skills, consciousness, alertness and motor control mature along with different areas of the brain (Louw & Louw, 2007). Early childhood sees the development of intellectual capacity, emotional well-being, self-confidence, self-esteem and resilience (REPSSI, 2007). Changes in the child's emotional experiences during this stage are influenced by their increased cognitive and social development (Louw & Louw, 2007). They show an increased ability to regulate their emotions and begin to reflect a more complex understanding of the self and social relationships (Louw & Louw, 2007). Self-esteem is usually high and young children tend to display idealistically positive self-perceptions (Louw & Louw, 2007; Wenar & Kerig, 2005). Family relationships occupy a critical role in their development and attachment, although less visible, remains important (Louw & Louw, 2007). Sibling relationships are important in assisting young children to develop social relationships with their peers, which is enhanced in early childhood due to improved communication skills, self-awareness and empathy (Louw & Louw, 2007).

Much of the healthy development of the child takes place naturally in the family environment (REPSSI, 2007; Richter et al., 2006). Very young children have specific needs in terms of nurturance and love, stable care, protection and a stimulating environment (Richter et al., 2006). Families severely affected by HIV/AIDS may not be privileged enough to have such an environment, thereby compromising their ability to provide for the needs of their children (REPSSI, 2007). Heredity, hormones, nutrition and emotional stress are all aspects that can influence the child's physical and emotional development (Louw & Louw, 2007; Wenar & Kerig, 2005). Children that lose their primary caregiver during this stage are at great risk of serious long-term consequences (Richter et al., 2006). To ensure a more holistic understanding of the impact of becoming orphaned and living in a CHH these normal developmental characteristics of the young child should be kept in mind while reading the remainder of this chapter. The effects of poverty are inextricably linked to HIV/AIDS and the growing child and thus these will be considered prior to discussing the familial context, the process of becoming orphaned and characteristics of living in a CHH.

A BACKDROP OF POVERTY

Fifty-seven percent of South Africa's population live in poverty with 40% of children being raised in abject poverty (Swift & Maher, 2008). It is estimated that two-thirds of children under 5 years of age live in homes that are considered "ultra-poor" (Swift & Maher, 2008, p. 11). The effects of poverty

influence all facets of an individual's and community's functioning: "It affects the physical and psychological development of a person; it becomes a way of life, a subculture in the community from which it is very difficult to escape" (Louw & Louw, 2007, p. 365). A child's development may be negatively impacted because of inferior access to services, adverse environmental circumstances, insufficient provisions, social volatility and dispirited and overworked caregivers (Richter et al., 2006). When subjected to this environment, together with the infiltration of disease and disintegration of support structures, children are more susceptible to infant death, low birth weight, stunted growth, severe illness, lower IQ and lack the energy necessary to engage with their environment and learn, which may result in poor school adjustment and grade repetition (Ghosh & Kalipeni, 2004; Louw & Louw, 2007; Richter et al., 2006; Swift & Maher, 2008). This can induce insecurity, stress and loss of hope, which may result in excessive clinging (Richter et al., 2006; Swift & Maher, 2008). If this is experienced for most of the child's early years, it may delay or have an enduring impact on their physical, cognitive, psychological and social potential (Richter et al., 2006; Swift & Maher, 2008; Wenar & Kerig, 2005). This renders children onerous to adults resulting in punitive, distant and inconsistent parenting and may impact a caregiver's capacity to show love and respond positively to the psychological and physical needs of the child (Donald et al., 2007; Swift & Maher, 2008; Townsend & Dawes, 2004).

Children living in informal settlements or poor households are more likely than their wealthier peers to lose one or both parents to AIDS (Brookes et al., 2004). HIV/AIDS exacerbates the effects of poverty on young children as the pandemic is rooted in and reciprocally contributes to poverty (Richter et al., 2006; Swift & Maher, 2008). Impoverished communities usually have the highest infection rates as they provide an environment that is conducive to the rapid transmission of HIV (Hunter & Williamson, 1997). In turn, HIV/AIDS strains communities by increasing poverty, reducing the labour pool (especially for skilled and agricultural labour), threatening the potential to sustain infrastructure, decreasing access to education and health care, increasing mortality and generally contributing to the loss of resilience in people (Hunter & Williamson, 1997). Thurman et al. (2006) claim evidence is accumulating that the amount of social capital in a community predicts the psychosocial functioning of the members of that community. They define social capital as "the features of social relationships that facilitate collective community action for the mutual benefit of members" (Thurman et al., 2006, p. 220). It has been argued that a community's ability to cope can be measured by the number of orphans in the community and how successfully it can absorb them into the extended family rather than leaving them to live alone (Schenk et al., 2008; Thurman et al.,

2006). Consequently, the psychosocial well-being of orphans depends largely on the ability of the community to sustain and rear them (Landry, Luginaah, Maticka-Tyndale & Elkins, 2007).

THE FAMILY

Historical Context

Family life in any community is formed by the socio-economic and historical circumstances of that society (Goldblatt & Liebenberg, 2003). South Africa's migrant labour system, created by its colonial past, and the legacy of apartheid have had far reaching implications for the organisation of family life (Goldblatt & Liebenberg, 2003; Swift & Maher, 2008; Tolfree, 2006). The fragmentation of African families began "long before the world became concerned that HIV and AIDS were taking primary carers out of families" (Swift & Maher, 2008, p. 16) with the introduction of industrialisation in colonial times. Traditionally there has been mobility between households and geographical areas: "Household boundaries were…fluid as kin came and went in search of work or social network support, and children were moved with the aim of seeking out resources, education, care and support, or providing care or domestic labour to relatives needing assistance" (Meintjies et al., 2003, p. 12)

As many parents migrated to the urban areas to find work children were, and still are, left in the care of family members, typically the grandmother, who plays a key role in child rearing (Swift & Maher, 2008). Father absenteeism has always been high due to migration and because many fathers do not live with the mother of their child (Andrews et al., 2007; Parikh et al., 2007). Child rearing has traditionally been a collective activity in African communities, especially in rural areas, where older siblings, aunts, grandparents and other adults are involved (Ghosh & Kalipeni, 2004; Goldblatt & Liebenberg, 2003; Swift & Maher, 2008; Townsend & Dawes, 2004). It is also common for older children, especially girls, to fulfil some of the roles of the primary caregiver (Goldblatt & Liebenberg, 2003; Landry et al., 2007; Tolfree, 2006). Thus, informal child fostering has been, and remains, common practice in many parts of Africa (Schenk et al., 2008; Urassa, Walraven & Boerma, 1997). Hence, it is vital to consider the local context when considering the orphan problem (Urassa et al., 1997).

The Impact of HIV/AIDS

Many of these traditional arrangements remain but have been exacerbated and challenged since the onslaught of HIV/AIDS. While African families have a long history of family dispersal that precedes the onset of HIV/AIDS, what has changed because of bereavement, especially for the many grandmothers caring for children, is that their support base has been destabilised:

> They may find themselves on their own looking after grandchildren and possibly other orphans at a time when they are mourning the loss of their own offspring, instead of enjoying their support, and they may be frail or unwell themselves. As well as losing loved ones, they have lost financial support and family helpers. The pension designed to meet their needs is stretched to secure the survival of several people. (Swift & Maher, 2008, p.43)

Freeman and Nkomo (2006) surveyed current and prospective South African caregivers and found that 30% of children were not living with their biological parents. For approximately a third of these children this was due to the death of a mother or father. Many of these deaths were HIV/AIDS related. It is expected that most orphans will be provided for by their extended families and "by far the majority of orphaned children are indeed living in or with extended families" (Freeman & Nkomo, 2006, p. 303). Research (Andrews et al., 2006; Richter et al., 2006) estimates that the extended family has assumed responsibility for 90% of orphaned children in most countries in sub-Saharan Africa. Participants surveyed by Freeman and Nkomo (2006) stated that, in principle, they were willing to or presumed they would take care of family members' children should they need to. They found "the *in principle* willingness of people of various relationships to children to take in OVC… highly encouraging and supports the view that rather than constructing institutions to house OVC, families and communities will incorporate children" (Freeman & Nkomo, 2006, p. 309). This was seen as a sign that traditional and cultural arrangements and the spirit of *ubuntu* were still dominant among the extended family. *Ubuntu* represents "humanity, community, selflessness or love and concern for others – often expressed in the notion 'your child is my child'" (Swift & Maher, 2008, p. 5) or "I am what I am because of who we are" (Freeman & Nkomo, 2006, p. 308).

However, Freeman and Nkomo (2006) point out that it is probable that people's willingness to help in principle may be jeopardised by the "economic and social difficulties that come with providing a home for a child" (p. 308). They cite research that predicts that traditional and cultural norms will be contested as financial resources become compromised. This was confirmed in Swift and Maher's

(2008) recent review of the impact of HIV/AIDS and poverty on very young children: "This idea that 'your child is my child' and the traditional helping mechanisms that derive from and feed into the creation of a strong sense of community appear to be under concerted attack in the rapidly changing South Africa" (p. 32). Their participants, although not a representative sample, believed that customary values and the traditional support from the extended family and the community were decreasing. Kistner quotes a participant of hers: "*Ubuntu* is dead. AIDS has killed *ubuntu*. Everybody is busy with their own loneliness" (cited in Swift & Maher, 2008, p. 66). Thus, Freeman and Nkomo (2006) highlight that for the extended families' good intentions and readiness to help to transform into reality they will need to be strongly supported financially and by other family members.

Although remarkable efforts have been made to integrate OVC into families and to care for the young under severe conditions of poverty and stress, there is a growing concern that families are finding it increasingly difficult to cope and perhaps reaching saturation point (Barnett & Blaikie, 1992; Daniel, 2005; Dunn, 2005; Ebersöhn & Eloff, 2002; Freeman, 2004; Germann, 2003; Hlatshwayo, 2003; Landry et al., 2007; Li et al., 2008; Townsend & Dawes, 2004, 2007; UNAIDS, 2006). Ghosh and Kalipeni (2004) highlight that the challenge of absorbing escalating numbers of orphans into resource-poor households has "surpassed the material ability of most households, regardless of the willingness or desire to help. It is clear from research in southern and eastern Africa that the traditional way of caring for orphans is now beyond the extended family's ability to cope" (p. 313). Freeman and Nkomo (2006) add: "Hopes that the extended family would be sufficient to absorb the full social, economic and psychological impacts arising from the AIDS epidemic seem to be unrealistic" (p. 303). This leads to less willingness to care for OVC (Thurman et al., 2006; Urassa et al., 1997).

The common phrase, which describes orphans as being absorbed into the extended family assumes that this is always beneficial to the child but it "masks a variety of outcomes" (Swift & Maher, 2008, p. 36). While many placements within the extended family are positive, this is not always the case: "'Absorption' can refer to children being moved from a defeated family to a very vulnerable one. Absorption from poverty and disease into a new context of poverty and disease offers few guarantees and is more of a lifeline or a life thread, than a safety net" (Swift & Maher, 2008, p. 36). Because of the geographic concentration of HIV/AIDS in impoverished areas "vulnerable children are cared for by vulnerable families and reside in vulnerable communities" (Hunter & Williamson, 1997, p. 3). Research (Landry et al., 2007; Orner, 2006) has found negative impacts on caregivers' mental health at a household level because of the considerable demands placed on them. The psychosocial

impact is exacerbated by insufficient revenue and extreme poverty, lack of support, extensive fatigue, lack of sleep, eating problems, isolation and stigma, anger, frustration and the additional obligation of caring for more household members (Landry et al., 2007; Orner, 2006). Landry et al. (2007) call caregivers the "hidden victims" (p. 93) of HIV/AIDS. Carers can become overburdened to their own detriment, as well as the detriment of their own children and the orphaned children in their care (Richter et al., 2006; Swift & Maher, 2008). Thus, a carer may unwillingly accept responsibility for children, leaving them vulnerable to neglect or abuse – the relationship may be more functional than emotional (Howard, Matinhure, McCurdy & Johnson, 2006; Swift & Maher, 2008). Thus, traditional fostering arrangements are being replaced by crisis fostering (Yamba, 2005). Whereas voluntary fostering normally has economic benefits (for example, sharing child-rearing costs, cheap child labour and reciprocity agreements), Daniel (2005) found that reciprocity is often absent in crisis fostering "which might explain why fostering children orphaned by AIDS is problematic" (p. 196).

Little documented evidence exists on how prepared caregivers are to respond to an orphan's emotional needs (Howard et al., 2006; New, Lee & Elliot, 2007). In a survey conducted by Africare, 85% of caregivers claimed orphans in their care were content and well adjusted (Howard et al., 2006). However, results intimated that emotional problems might go unrecognised, which may "impede the healthy development of the child and, on a massive scale, the society" (Howard et al., 2006, p. 80). Risk and resilience research suggests that the quality of care in new homes impacts on how the child will adjust (Cluver & Gardner, 2007b). Without empathic caregivers (attachment figures) who can enable the child to recognise and express grief, children run the risk of developing emotional and behavioural problems, which are often expressed in the form of negative emotions such as depression and anger (Li et al., 2008). The quality of care, including support, praise, homework assistance and attending school meetings, was perceived by caregivers as an important protective factor (Cluver & Gardner, 2007b).

With high mobility between communities, children may not have lived in an area long enough at parental death for community members to feel a sense of obligation towards them (Roalkvam, 2005). Thus, the word community portrays a sense of comfort "but it is not an easy fix to complex problems" (Roalkvam, 2005, p. 217). While there are defined rules for inclusion in a community, there are similarly compelling rules for exclusion (Roalkvam, 2005). The predominant belief is that OVC are best looked after within their families and, if the family's capabilities are compromised, another family or community-based solution should be sought (Richter et al., 2006; Swift & Maher, 2008). However, in the context of HIV/AIDS, this is easier said than done. Communities and families are not

necessarily satisfactory places for children and thus broader services and social infrastructures need to be in place (Swift & Maher, 2008).

Other Strategies for Taking Care of Children

As a result of family disruption, children are at heightened risk of needing care outside of the family (Tolfree, 2006). Should the extended family not be able to care for its orphaned children alternative strategies must be found. Possible alternatives are mentioned below.

Adoption

When a child's parentage is unknown (for example, abandoned babies) or when it is unlikely that the family will resume care, adoption is often the preferred option and is beneficial in that it provides permanent care for the child (Tolfree, 2006). Generally, people adopting prefer very young children (Tolfree, 2006; Townsend & Dawes, 2004). Historically, the West influenced South African policy and practice, thus adoption was generally limited to white, childless, middle-class, married couples (Townsend & Dawes, 2007). However, the criteria for eligibility has recently changed to include individuals who were once believed to be unsuitable, such as single parents, gay and lesbian parents and parents from different cultures (Townsend & Dawes, 2007). Adoption among black people has also become more common. Townsend and Dawes (2007) argue that while adoption and foster care remains "underpromoted and underutilised by the majority of South Africans, they do present viable options for increasing the pool of potential caregivers" (p. 824).

Orphanages

Brookes et al. (2004) suggest that the focus of orphan care should be on community-based support "given the negative impact of institutionalisation on children" (p. 41). Giese and Dawes (1999) document the historical development and concern over the institutionalisation of children. Institutionalisation correlates to delays in social-emotional, language and cognitive development. In their formal assessment of institutionalised orphans they confirmed developmental delays in receptive and expressive communication, socialisation and self-awareness, body management and mobility and interaction with objects and fine motor coordination. Institutionalising a child is likely to lead to greater disconnection from their extended family, culture and community (Richter et al., 2006). Internationally, it is accepted that family care is more desirable as residential facilities seem to do more damage than good (Richter & Rama, 2006). Thus, placing children whose primary caregivers have passed away, or are incapable of caring for them, in institutions should be a

temporary measure utilised in an emergency situation (Li et al., 2008; Swift & Maher, 2008; Van Vuuren, 2004). Further, orphanages are costly and can only service a small number of children (Richter et al., 2006; Urassa et al., 1997).

Foster Care

Although informal child fostering is common in African families, some orphans are placed in formal foster care outside the family (Swift & Maher, 2008). The following discussion is relevant to both relative and non-relative foster placements. While government has backed the roll-out of foster placements and pays a monthly foster care grant to custodians for each child, it is a complex process that entails birth and identity documentation, which many people do not have, plus the involvement of a social worker, who may be unavailable (Meintjies et al., 2003; Swift & Maher, 2008). Further, migration levels have increased concurrently with the rise of HIV/AIDS and yet statutory foster care placements require that children reside with the legal foster parent, which disrupts mobility between households (Ansell & Young, 2004; Meintjies et al., 2003). This compromises resources and support for the foster parent. Thus, while foster placements are government backed and the grant is considered a "critical mechanism of support" (Meintjies et al., 2003, p. 2), there are unintended consequences.

Orphans often report being discriminated against in foster homes and are particularly vulnerable to emotional, physical and sexual abuse (Dunn, 2005; Hlatshwayo, 2003; Landry et al., 2007; REPSSI, 2007; Tindyebwa et al., 2006). The foster care grant often serves as an incentive to foster a child rather than more altruistic intentions (Donald et al., 2006). Caregivers often favour their own biological children and thus OVC may not get adequate food, clothing or love (Davids & Skinner, 2006; Freeman & Nkomo, 2006; Howard et al., 2006; Landry et al., 2007). Orphan focus groups in a situational analysis conducted in Zambia identified significant current care problems as a "lack of love, outright discrimination, and the feeling of being excluded" (Lusk et al., 2000, p. 12). In Zimbabwe, research showed that most orphans believed they were treated well in their homes but still reported victimisation, receiving less food and more household chores (Howard et al., 2006). Cluver and Gardner (2007b) found that orphaned children felt discriminated against and isolated as the non-biological child in the family and reported a sense of abandonment and not belonging. Sometimes young girls are allowed, with the tacit approval of caregivers, to pursue sexual relations with older men for "the potential monetary gain, bride-wealth, or other rewards that can be extracted from him" (Yamba, 2005, p. 208). Marriage is seldom the result of these liaisons and girls are often left infected with HIV/AIDS. Younger children reported greater distress about unequal treatment in

Howard et al.'s (2006) study, but it was unclear whether this was simply due to greater honesty on their part. However, Parikh et al. (2007) reported no significant intra-household differences, with only a few exceptions (for example, paternal orphans were more likely to be behind in school), in various education and health outcomes between recently orphaned children and non-orphans. However, parental death may have been too recent for significant effects to be evident.

Townsend and Dawes (2004) established that adoptive and foster parents were more willing to care for an orphan from their own families. Some research (Dunn, 2005; Lusk et al., 2000) has found that families are least likely to foster a child less than 5 years of age, as these children are completely reliant, require the most intensive care and can contribute very little in terms of household work. Placement may be further complicated in that many believe that HIV is automatically transmitted from an HIV-positive mother to her child (Dunn, 2005). Young children are susceptible to possibly fatal malnutrition, pneumonia and diarrhoea, and are therefore more expensive to care for and their chances of survival are lower than those of older children affected by HIV/AIDS (Lusk et al., 2000). Hence, their health care is often compromised as families or caregivers do not see the value in investing in improving or prolonging the life of a potentially terminally ill child (Dunn, 2005; Richter & Rama, 2006; Townsend & Dawes, 2007). On the other hand, Townsend and Dawes (2004) reported that young children were easier to place in both adoptive and foster families. The HIV status of the child impacts the likelihood of placing that child (Barnett & Blaikie, 1992; Freeman & Nkomo, 2006; Li et al., 2008; Townsend & Dawes, 2007). While close family members are less likely to be influenced by a child's positive status, it would influence more distanced adults' decisions to look after a child (Freeman & Nkomo, 2006). Townsend and Dawes (2004) established that although more respondents reported being more willing to care for an HIV-negative child the difference was not significant. They did find that potential adoptive parents were less inclined to care for an HIV-positive child than foster parents. In a later study, Townsend and Dawes (2007) ascertained that 76% of foster and adoptive parents were willing to care for an HIV-negative child and 62.2% were willing to care for an HIV-positive child. In their earlier study they found that "HIV-negative female orphans who are younger than 6 years, and who are family members, or from the same cultural background as the potential caregivers and do not have surviving relatives or siblings" (Townsend & Dawes, 2004, p. 69) are most likely to be taken into foster care or adopted.

Child-headed Households

As a consequence of unsuitable alternatives, some children end up living in CHHs (Donald et al., 2006). CHHs are usually more evident in communities where HIV/AIDS has weakened the safety net

of the extended family (Landry et al., 2007). In reality CHHs are often a temporary arrangement until more suitable arrangements can be made (Schenk et al., 2008; Swift & Maher, 2008). Only a very small number of very young children live in CHHs (Swift & Maher, 2008). Swift and Maher (2008) cite statistics from the *General Household Survey 2005* which claims that there are approximately 118,500 children in South Africa, of which 0,2% are between 1 and 5 years of age, living in a total of 66,500 households headed by children. Nonetheless, the incidence of CHHs is rising and South Africa has probably not yet experienced the full effect of this living arrangement (Donald & Clacherty, 2005; Germann, 2003; Louw & Louw, 2007; Ross & Deverell, 2004; Swift & Maher, 2008). Richter and Desmond (2008) established that 2% of children were living in CHHs in 2005, which represented a six-fold increase in the decade from 1995 to 2005. In CHHs, older siblings are required to take on parental responsibilities (Dunn, 2005; Tindyebwa et al., 2006). The eldest child usually takes over the role as head of the household, although responsibilities are sometimes shared amongst the older siblings (Richter, 2004). Research suggests that girls are more likely than boys to head the household and care for younger siblings (Louw & Louw, 2007; Schenk et al., 2008). On the other hand, Richter and Desmond (2008) argue that "the needs of these households may be contrary to media stereotypes; child-only households tend, in the main, to consist of only one child, most frequently a boy older than 15" (p. 1026).

Some experts argue that CHHs should not be summarily rejected as a child care option as, with appropriate support systems, for example, from the extended family, government and community, they could be a workable option (Louw & Louw, 2007; Tolfree, 2006). A mentorship model has been proposed whereby an adult household mentor, appointed by the Department of Social Development, a recognised non-governmental organisation (NGO) or the court, oversees a number of CHHs and is able to access social benefits and grants on their behalf but may not make decisions concerning them without consulting them first (Rosa, 2003). The model provides "legal recognition for child-headed households as a placement option for orphaned children" (Rosa, 2003, p. 24). Such a model has grown out of the recognition that, in selected conditions, it may be preferable for a child to live without adult caregivers and some children have expressed that this is their preferred option (Goldblatt & Liebenberg, 2003; Rosa & Lehnert, 2003; Tolfree, 2006). Tolfree (2006) claims that it is not possible to define exactly when this would be a suitable option but mentions some of the following criteria as important considerations: the age and gender of the household head and his or her capacity to give adequate care; the ability of children to provide for themselves economically; the capability of the head of the household to follow his or her own education; the age and gender of the other children; the accessibility of protection and support from agencies or the local community; and

the presence of other alternatives for example, foster care. A crucial factor in whether or not to support a CHH should be based on the expressed wish of the children involved (Tolfree, 2006).

<div align="center">PRECURSOR TO ORPHANHOOD: PARENTAL ILLNESS AND DEATH</div>

The psychological, material and social deterioration of the family unit usually commences at the onset of parental illness (Li et al., 2008). Dunn (2005) argues that most children born to HIV-positive parents are at least 5 years old when their parent dies, while Richter et al. (2006) estimate the average age of orphaning to be about 8 years. UNAIDS (2006) mentions data obtained from four longitudinal research sites that found that approximately 40% of children lost their parent between the age of 10 and 14 years, whereas about 25% of children experienced parental death prior to the age of 5. Hence, many children suffer emotional anguish and trauma while observing a parent and/or another family member slowly dying and start grieving and become vulnerable long before they become orphans (Andrews et al., 2006; Chitiyo, Changara & Chitiyo, 2008; Landman, 2002; Li et al., 2008; Louw & Louw, 2007; Schenk et al., 2008; Tindyebwa et al., 2006; Townsend & Dawes, 2004; UNAIDS, 2006). However, because very young children may not grasp that a caregiver is going to die, they may not be prepared for the death and so may experience it as sudden and shocking (REPSSI, 2007). The progressively ill parent is increasingly unable to care for their children or themselves, and therefore their children rarely obtain adequate attention and necessary care-giving during a critical stage of their development (Andrews et al., 2006; Dunn, 2005; Li et al., 2008, REPSSI, 2007). This may have considerable repercussions for their psychological well-being (Townsend & Dawes, 2004).

Living with a Terminally Ill Parent

HIV-positive women who are terminally ill are at high risk of developing symptoms of depression, often leading to non-compliance with medication and decreased self-care, which may be harmful to family life and result in child developmental problems (Foster, 2006; Freeman, 2004; New et al., 2007; Swift & Maher, 2008). They are likely to spend the little money they have on necessities such as food for their children rather than on their medication, which, ironically, may accelerate their death and have a longer-term harmful effect on their children (Freeman, 2004). Because of the stigma associated with the disease, HIV-positive mothers are less likely to disclose their status and hence have less support (Freeman, 2004; Howard et al., 2006). Psychologists at Ububele, an African Psychotherapy Resource Centre, found that the attachment of an HIV-positive woman to her infant is

affected "either through rejection, feeling herself guilty or murderous, or she might become over-involved emotionally and overly dependent upon her child" (cited in Swift & Maher, 2008, p. 38). They believe it is more likely to be the latter "because the child is the one place where she can feel not judged, express her loving feelings and so on" (cited in Swift & Maher, 2008, p. 38). On the other hand, Foster (2006) reports that bonding between an HIV-positive mother and her child may be compromised because of HIV prevention programmes that promote the early cessation of breastfeeding. In short, stressed, ill and dying mothers may unwittingly compromise their child's development (Foster, 2006).

Most OVC assume household responsibilities soon after parental illness or death, including earning an income, nursing ill family members and caring for younger siblings (Chitiyo et al., 2008; Germann, 2003; Schenk et al., 2008). Accordingly, they may be physically, emotionally and financially strained, leaving them vulnerable to exploitation and abuse (Chitiyo et al., 2008; Li et al., 2008). As productivity decreases and expenses increase with rising medical costs, many experience a decline in household income, by as much as 60%, and downgraded living standards prior their parent's death (Germann, 2003; Ghosh & Kalipeni, 2004; Li et al., 2008; Louw & Louw, 2007; REPSSI, 2007). Because of the impoverishing effects of living in a household with a terminally ill parent, few assets remain following parental death (Li et al., 2008). Role-reversal, or parentification, may occur when children are left with the burden of caring for their sick and dying parent (Donald et al., 2006; Louw & Louw, 2007; Wenar & Kerig, 2005). This creates psychological stress, leaving these children at greater risk of developing mental health problems: "Having to bath, feed and medically treat a deteriorating person is emotionally exhausting, especially if there is no respite" (Freeman, 2004, p. 149). Studies show that parentification in the early years can result in internalising, behavioural and social problems, including depression, anxiety, eating disorders and low self-esteem (Wenar & Kerig, 2005). Freeman (2004) reports that in some resource-poor countries, children as young as 6 years are assuming care-giving responsibilities for their critically ill parent, which places considerable additional stress on the child. These children are denied their childhood, loose opportunities (for example, schooling) and are often inadequately prepared for their impending loss (Louw & Louw, 2007; REPSSI, 2007). Thus, during the period of parental illness, children's circumstances may be dramatically disrupted in the face of negotiating changing financial positions and caring for a sick person over extended periods (Schenk et al., 2008).

Findings indicate that children are most affected by parental HIV/AIDS prior to the actual death of their parent due to anticipatory grief and the deterioration of parenting skills, leaving them vulnerable

to the development of adjustment problems (Foster, 2006; Pelton & Forehand, 2005). Research performed in the United States (U.S.) found a "higher percentage of pre-orphans and orphans before and two years after their mother's death manifested problem behaviours in the borderline clinical or clinical range" when compared to control groups, which consisted of children whose mother's were either HIV-positive but continued to live or were not infected (Pelton & Forehand, 2005, p. 590). Thus, children may display internalising and externalising problems prior to their mothers' death. No significant differences were found in comparison to the control groups 6 months after a mother's death but significant differences were found for internalising problems 2 years after death. The researchers hypothesised that the delay in symptoms could be attributed to the child being traumatised so soon after the death, uncertainty as to the consequences of displaying emotional or behavioural problems when adjusting to new caregivers or a new caregivers' possible reluctance to describe the child's behaviour as problematic. Young children may also go through a period of denial after parental death, pretending that they are alive or coming back (REPSSI, 2007). Based on their findings, Pelton and Forehand (2005) propose that "interventions to facilitate the adjustment of children whose mothers are HIV infected should be initiated at the pre-orphan stage and can involve both individual interventions with children and parenting interventions with the mother and future caregivers" (Pelton & Forehand, 2005, p. 591). Similarly, Howard et al. (2006) recommend that psychosocial and material support should begin as parental illness starts.

As is evident from the disheartening discussion above, "keeping parents alive is *the* most effective preventative intervention with regard to the 'OVC crisis'" (Freeman & Nkomo, 2006, p. 302). Keeping the primary caregiver alive, even for a few more years, can make a crucial difference to the outcome of very young children (Swift & Maher, 2008). Cati Vawda (cited in Swift & Maher, 2008) of the Children's Rights Centre points out that "if you could keep more adults alive for longer and help them have healthier lives you would at least have older orphans and their shorter period of being orphaned might mean a very different quality of childhood" (p. 60).

Bereavement

Cross-cultural research suggests that "most humans need to recognise their grief and be able to express it directly to resolve their loss" (Li et al., 2008, p.148). However, children are often inadequately prepared for an AIDS related death because of the stigma, denial or lack of awareness that surrounds the disease, as well as the crippling lack of alternatives for a parent in ensuring his or her children's future (Ansell & Young, 2004; Howard et al., 2006). Communication is often

complicated because of the disease's association with sex and sexuality, reinforcing it as a taboo subject (Snipstad, Lie & Winje, 2005). Further, in traditional African families a hierarchy exists based on age and gender where older men assume the highest status and children occupy "the bottom of the pecking order" (Swift & Maher, 2008, p. 30). Commonly, adults are not concerned with children's feelings and there is an apparent unawareness of the interior life of the child (Swift & Maher, 2008). Noreen Ramsden from the Children's Rights Centre reiterates this sentiment: "The emotional needs of the very young are often…not even noticed. Small children are invisible, often" (cited in Swift & Maher, 2008, p. 31). Such traditions leave little room for candid conversations about AIDS and death and frequently children are not told about a parent's death directly (Daniel, 2005; Swift & Maher, 2008). Some children are told their parent has gone on a journey or a sleeping child may have the news whispered in their ear (Daniel, 2005). However, "being told indirectly about something important is not the same as knowing, and this can be particularly disturbing for a very young child" (Swift & Maher, 2008, p. 53). This secrecy and silence can worsen a child's sense of insecurity and if their questions are discouraged or not answered they may fantasise answers that might be more frightening than the real ones (Daniel, 2005; REPSSI, 2007).

Very young children may experience confusion as to the nature of death, which may perpetuate myths such as the belief that children do not experience grief or are too young to understand but, like adults, children need to grieve (De Witt & Lessing, 2005; REPSSI, 2007). They may not be able to completely differentiate between life and death, possibly believing that the deceased parent continues to live (Louw & Louw, 2007). However, babies and young children are totally dependent on their caregiver to meet their physical and social needs and thus "separation or death of a regular caregiver is one of the most frightening and painful events children might experience" (REPSSI, 2007, p. 30). Anxious attachment to a caretaker is a child's main response to a traumatic event, indicating a fear of abandonment, and often expresses itself by excessive clinging (Louw & Louw, 2007). Because of their inability to express themselves verbally in response to death, young children may communicate their sense of loss through crying, withdrawal and other non-verbal signs (REPSSI, 2007). Children under 5 years of age typically exhibit problems through sleep disorders (especially nightmares), eating, bedwetting, separation anxiety and regression and they may fear that they will also die (Louw & Louw, 2007; REPSSI, 2007). Because of their emotional dependency and intellectual immaturity children are at greater risk of developing complicated or unresolved bereavement (Daniel, 2005; Li et al., 2008). Complicated grief has been defined as "the deviation from the cultural norm in the time, course or intensity of specific or general symptoms of grief" (Li et al., 2008, p.149).

Movement between homes is particularly unsettling for very young children during periods of stress and yet it is preschool children who are more likely to be frequently relocated in the context of HI/AIDS (Richter et al., 2006). They might feel insecure settling into new living arrangements and have a greater need for care and protection, which may lead to adjustment problems (Chitiyo et al., 2008; Howard et al., 2006; Townsend & Dawes, 2007). When young children face stress normalisation in the form of familiar routines, being nurtured and loved by supportive adults, attending school and playing with friends are particularly important (Richter et al., 2006). Hence, disruption of their routine and relationships may exacerbate their sense of instability and negatively impact their development, health and well-being (Howard et al., 2006; Li et al., 2008; REPSSI, 2007; Richter et al., 2006). Because of the typical mobility between households at this age as well as being cared for by over-burdened caregivers, it is unlikely that the needs of young children will be met, leaving them vulnerable to lasting intellectual, social, physical and emotional problems (REPSSI, 2007).

Research suggests that the effects of bereavement on children are worse when they are not assisted in resolving or understanding their loss (Swift & Maher, 2008). Funeral attendance varies according to the community. Many children in Botswana, especially those younger than 14 years, are excluded from their parent's funeral (Daniel, 2005). Conversely, most orphans in rural eastern Zimbabwe had attended their parent's funeral but few reported any other activity surrounding mourning (Howard et al., 2006). Many wished they could forget their loss as opposed to remembering their deceased parent. However, this may serve as a defence mechanism or an adaptive strategy in adjusting to new family arrangements (Howard et al., 2006). Nevertheless, in bypassing the grieving process, orphans may be denied the opportunity to heal and build identity. To complete the task of mourning successfully, children need to know that they will be safe and cared for in an environment that excludes their parent. Sources of distress for children during this stage include anxieties about shelter, food, schooling and care giving arrangements (Howard et al., 2006; Landry et al., 2007). Most orphans in Nyanza, Kenya, stated that they were never informed by their parent who would be caring for them on their death, which was experienced as extremely stressful (Landry et al., 2007). Research has shown that age-appropriate information and shared time with a terminally ill parent can prepare the child to accept their loss (Howard et al., 2006). Assisting a grieving young child in comprehending what is happening is crucial to their future development (REPSSI, 2007). Grieving and memorial activities "help the child to 'relocate' the deceased parent within the child's life by acknowledging the death, honouring the deceased, and obtaining comfort and support" (Howard et

al., 2006, p. 72). Memory book or memory box projects encourage child-parent communication and have been shown to aid the transfer of life-skills from parent to child, to decrease isolation and stigma, to decrease property-grabbing and to benefit family relationships (Howard et al., 2006; REPSSI, 2007). Thus, in addition to technical and financial aid, age-appropriate parental communication about the illness and impending death, grieving and memorial activities and psychosocial support serve as protective factors for the child (Howard et al., 2006).

Foster (2006) states that "the mental-health impact of chronic parental illness is one of the most poorly understood and neglected difficulties that children affected by HIVAIDS in poor countries face" (p. 700). However, research (Ebersöhn & Eloff, 2002; Ghosh & Kalopeni, 2004; Howard et al., 2006; Li et al., 2008; Louw & Louw, 2007; REPSSI, 2007; Richter et al., 2006; Swift & Maher, 2008) suggests that parental illness and death, especially of a mother, during childhood has a profound and enduring bearing on a child's psychosocial well-being, leaving him or her at high risk for developing psychological problems. Pelton and Forehand (2005) report that because of the "combined impact of grieving the loss of a parent and the myriad psychosocial stressors present in poor, urban communities, the orphans of women who die of AIDS are at great risk of clinically significant behavioural and emotional problems" (p. 585). They may suffer clinically elevated and lengthy episodes of anxiety and stress and possibly feel immense grief and depression along with loneliness, anger, confusion, social dysfunction, guilt, helplessness, decreased optimism, withdrawal, fear of being left alone, post-traumatic stress symptoms and suicidal ideation (Andrews et al., 2006; Cluver, Gardner & Operario, 2007; De Witt & Lessing, 2005; Dunn, 2005; Foster, 2006; Freeman, 2004; Howard et al., 2006; Louw & Louw, 2007; REPSSI, 2007; Townsend & Dawes, 2007). Chitiyo et al. (2008) found that orphans also experience feelings of hopelessness, unhappiness and frustration. Furthermore, children may have difficulty eating and experience somatisation problems, for example, migraines, headaches and stomachaches (Freeman, 2004). Some suffer from survivor guilt, blaming themselves for the death of their parent (Cluver & Gardner, 2007b; REPSSI, 2007; Swift & Maher, 2008). Children experiencing extreme stress may develop psychotic disorders (REPSSI, 2007) and many suffer a form of post-traumatic stress syndrome as a result of "the loss, the fear, the incredible suffering and indignities that the disease and discrimination call forth" (Ryan cited in Ross & Deverell, 2004, p. 211). These emotions may be compounded by the separation from siblings and ostracism faced from the community because of the stigma that still surrounds the disease (Dunn, 2005; Landman, 2002).

Children living in CHHs are "particularly vulnerable to extreme poverty, poor nutrition, poor housing, discrimination, exploitation, educational failure and physical and sexual abuse" (Townsend & Dawes, 2004, p. 70). As we have seen, orphans have already been exposed to substantial psychosocial turmoil prior to occupying a CHH. Not only have they witnessed their parent suffer through their illness and eventual death, but they have also usually experienced tremendous upheaval in their living arrangements. They are likely to have experienced multiple moves between households. Such instability, especially for very young children, is likely to be detrimental (Donald & Clacherty, 2005; Richter et al., 2006). All the child heads of households that participated in Donald and Clacherty's (2005) study reported that they had experienced the death of at least three close relatives, with half the sample stating that they had experienced more than five deaths. Thus, these children are faced with loss, abandonment and the full spectrum of emotions that accompany these experiences. Landman (2002) points out that "each and every one of these youngsters faces the same fate of dealing with too much, too soon – the untimely death of parents, emotional upheaval and lack of security which is unavoidable when the family unit crumbles" (p. 270).

However, before discussing CHHs in more detail it should be noted that, in spite of their trials, not all children orphaned by HIV/AIDS are dysfunctional. Research indicates that, while key mental health needs can be identified, most children do not develop considerable mental health problems or exhibit mental health disorders (Howard et al., 2006; Li et al., 2008; New et al., 2007; Tolfree, 2006). A child's psychosocial well-being depends on the relative balance between risk and protective factors (Li et al., 2008). How children cope depends on multiple factors including the past, current and future qualities of the child, their family and the wider social environment (Freeman, 2004; REPSSI, 2007). Their ability to cope depends on resilience at all these levels (REPSSI, 2007). Although most children do cope despite enormous suffering, this does not imply that they do not need support (Richter et al., 2006). While parental bereavement constitutes a major risk for emotional or behavioural problems (Cluver & Gardner, 2007b), different experiences of being orphaned, for example, double, paternal or maternal orphaning, the quality and type of care of the child, the parent-child relationship, family supports, the mother's health, parental depression, stressful life events, socioeconomic status and the child's age all impact on the mental health outcome of the child (Freeman, 2004; Li et al., 2008; Parikh et al., 2007).

Advantages of Living in a Child-headed Household

Siblings Remain Together

Some children choose to live in a CHH even when there is the option of moving in with another family (Freeman & Nkomo, 2006). The CHH allows siblings to remain together, possibly to remain in the family home and to attend the same school (Louw & Louw, 2007; Tolfree, 2006). Groups of siblings are often hard to place in alternative care (Townsend & Dawes, 2004). Thus, to ease the burden of care, siblings may be distributed among a number of households, which, through the breaking of attachments, could contribute to psychological trauma (Freeman & Nkomo, 2006; Landry et al., 2007; Lusk et al., 2000; Urassa et al., 1997). Siblings rely strongly on each other following the death of a parent and grief may be compounded if they are forced to live in separate households (Freeman & Nkomo, 2006; REPSSI, 2007). The separation of siblings has been found to be a risk factor in the development of emotional and behavioural problems (Cluver & Gardner, 2007b). On the death of a parent many orphaned children require more emotional support from their new primary caregivers than they did from their original carer because of the stress endured during the prolonged illness and death of a parent, yet emotional nurturance and acceptance are not automatic in new environments (Freeman & Nkomo, 2006; Richter et al., 2006). As young children tend to be insecure when their routines and care arrangements are disrupted following parental death, the CHH could afford some stability during a traumatic period (REPSSI, 2007).

Adaptive Strategies

A comparative study of the experiences of children living in CHHs and adult-headed households (AHHs) in Pietermatizburg, showed that those living in CHHs faced vulnerabilities in revenue, accessing social services, capacity to generate resources and emotional and psychological adjustment (Donald & Clacherty, 2005). Yet they surpassed those in AHHs in terms of time management, social networking strategies and greater family cohesiveness. Thus, children living in CHHs adopt adaptive strategies, showing resilience and the ability to cope, characteristics which should be developed in future (Donald et al., 2006).

Issues Children Face Living in a Child-headed Household

Children living alone face numerous challenges, many of which are discussed below. Although much of the information may be relevant to OVC generally, I have tried where possible to highlight information specific CHHs.

Attachment

Attachment can be defined as "a close emotional relationship between two persons, characterised by mutual affection and a desire to maintain proximity" (Shaffer, 2002, p. 388). A paper on orphan care in Kenya states: "Infants and young children...need to establish secure attachments to an adult care provider and develop a sense of trust, self-worth and autonomy. Accomplishing these developmental tasks helps shape the child into the person he or she will become" (Donahue, Hunter, Sussman & Williamson cited in Lusk et al., 2000, p.13). Richter et al. (2006) reiterate this finding: "All children must have at least one person who uniquely loves them and has a deep vested, future-oriented interest in their wellbeing" (p. 13). Children with safe attachments are more likely to explore their environment freely and interact competently with unfamiliar adults in the presence of a caregiver (Wenar & Kerig, 2005). The quality of attachment relationships before and after parental death, along with income predictability and food stability, is an indicator of the child's long-term development, including language, social, emotional and educational adjustment, and their ability to develop resilience (Li et al., 2008; Richter & Desmond, 2008; Richter et al., 2006; Wenar & Kerig, 2005). Resilience is the ability to tolerate and recuperate from significant suffering (Richter et al., 2006). Thus, attachment serves as a protective factor (Daniel, 2005). To be able to realise their potential and develop life-long resilience, it is crucial for very young children to experience being nurtured, loved and valued by a steady caregiver (Swift & Maher, 2008). Many young children living in CHHs are denied secure attachments and may grow up without enough nurture, love and guidance (Lusk et al., 2000; Tolfree, 2006).

Attachment problems are exacerbated by poverty and stress, making access to a holistic package of care and support unlikely (Dunn, 2005). Dunn (2005) asserts that this lack of care and support "may affect their health, their chance of receiving an education, their social relationships, their future economic production and even the likelihood of becoming HIV positive themselves in later life" (p.1). The breakdown of family structure negatively impacts the child's psychosocial competence, or their ability to maintain a state of psychological well-being while dealing adaptively with the challenges and demands of their social and cultural environment (The Starfish Greathearts Foundation [Starfish], n.d). They may never cultivate the coping mechanisms that are developed in a loving, caring environment, which can leave deep psychological scarring (Davids & Skinner, 2006). Louw and Louw (2007) point out: "A lack of emotional care often lies at the root of a subsequent lack of sympathy for others and results in antisocial behaviours such as delinquency" (p. 372). Thus, there may be long-term social, emotional, cognitive and physical consequences for children who are

deprived of consistent caregivers and simple environmental and interpersonal stimulation (Dunn, 2005; Lusk et al., 2000).

<u>Psychological Effects</u>

Although the many psychological possibilities related to bereavement discussed earlier will not be repeated here they are all relevant to children living in CHHs as they could lead to the development of enduring psychosocial problems (Cluver et al., 2007; Foster, 2006). Wenar and Kerig (2005) maintain that although many remarkable developments occur in the first 6 years of a child's life, they have not yet been empirically linked to psychopathology. However, research (Cluver et al., 2007; Li et al., 2008) suggests that children living in CHHs are at high risk of developing psychological problems because of the multiple stressors they are exposed to in addition to their lack of necessary emotional and social support. Despite their high risk for psychological problems, little empirical evidence exists on the psychological consequences of HIV/AIDS related orphanhood (Cluver & Gardner, 2007a, 2007b; Cluver et al., 2007; Howard et al., 2006). Cluver et al. (2007) established that children orphaned by HIV/AIDS were more likely to report symptoms of depression, post-traumatic stress, relationship problems with peers, conduct problems and delinquency when compared to non-orphaned children and orphans due to other causes in urban townships near Cape Town. They concluded, in line with increasing international data, that children orphaned by HIV/AIDS were notably vulnerable to emotional and, to a lesser degree, behavioural problems. Cluver et al. (2007) cite three US studies and two African studies that found conduct problems. Other sub-Saharan research confirms findings relating to the internalisation of problems, whereas findings were mixed concerning conduct problems (Cluver et al., 2007). Li et al. (2008) reported a relation between bereavement and internalising problems, such as depression, anxiety and withdrawal, but results were inconsistent regarding externalising problems, somatic symptoms and developmental effects. Makame, Ani and Grantham-McGregor (2002) found that, compared to non-orphans, orphans obtained higher scores for internalising problems and were almost three times more likely to contemplate suicide. Research also shows a predictive association between depressive symptoms and sexual risk behaviours in both genders (Earls et al., 2008). Other research (Starfish, n.d; Tindyebwa et al., 2006) suggests orphans are vulnerable to adopting negative defence mechanisms, which may lead to drug problems, or they may become aggressive, disruptive, restless or withdrawn.

<u>Cumulative Stress</u>

Orphaned children are exposed to multiple stressors, all of which may impact their psychosocial health, complicate the grieving process and contribute to cumulative stress (Cluver & Gardner,

2007a; Cluver et al., 2007; Freeman, 2004). Stressors may include lack of adequate care, parental and own illness, multiple losses, poor nutrition, economic deprivation, disrupted schooling, uncertainty, stigma and social isolation (Cluver et al., 2007; Freeman, 2004; Swift & Maher, 2008; Wild, 2001). Howard et al. (2006) view increased workloads, migration to new homes, possible separation from siblings and peers along with "the loss of love, guidance, socialisation, and skills transfer by their parents, who often die in quick succession" (p. 71) as possible additional stressors. Household heads are confronted with balancing their need for education, care of younger siblings and the cultivation of economic opportunities (Tolfree, 2006). Generally, it is agreed that very young children are most severely affected by the combination of stressors and the orphaning process (Swift & Maher, 2008).

Multiple Losses

The stress of parental death is often complicated in orphaned children as many have faced multiple losses in their family or community, leading to recurrent psychological impact (Daniel, 2005; Townsend & Dawes, 2004): "If children have had a previous painful loss or separation that has not been fully dealt with, this makes them even more vulnerable to the difficulties of a subsequent bereavement" (Li et al., 2008, p. 154). Donald and Clacherty (2005) established that negative emotional memories of children living in CHHs were still experienced as hurtful and unresolved while Cluver and Gardner (2007b) found heads of CHHs to have high levels of anger and grief. Daniel (2005) established that hidden grief surfaced in the form of intrusive thoughts about the parent, deep unhappiness and fear of death. Other research (Cluver & Gardner, 2007b; Freeman, 2004; Li et al., 2008; Swift & Maher, 2008) cites "clinically elevated levels of psychological distress" (Freeman, 2004, pp. 149-150) when multiple family members are infected and die as this complicates and exacerbates the psychological impact. Multiple family deaths also influence the ability of other family members to provide support because of their own bereavement (Li et al., 2008). Caregivers may find little time to grieve as they may be preoccupied with survival issues: "The struggle for survival leaves little time for tears, for the treasuring of memories, for the rituals that speak of love and belonging" (Kistner cited in Swift & Maher, 2008, p. 47).

Relationships with Relatives and the Community

Thurman et al. (2006) argue that a sense of social and emotional connection to their communities, neighbours, relatives and peers is essential to the survival of orphans. Donald and Clacherty (2005) found that all child heads of households had some form of adult support. Thurman et al. (2006) caution that one should not assume that family support is automatically low in communities hosting

large numbers of CHHs and cite research where children living in CHHs reported close bonds with their relatives. However, those children living in CHHs in Thurman et al.'s (2006) sample from Gikongoro, Rwanda, reported "more willingness of neighbours to assist them than their extended family. Only one-third of respondents stated their family looked out for their best interests" (p. 226), but 92% of heads of households claimed they had significant peer relationships. Other African research confirms "incidents of exploitation and property grabbing by the extended family" (Thurman et al., 2006, p. 226). Thus, in some instances unrelated community members may better protect and support orphans. Despite this, almost 50% of the respondents in Thurman et al.'s (2006) study felt that they had nobody that cared about them and reported high levels of marginalisation. Similarly, in exploring patterns of children's vulnerability in Zambia, Schenk et al. (2008) found that children in CHHs were resentful toward relatives and the community for not offering them adequate support. Cluver and Gardner (2007b) identified contact with the immediate and extended family as a perceived protective factor for orphans.

In her ethnographic fieldwork in Seke, a semi-rural area outside Harare, Zimbabwe, Roalkvam (2005) was struck by the isolation and invisibility of CHHs and found it extraordinary that the extended family and community had "seemingly vanished" (p. 212). She looked at kinship issues in order to understand this disappearance. In 3 of the 11 CHHs that she worked with, Roalkvam (2005) identified isolation to be a result of "unresolved *lobola* issues" (p. 217). Lobola represents payment from the groom's family to the bride's family upon marriage and "when successful, secures not only the identity, belonging and care for children, but in fact organises relations between families, lineages and communities" (Roalkvam, 2005, p. 218). In communities affected by abject poverty, lobola may be paid in instalments, which "remains an unfinished and vulnerable business throughout the span of a marriage" (Roalkvam, 2005, p. 218). Premature deaths due to HIV/AIDS render the settlement of lobola an unfinished exchange: "Consequently, a child-headed household…is isolated because the relationships that should give the child protection and care must still be made, recognised and named" (Roalkvam, 2005, p. 217).

Economic and Social Effects

On parental death, an orphan's already poor economic situation is likely to worsen (Townsend & Dawes, 2004). Socioeconomic threats include the effects of poverty, neglect, migration, housing problems, malnutrition, homelessness, disruption in education and involvement in crime (Cluver & Gardner, 2007b: Ebersöhn & Eloff, 2002; Foster, 2006; Germann, 2003; Ghosh & Kalipeni, 2004). Conditions of poverty also contribute to difficulties accessing social welfare grants, social workers,

birth certificates and medical care (Cluver & Gardner, 2007b). Official wills are rare in poor communities in sub-Saharan Africa and thus property dispossession is common (Germann, 2003; UNAIDS, 2006). Orphans may lose the land their parents cultivated to debt collectors (REPSSI, 2007) or "unscrupulous relatives" (Ghosh & Kalipeni, 2004, p. 309). Hence they are vulnerable to economic exploitation and risk turning to antisocial behaviour in order to survive (Cluver & Gardner, 2007a; Howard et al., 2006; Louw & Louw, 2007). Girls may be enticed into commercial sex work and orphans are vulnerable to being co-opted into cheap child labour (Germann, 2003). Research (Davids & Skinner, 2006; Ghosh & Kalipeni, 2004; Howard et al., 2006; Li et al., 2008; Richter & Rama, 2006; Rosa, 2003) shows that basic needs such as food, shelter, clothing, access to money and general material needs are the main priority of these children. Conditions of poverty are likely to contribute to an orphan's sense of social exclusion as they cannot afford shoes, clothes, uniforms or cleaning products and are likely to be excluded from birthday celebrations or activities with friends (Cluver & Gardner, 2007b). These basic needs exceeded the psychological and social needs (Rosa, 2003). However, Howard et al. (2006) argue: "Given poverty's mental and emotional toll, any economic support is psychosocial support as well" (p. 71). Thus, minor material differences can positively impact a child's sense of well-being and security.

To become economically viable members of the community children need access to education, vocational guidance and life-skills training so they can contend with their emotions, stress and decision-making (Starfish, n.d). In some communities, OVC are helped with basic needs but little provision is made for their psychological needs, particularly in dealing with coexisting issues of bereavement or loss (Davids & Skinner, 2006). The Human Sciences Research Council accentuates the need for training in HIV/AIDS, sexuality and bereavement issues so that nurturance and counselling can be provided (Davids & Skinner, 2006). Similarly, Dunn (2005) states that until recently psychosocial support has been a neglected area of study in comparison to research into the health, nutritional and shelter needs of OVC. However, Richter et al. (2006) report that "the pendulum may have swung too far. There is now concern that some approaches address only psychosocial needs and overlook the educational, health, material and physical needs of children and families" (p. 9).

Stigma and Denial

Studies have shown that children orphaned due to HIV/AIDS are subjected to stigmatisation and discrimination in their schools, foster homes and communities (Landry et al., 2007). Stigma often leads to discrimination, which may intensify psychological distress (Chitiyo et al., 2008; Dias, Matos

& Gonçalves, 2006). Stigma is "a process of devaluing an individual or group through beliefs and attitudes that discredit them" (Swift & Maher, 2008, p. 57). Swift and Maher (2008) describe discrimination as "'enacted stigma' – actions and institutional patterns that have a detrimental impact on those who are stigmatised" (p. 57). Stigma decreases the likelihood of neighbourly support and serves to marginalise and isolate orphans from their peers as community members may prohibit their children from playing with them (Donald et al., 2006; REPSSI, 2007; Swift & Maher, 2008). Children orphaned by HIV/AIDS are susceptible to ostracism, gossiping and teasing, a possible outcome of HIV/AIDS-related stigma (Chitiyo et al., 2008; Cluver & Gardner, 2007a, 2007b; Freeman, 2004). To avoid isolation and ridicule from both learners and teachers orphans may refrain from attending school, thereby depriving themselves of a vital part of their social development (Louw & Louw, 2007). Chitiyo et al. (2008) claim that "stigma has terrible negative effects yet it is so rampant that it has been considered an epidemic itself" (p. 385). Swift and Maher (2008) confirm this: "Stigma is one of the most intractable problems associated with AIDS" (p. 60). It may cause anxiety and apprehensiveness to disclose parental illness or death and thus compromise children's ability to express grief (Li et al., 2008). Denial can be seen as a "desperate coping mechanism" (Swift & Maher, 2008, p. 57) in people afraid of the prospect of caring for significant others when their own household is threatened. Stigma reinforces denial (Swift & Maher, 2008). Although orphans require added health and psychosocial support services, the secrecy and stigma associated with HIV/AIDS may prevent them from seeking these out (Ross & Deverell, 2004).

HIV Infection

Children 0 to 3 years old are 3.9 times more likely than their older counterparts to die in the year prior to or after their mother's death, no matter what the cause (UNAIDS, 2006). Infants born to HIV-positive women have higher mortality rates and many are HIV-positive themselves, resulting in declining physical and mental health (Foster, 2006; Landman, 2002; Townsend & Dawes, 2007). Some have to confront their own issues of being terminally ill and face their own mortality. In children the disease usually develops rapidly and many will die in early childhood, most before their fifth birthday (Earls et al., 2008; Urassa et al., 1997). Thus, HIV infection acts as a further stressor affecting a child's psychosocial adjustment (Ebersöhn & Eloff, 2002; Li et al., 2008). Orphans are particularly vulnerable to HIV infection because of an increased probability of sexual exploitation and abuse, an earlier onset of sexual activity, seclusion and stigmatisation (Howard et al., 2006; Richter & Rama, 2006; UNAIDS, 2006). HIV-positive children are often neurologically affected, with the possibility of cognitive deficits, slow learning, sleep disorders and attentional disorders (Cluver & Gardner, 2007a; New et al., 2007). They are more vulnerable as they are predisposed to many

health problems including malnutrition, respiratory infections, diarrhoea, weight loss and developmental delays (Chitiyo et al., 2008; Swift & Maher, 2008). Further, frequent infections may result in loss of physical stamina and general weakness (Swift & Maher, 2008).

Data is lacking concerning the mental health challenges that young HIV-positive children face (New et al., 2007; Scharko, 2006). However, research highlights that children with any form of chronic illness are likely to suffer from increased rates of psychiatric problems (New et al., 2007; Scharko, 2006). Scharko (2006) suggests that "ADHD [attention deficit hyperactivity disorder], anxiety and depression are all exceedingly common in HIV-infected children and adolescents" (p. 442), although it is impossible to determine whether this is a direct result of the disease itself, the treatment or an emotional outcome of living with the virus. Scharko (2006) indicates that the prevalence of clinical problems may vary with the child's age and age of infection: "For example, those children with vertical HIV infection may be more likely to have ADHD while those infected in adolescence may be more likely to have depression" (p. 442). Freeman (2004) reports higher incidents of mood disorders, including major depression and "AIDS mania" (p. 148), personality disorders and suicidal ideation amongst populations infected by HIV. AIDS-related psychosis may be experienced by HIV-positive children and later in the disease, AIDS-associated dementia or delirium (Cluver & Gardner, 2007a). Self-esteem, school functioning and long-term adjustment may serve as protective factors in chronically ill children (Scharko, 2006).

Physical, Sexual and Emotional Abuse

Physical, sexual and emotional abuse are considered risk factors for emotional and behavioural problems (Cluver & Gardner, 2007b). Children under the age of 8 have little ability to identify potentially dangerous scenarios, which raises their vulnerability (Swift & Maher, 2008). All children are susceptible   to sexual abuse but children orphaned due to HIV/AIDS, especially those in CHHs, are more at risk as they tend to be socially isolated, financially distressed and emotionally exposed (Chitiyo et al., 2008; Howard et al., 2006; Louw & Louw, 2007; REPSSI, 2007; Swift & Maher, 2008). Schenk et al. (2008) found children in CHHs in Zambia were more likely to engage in risky behaviours as a result of financial hardship, pushing some girls into sex work and boys into crime. Donenberg and Pao (2005) report that childhood sexual abuse is consistently linked to elevated rates of HIV risk behaviour including "earlier sexual debut, more frequent sexual activity, less consistent condom use, lower self-efficacy for condom use, increased concern with conforming to peer sexual norms, anxiety about partner rejection, and more lifetime sexual partners than nonabused peers" (p. 732). Nyamukapa et al. (2008) argue that due to greater psychosocial distress

in orphaned adolescents, they are more likely than non-orphaned children to be sexually active at a young age. Children may be deceived into seeing abuse as a sign of protection and love, which helps them to cope (REPSSI, 2007). Swift and Maher (2008) claim that data on reported rapes among very young children is elusive, although in their interviews they found the rape of young children to be a "serious, if largely hidden, problem" (p. 22). Urassa et al. (1997) reiterate this: "The evidence…increasingly shows that such practices are common, although the extent is difficult to establish" (p. 339). This high exposure to risk and early onset of sexual activity increases the potential for HIV/STI (sexually transmitted infection) infection (Li et al., 2008; New et al., 2007; Nyamukapa et al., 2008).

Education and Peers

Education is crucial in preparing children for the future and in combating HIV/AIDS (Yamba, 2005) yet it is commonly disrupted when a family is affected by the disease (Ansell & Young, 2004; Germann, 2003; Ghosh & Kalipeni, 2004; Howard et al., 2006; Li et al., 2008; Schenk et al., 2008; UNAIDS, 2006). A lack of schooling limits an orphan's prospects of raising themselves out of exploitation and poverty (Yamba, 2005). Although Parikh et al. (2007) found income level to be a better predictor of school enrolment than orphaning, other research (Andrews et al., 2006; Germann, 2003) reports lower attendance and access to schooling for orphans when compared to non-orphans. Donald and Clacherty (2005) established that a higher proportion of children living in CHHs experienced difficulty in obtaining money for school fees and uniforms compared to those living in AHHs. Financial difficulties, caring for a sick parent, stigma associated with a parent's HIV/AIDS related death and resistance of guardians to sending children to school, all contribute to absenteeism or the likelihood of a child dropping out (Andrews et al., 2006; Barnett & Blaike, 1992; Chitiyo et al., 2008; Ebersöhn & Eloff, 2002; Ghosh & Kalipeni, 2004; Landry et al., 2007; Li et al., 2008). Absence from school deprives bereaved children of an important source of support as school "affords children the opportunity to socialise with their peers and to overcome the negative feelings and emotions of grieving" (Li et al., 2008, p. 153). Donald and Clacherty (2005) found friends to be an important source of emotional support to children living in a CHH and most assisted them with school-work. In a Zimbabwean study, children reported that school was the place where they felt happiest (Howard et al., 2006). Thus, school enrolment and peer support is likely to mitigate psychosocial distress (Cluver & Gardner, 2007b; Nyamukapa et al., 2008). Many orphans feel tired and dejected because of their experiences and thus generally do not perform well at school (Swift & Maher, 2008). Child heads of households complained that their additional responsibilities restricted their peer friendships, which served as a risk factor (Cluver & Gardner, 2007b). Gender disparities in education have

increased with HIV/AIDS as girls are more likely to stay home to nurse sick parents and to care for their siblings once their parent has died (Andrews et al., 2006; Germann, 2003; Ghosh & Kalipeni, 2004). Schools also play an important role in providing nutritional support (Swift & Maher, 2008). Thus, without quality care in their early years many abandon their schooling and are more at risk to turn to the streets to beg or enter the world of crime and prostitution, thereby perpetuating the cycle of poverty as adults (Davids & Skinner, 2006; Landman, 2006; Lusk et al., 2000).

CONCLUSION

Literature and research pertinent to the research topic was reviewed in this chapter. Although it may appear that there is a wealth of information on the psychosocial issues relating to young children living in CHHs, a perusal of the reference list at the end of this dissertation will show very little specific literature relating to the research problem. This could be due to the low instance of very young children living in this type of household, but also points to the general invisibility of this age group. Research and programming has focused on older children or covers the whole 0- to 18-year-old age range (Swift & Maher, 2008). In assessing the impact that a CHH has on a very young child, much can be inferred from established developmental theory, some of which was mentioned at the beginning of the chapter. This chapter contextualised the young orphan in his or her socioeconomic and familial environment and discussed issues surrounding parental illness and death. The remainder of the chapter reviewed issues impacting the young child living in a CHH, although much of this was relevant to OVC generally. The next chapter reviews the ecosystemic approach, the paradigm that guided this research.

CHAPTER 3

AN ECOSYSTEMIC EPISTEMOLOGY

If I had a world of my own, everything would be nonsense.
Nothing would be what it is, because everything would be what
it isn't. And contrary-wise; what is, it wouldn't be, and what it
wouldn't be, it would. You see?

- Disney, (1951) Alice in Wonderland

INTRODUCTION

In the early stages of the HIV/AIDS pandemic, the disease was approached from a purely medical perspective and intervention was directed at the individual. It was hoped that education would result in behaviour change (Richter & Rama, 2006). The context of the disease was largely ignored. However, it is now clear that community, cultural, economic and political interventions are also necessary (Ross & Deverell, 2004). While HIV/AIDS is a medical illness, there are multi-faceted processes underlying the incidence of the disease and thus, in addressing the issues of orphanhood, attention needs to be given to the various systemic levels in society (Donald et al., 2006; Visser, Schoeman & Perold, 2004). I felt that there was a marriage between the complexities surrounding the orphan crisis and the ecosystemic approach's search for complexity. Hence, an ecosystemic paradigm was adopted in this research as it offers the researcher a comprehensive conceptual framework for processing and utilising a vast amount of information (Jasnoski, 1984). This chapter looks at the central tenets of the ecosystemic approach. As epistemological principles are central to the approach, the chapter begins by clarifying what is meant by the term epistemology.

EPISTEMOLOGY

Bateson (1979) defines epistemology as: "A branch of science combined with a branch of philosophy. As science, epistemology is the study of how particular organisms or aggregates of organisms *know, think* and *decide*. As philosophy, epistemology is the study of necessary limits and other characteristics of the processes of knowing, thinking and deciding" (p. 242). Auerswald (1985), on the other hand, defines epistemology as "a set of imminent rules used in thought by large groups of people to define reality" (p. 1). It is the rules used by a person or cultural group, not necessarily consciously, that organise their reasoning or knowledge (Carpenter, 2001; Goldenberg &

Goldenberg, 2008; Keeney, 1983). Epistemology concerns itself with how we acquire knowledge and the underlying assumptions we make when we try to understand something (Barker, 2007; Goldenberg & Goldenberg, 2008; Keeney & Sprenkle, 1982). The spoken or written expression of this knowledge is rooted in prior beliefs (Auerswald, 1985). An epistemology is the "conceptual grid or filter through which the therapist interprets the behaviour presented during the session" (Stachowiak & Briggs, 1984, p. 7) or "a particular way of thinking, which determines how we know and understand the world around us" (Meyer, Moore & Viljoen, 2003, p. 463). Thus, epistemology functions at a metalevel that allows us to understand how we understand our realities (Lloyd, 2003). It is our "thinking about thinking" (Auerswald, 1985, p. 1).

ECOSYSTEMIC EPISTEMOLOGY

An ecosystemic epistemological approach represents a return to ancient indigenous knowledge systems such as African and Aboriginal worldviews, Buddhism and Taoism (Ashdown, 2006). It embodies a move away from seeing the universe mechanistically and is attuned to ecology, holism, context, relationships and the complexity inherent in human lives (Carpenter, 2001; Jasnoski, 1984; Keeney, 1979, 1983; Lifschitz & Fourie, 1990). An ecosystemic epistemology shifts away from construing behaviour according to linear cause-and-effect progression to viewing behaviour as arising from a reciprocally causal system of interaction (Stachowiak & Briggs, 1984) or "an ecology of relationships" (Keeney, 1984, p. 27). Fourie (1998) states: "The term ecosystemic approach combines the focus on systems and on ecology and emphasises the complicated interlinked and ever-changing networks of ideas and meanings within and between systems" (p. 17). These networks survive in language, both verbal and non-verbal, as language is the principal mode for the sharing of meanings and ideas (Fourie, 1998). The approach focuses on systems when assessing human functioning, and uses ecological and cybernetic principles as its point of departure (Meyer et al., 2003). Thus, it is based on the principles of systems theory, cybernetics and human ecology, all of which emphasise epistemological principles (Keeney, 1979, 1983; Keeney & Sprenkle, 1982; Meyer et al., 2003; Stachowiak & Briggs, 1984). Each of these elements is discussed below.

Ecology

Ecological theory studies the interdependence between the living organism and the environment that it inhabits (Donald et al., 2006; Thomas, 2005). Thus, to understand an organism it should be viewed holistically in the context of its natural environment (Donald et al., 2006): "To understand a

tree, it is necessary to study both the forest of which it is a part as well as the cells and tissues that are part of the tree" (Levine & Perkin cited in Visser & Moleko, 2003, p. 36). Similarly, individuals cannot be appreciated without understanding their ecological context (Holahan & Spearly, 1980). The concept of ecology assumes that all properties in nature are linked to each other in an intricate and systematic manner – mentally, morally and physically (Keeney, 1984; Keeney & Sprenkle, 1982; Meyer et al., 2003). Hence, a change in one part of the ecosystem can affect the other parts and ultimately the whole ecological system (Donald et al., 2006). O'Connor and Lubin (1984) define an ecosystem as "any organisational unit or interactive system composed of populations and their related environments" (p. 1). Thus, "ecology is networks…to understand ecosystems will be to understand networks" (Pattern cited in Capra, 1997, p. 35). Similar concepts have been applied by systems theorists to interactions between individuals, groups of people and their social context (Donald et al., 2006).

General Systems Theory and First-order Cybernetics

The emergence of general systems theory and the science of cybernetics were closely linked (Fourie, 1998). Beer (cited in Becvar & Becvar, 2006) states: "For some cybernetics and General Systems Theory are co-extensive, while those could be found who regard each as a branch of the other" (p. 65). The approaches differ in application, rather than in fundamental concepts and theoretical stances (Becvar & Becvar, 2006). The underlying assumptions are the same and include reciprocal causality, holistic, subjective, focus on the present, relational, relativistic, contextual and dialectical (Becvar & Becvar, 2006; Goldenberg & Goldenberg, 2008). Therefore, the terms are considered synonymous and are used interchangeably in this study.

General systems theory signifies a departure from the traditional scientific view based on the individual to a more holistic perspective. General systems theory holds that the individual cannot be understood apart from the context in which he or she exists (Fourie, 1998; Meyer et al., 2003; Prochaska & Norcross, 2003). It allows for a synthesis of the individualistic and situational perspectives, where the reciprocal impact of the person and the environment, as well as their interrelationship, is considered (Holahan & Spearly, 1980; Jasnoski, 1984). Thus, it is an interactionist approach where the interchange between the individual and the environment is viewed in terms of a process of reciprocal causation (Jasnoski, 1984). Von Bertalannfy defined a system as "a complex of interacting elements" (cited in Barker, 2007, p. 29). A system is organised around a "set of units that stand in some consistent relationship to one another" (Goldenberg & Goldenberg,

2008, p. 79). The system encompasses both the individual elements and the interactions between those elements (Prochaska & Norcross, 2003). The approach shifts the focus "from elements to organised wholes, the wholes [are] regarded as systems made up of elements and the interrelationships between them" (Fourie, 1998, p. 13). Some of the key ideas of general systems theory and cybernetics will now be discussed.

<u>Sub-systems and Supra-systems</u>

Systems theory views the individual as comprised of smaller elements, or sub-systems, but also as comprising part of wider supra-systems (Barker, 2007; Fourie, 1998; Meyer et al., 2003; Thomas, 2005). The human system is analogous to the earlier example of the tree and the forest. To understand a person one would need to understand their internal subsystems (for example, physiological functioning and emotional characteristics) as well the larger supra-systems within which they are contained (for example, the family system, the neighbourhood and the community) (Barker, 2007; Dalton, Elias & Wandersman, 2001; Meyer et al., 2003). Hence, systems are conceptualised as being hierarchically organised; systems interact with each other according to a chain of hierarchic levels (Capra, 1997; Prochaska & Norcross, 2003). Components of a system exist in a constant relationship with each other, they perform specific functions or processes within the system as a whole (Donald et al., 2006; Goldenberg & Goldenberg, 2008; Prochaska & Norcross, 2003). While the person remains pivotal to the ecosystem, they also interact with other layers of the system (Jasnoski, 1984; Meyer et al., 2003). In order to understand the individual one needs to explore the interaction, collaboration and opposing reaction of subsystems within the greater context (Meyer et al., 2003). In other words, the basic unit of analysis in human ecology is the human ecosystem, which cannot be understood effectively apart from its ecological context (Jasnoski, 1984).

Jasnoski (1984) argues that the human ecosystem operates within a structural framework. She presents a schematic that illustrates the above principles. Figure 3.1 depicts Jasnoski's (1984) structural representation of the human ecosystem. Each concentric circle represents a boundary that offers a useful ecological unit for analysis. These boundaries are semi-permeable in open living systems, allowing for exchange of information between levels and for systems to influence each other (Jasnoski, 1984; Meyer et al., 2003). Holahan and Spearly (1980) describe the ecological environment as "a nested arrangement of circumjacent contexts which surround each immediate setting in which the person participates" (p. 672). Jasnoski (1984) admits that the schematic is a simplified representation of the human ecosystem in that the two-dimensional diagram implies that

only adjacent circles connect with each other but, in reality, it is possible for non-adjoining levels to interact (for example, the cultural level can directly impact the individual).

Synergy. A system can be defined as "a functional whole consisting of components or subsystems where the organisation of the components as a whole changes the characteristics of the individual components" (Visser & Moleko, 2003, p. 65). Prochaska and Norcross (2003) argue that the concepts of "organisation and system are virtually synonymous" (p. 375). The organisation of the parts within the system determines the characteristics of that system (Donald et al., 2006). Change in one part of the system will bring about change in its overall functioning. A system operates as a distinct entity as a result of the notion of synergy (Stachowiak & Briggs, 1984). That is, the interaction of the elements of the system as a whole have a greater overall effect than the sum of the individual effects of each part (Capra, 1997; Goldenberg & Goldenberg, 2008; Prochaska & Norcross, 2003; Stachowiak & Briggs, 1984; Thomas, 2005) or "the whole is always more than the sum of its parts" (Meyer et al., 2003, p. 472). Although the means by which the parts are organised cannot be changed without perturbing the total systems' functioning, the individual parts can be substituted with comparable components with minimal disturbance to the system (Jasnoski, 1984). Therefore, what the part does for the organisation of the whole is more significant than what the part is (Jasnoski, 1984).

These ecosystemic principles contribute to understanding the development of the HIV/AIDS pandemic and possibly explain why early interventions failed. Initial interventions focused at the individual level and the disease was treated as a medical illness. However, the ecological context of the disease, especially in developing countries, was ignored. At a community level HIV/AIDS is linked to social problems such as overcrowding, poverty, urbanisation, shortage of health services and recreational facilities, family breakdown and the perceived lower status of women (Visser et al., 2004). Research shows that at a community level, HIV/AIDS has increased most rapidly in poor and low-resourced communities and "flourishes in areas where high levels of unemployment, homelessness, welfare dependency, prostitution, crime, high school dropout rates and social and political instability are rife" (Visser et al., 2004, p. 265). Cultural factors have been one of the largest obstacles to the prevention of the spread of the disease in that they influence the impact of campaigns, determining whether or not the messages are internalised (Ross & Deverell, 2004). Ansell and Young (2004) argue that the complex problem of poverty, in which HIV/AIDS thrives, can only be effectively dealt with at government and international levels. In the HIV/AIDS context, government expenditure and budget allocation plays a large role in impacting all other ecological

levels (Van Vuuren, 2004). Thus, to understand the orphan crisis, one needs to look at these separate issues and how they interact with each other to form a complex whole.

Recursion

The principles of recursiveness and feedback/self-correction are fundamental aspects of a cybernetic system (Becvar & Becvar, 2006). In systemic/cybernetic theory "we do not ask the question, Why?" (Becvar & Becvar, 2006, p. 65), as an act in one element of the system does not cause a reaction in a different part in a simple, uni-directional way (Donald et al., 2006). Rather, cause-and-effect occurs in cycles because of the interrelationship between parts (Donald et al., 2006). Thus, the terms cause and effect become redundant in the systemic approach (Carpenter, 2001). Rather than viewing people in isolation, meaning is obtained by looking at relations, at how individuals and events mutually interact with and influence each other (Becvar & Becvar, 2006; Holahan & Spearly, 1980). Hence, the context of relationships becomes central; people are seen to impact one another in a circular, reciprocal manner (Lloyd, 2003). This principle is based on the assumption of recursiveness or reciprocal causality (Becvar & Becvar, 2006). From a systemic perspective a solitary cause-and-effect incident is merely a fractional arc of the bigger pattern of circularity: "We see the behaviour of A as a logical complement to the behaviour of B, just as B's behaviour is a logical complement to the behaviour of A" (Becvar & Becvar, 2006, p. 65).

Feedback

Feedback refers to the process by which information about past behaviours or the current functioning of the system is reintroduced into the system in a circular manner (Dallos & Draper, 2000; Becvar & Becvar, 2006). In a wider sense, feedback amounts to the transmission of information regarding the consequence of any process to its source (Capra, 1997). Feedback mechanisms regulate a system through the exchange of information, matter or energy, thereby allowing the system to become aware of its functioning and make adjustments if necessary (Dallos & Draper, 2000; Jasnoski, 1984). Feedback is the aspect of recursion that involves self-correction (Becvar & Becvar, 2006; Carpenter, 2001). There are two types of feedback loops, positive and negative, which correspond to the stabilising and growth functions respectively (Barker, 2007; Jasnoski, 1984; Meyer et al., 2003). Negative feedback loops can be seen as deviation minimising in that they attempt to perpetuate the status quo by stabilising the system, or restoring balance, by reducing digressions from the preferred equilibrium (Barker, 2007; Carpenter, 2001; Dallos & Draper, 2000; Jansen, 2005; Jasnoski, 1984; Prochaska & Norcross, 2003). Positive feedback loops, on the other hand, are deviation amplifying and represent the growth function where change is facilitated, allowing flexibility to change the status

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quo in response to external or internal information (Barker, 2007; Capra, 1997; Dallos & Draper, 2000; Jansen, 2006; Jasnoski, 1984; Prochaska & Norcross, 2003). These positive and negative loops perform simultaneously in the human ecosystem to defend "the functional integrity" (Jasnoski, 1984, p. 46) of the system as internal and environmental circumstances alter. Thus, feedback cycles assist living systems in self-regulating and adapting to changing situations, thereby maintaining their dynamic balance (Dallos & Draper, 2000).

Visser and Moleko (2003) illustrate how feedback mechanisms operate in the context of HIV/AIDS. The escalating HIV/AIDS pandemic provides an example of a positive feedback cycle. The unrestrained escalation of HIV/AIDS is partially a result of the slow process of negative feedback as to whether an individual has contracted the disease because of, for example, the long incubation period. Hence, individuals continue with their risky behaviour, thereby spreading the virus. Consequently, the negative feedback cycle of becoming familiar with the disease, or becoming aware of one's status, does not encourage self-correction within the system. Further, because of the associated stigma, people are reluctant to reveal their status, resulting in low feedback about the prevalence of the disease within the community. Consequently the virus persists in spreading in the form of a positive feedback cycle. A healthy community would be represented by a balance between positive and negative feedback.

Homeostasis. Systems theory calls the dynamic balance discussed above homeostasis. Homeostasis describes how living systems maintain a steady state (Barker, 1998; Dallos & Draper, 2000; Prochaska & Norcross, 2003). In order to adapt to changes in the environment, change should take place in a system (Barker, 1998). However, to operate effectively, the system also needs to regulate its functioning to maintain some organisation or balance (Barker, 1998; Dallos & Draper, 2000; Donald et al., 2006; Prochaska & Norcross, 2003). This is achieved through feedback loops, which allow parts of the system to stay in dynamic interaction (Prochaska & Norcross, 2003). The principle of homeostasis encourages behaviour to linger between particular limits (Fourie, 1998). This simple conceptualisation of homeostasis has been criticised by newer epistemologies for failing to deal with change: "More than seeking to maintain the status quo, homeostasis represents a tendency to seek a steady state when a system is perturbed" (Goldenberg & Goldenberg, 2008, p. 84). Because all systems continuously change and evolve, the new state always differs slightly from the previous steady state (Goldenberg & Goldenberg, 2008). Thus, a family or community affected by HIV/AIDS could be encouraged to move from its old state of equilibrium to a new level of stability through reorganisation and change.

<u>Rules and Boundaries</u>

A boundary is an invisible line of delineation that separates systems, sub-systems and supra-systems from each other (Carpenter, 2001; Fourie, 1998; Goldenberg & Goldenberg, 2008). Boundaries assist in defining the autonomy of a system by serving as gatekeepers for information transferring in and out of the system (Carpenter, 2001; Goldenberg & Goldenberg, 2008). The amount of information that flows across a boundary is determined by the boundary's permeability (Fourie, 1988). Systems can be either open or closed (Barker, 1998; Dallos & Draper, 2000; Donald et al., 2006): "How rigid (closed) or how flexible (open) these boundaries are, affects a system's functioning" (Donald et al., 2006, p. 39). In living systems boundaries are permeable, allowing for an exchange of information and energy within the system and across its boundaries that permits systems to influence each other (Fourie, 1998; Jasnoski, 1984; Meyer et al., 2003). Boundaries serve as a system's rules, which are based on the relationship configurations within the system (Carpenter, 2001; Prochaska & Norcross, 2003). These rules express the values, roles and behaviour that are appropriate to the system and they direct emotional exchanges, closeness and shared actions (Barker, 2007; Carpenter, 2001). For example, the rule that a marriage should be monogamous delineates a boundary in that system (Prochaska & Norcross, 2003). Clear boundaries define the roles of individuals in a family and permit them to meet their developmental needs. These boundaries should also be adaptable and change along with these developmental needs (Wenar & Kerig, 2006). Barker (2007) points out that boundaries of emotional and psychological systems are not obviously visible but are characterised by "restricted emotional interchange, compared with that between those individuals within the one subsystem" (p. 32).

As demonstrated in the literature review, family composition and traditional boundaries have been severely disrupted in South African families as a result of HIV/AIDS. With the increase in the number of orphans, grandmothers or older siblings (in the case of CHHs) find themselves assuming the role of primary caregiver and so the organisational rules of the family have had to be renegotiated. In placing parental responsibilities on a teenager that teenager is robbed of their right to be a child and particularly their right to education. This in turn has an impact on the availability of a skilled workforce in the country, and so the impact ripples throughout the system. Thus, to find some sort of equilibrium amid the HIV/AIDS crisis, rules at each ecosystemic level need to be redefined and new boundaries established.

Equifinality and Multifinality

Equifinality refers to the idea that in human systems a number of different pathways may lead to the same outcome (Barker, 1998; Fourie, 1998; Wenar & Kerig, 2005). For example, various factors may initiate the onset of depression in children including cognitive style, genetics and environmental stress (Wenar & Kerig, 2005). Conversely, multifinality assumes that the same point of departure can lead to different outcomes (Visser & Moleko, 2003). For example, there may be many outcomes for children raised in CHHs. Some may turn to crime or become non-productive members of society, or they may concentrate on their education and succeed in a given field.

Second-order Cybernetics

Dissatisfaction with the interactional or cybernetics approach emerged in the late 1970's and early 1980's, resulting in a shift from a first-order (simple cybernetics) to a second-order cybernetic model (the cybernetics of cybernetics) (Becvar & Becvar, 2006; Dalton et al., 2001; Erasmus, 2005; Hoffman, 1990). While general systems theory represents a shift away from reductionism it still implies a linear causality because of the focus on interaction and power (Carpenter, 2001). It focuses on a system's functioning and offers a description of interactions from an outsider's perspective (Carpenter, 2001; Fourie, 1998; Jansen, 2005). The observer is considered to be outside the system being observed and hence, is believed to be objective or 'the expert' (Dallos & Draper, 2000; Fourie, 1998). Second-order cybernetics deems neutrality to be impossible and abandons the idea (Fourie, 1998; Meyer et al., 2003): "The very act of observation influence[s] the behaviour of the people under observation" (Fourie, 1998, p.15). By definition, anyone striving to observe or alter a system is a participant who simultaneously influences and is influenced by that system (Goldenberg & Goldenberg, 2008). A researcher can no longer be considered an outside observer but is included in the system that they are observing (Becvar & Becvar, 2006; Horne & Passmore, 1991; Keeney, 1979; Lifschitz & Fourie, 1990; O'Connor & Ammen, 1997). Therefore, second-order cybernetics can be considered the cybernetics of 'observing systems,' a term coined by Von Foerster (Hoffman, 1990; Horne & Passmore, 1991).

Becvar and Becvar (2006, p. 78) represent the difference between first-order and second-order cybernetics graphically in Figure 3.2 and Figure 3.3 below.

Figure 3.2:   Simple cybernetics

Figure 3.3:   Cybernetics of cybernetics

A second-order cybernetic approach argues that any observation is influenced by the observer's way of thinking or epistemology (Fourie, 1998). Researchers influence and interpret the phenomenon that they study and their epistemology determines the way in which the observed data is arranged and how it is interpreted (Andersen, 1997; Keeney, 1979). This makes one more alert to how one's relationship with a system influences it, or permits one to appreciate that a specific interpretation is only one amid many potential versions (Hoffman, 1990). This implies that a higher order of observation is required, an observation of the observation (Carpenter, 2001; Fourie, 1998). Thus, second-order cybernetics is about the "homeostasis of homeostasis, control of control, stability of stability, change of change, and feedback of feedback" (Keeney, 1983, p. 87). Von Foerster (cited in Boscolo, Cecchin, Hoffman & Penn, 1987), one of the fathers of second-order cybernetics, explains the approach as follows:

> The observer enters into the description of that which is observed in such a way that objectivity is not at all possible. Furthermore, if the observer enters into that which is observed, there is no such thing as a separate observed system. Finally, since the observer perceives the world through the lens of culture, family and language, the resulting product represents not something private and self-contained but an 'observer community.' (p. 14)

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However, the shift from first- to second-order cybernetics is more complex than simply taking the position of the observer into account. The entire view of how systems functioned changed (Fourie, 1998). Systems were no longer viewed as mechanistically interacting with each other by means of feedback across boundaries striving for homeostasis (Carpenter, 2001; Erasmus, 2005). The focus shifted to the autonomy of the system as opposed to a focus on interaction (Fourie, 1998). There were three main influences that resulted in a fundamentally different way of viewing systems (Erasmus, 2005). These influences included the work of Maturana and Varela, Bateson and the constructivists, such as von Glasersfeld (Erasmus, 2005; Hoffman, 1990). The principal ideas relevant to this research are discussed below.

Structural Determinism and Autonomy

Maturana and Varela emphasised the self-determination of systems (Meyer et al., 2003; O'Connor & Ammen, 1997). They argued that "perception was determined by the perceiver and not by the perceived" (Fourie, 1998, p. 15). This led to the idea that it is not possible for systems to influence each other in a cause-and-effect manner (Becvar & Becvar, 2006; Carpenter, 2001; Fourie, 1998). A living system's functioning is determined by its structure and is not directly influenced by its external environment (Carpenter, 2001; Erasmus, 2005; Keeney, 1983; Meyer et al., 2003). Thus, living systems are autonomous or self-regulating and are typified by closed, recursive organisation (Carpenter, 2001; Keeney, 1983; Meyer et al., 2003; O'Connor & Ammen, 1997). For example, an orphan's internal processes, such as their cognitive ability, resilience and self-esteem, may largely determine how they respond to the event of being orphaned.

However, it is possible to interact with the wholeness of an autonomous system (Keeney, 1983). While the environment does not decide how a system performs, it can act as a pertubating agent (Becvar & Becvar, 2006). A perturbation refers to the fluctuations in a system and replaces the concept of input in simple cybernetics (Becvar & Becvar, 2006; Meyer et al., 2003). For example, the environment or historical context of the orphan may perturb or influence what their individual structure can achieve. How the system, or orphan, reacts to such perturbations, whether it decides to compensate or not compensate, is determined by the system, or orphan, itself (Carpenter, 2001; Fourie, 1998; Keeney, 1983). If a system loses its autonomy it will cease to determine its own actions or function as a system, which can result in death (Meyer et al., 2003; O'Connor & Ammen, 1997). Hence, systems strive to retain their autonomy and may even embrace patterns that seem dysfunctional to an observer (Meyer et al., 2003). Thus, on the death of a parent, the family will react in the way that its structure allows at that given time. A teenage child may assume a parental role in

an attempt to retain the autonomy of the family system, which may seem dysfunctional to an observer.

Structural Coupling

Even though the original system determines the reaction to the perturbation, two or more systems may couple or interact with each other in a given context and form another autonomous, self-determining composite system (Becvar & Becvar, 1993; Erasmus, 2005; Fourie, 1998). The concept of structural coupling is defined by the extent to which two or more systems are capable of mutually coexisting: "Organisms survive by fitting with one another and with other aspects of their context, and will die if that fit is insufficient" (Becvar & Becvar, 2006, p. 82). Thus, in order to survive orphans need to be coupled with other individuals and subsystems, such as the family and larger social and cultural networks.

In human systems, coupling occurs by means of an exchange of ideas through verbal or non-verbal communication: "Human social systems require the linguistic coupling of their components (individuals) such that they can operate with each other as observers in language" (Anderson & Goolishian, 1988, p. 379). Each system, or individual, attributes meanings based on their own structure (Carpenter, 2001). Therefore, the recipient in an interaction may attribute meaning that the communicator never intended to convey: "The recipient system…autonomously creates its own, often idiosyncratic meanings that might only superficially resemble the intended meanings of the communicator" (Carpenter, 2001, p. 37). Consequently, even though there may be continuous pertubations or interactions between systems, the context in which they exist is not deterministic (Becvar & Becvar, 2006). For example, orphaned children may couple with NGO's, who provide caregivers and support groups to mentor them. The individual child, though, determines how they will respond to these efforts to assist and whether or not they will accept and benefit from these interventions. Thus, how systems' are coupled creates or strengthens an individual's epistemological foundation on which their beliefs and behaviours are based (Keeney & Sprenkle, 1982).

Ecology of Ideas

Bateson (1972) saw human systems as functioning in terms of ecologies of ideas. This refers to the way in which opinions and ideas are interlinked within and between systems (Bateson, 1979; Fourie, 1998). It is a metaphor for the ideas and meanings that a group of people attach to a situation and to the events that take place in that situation (Fourie, 1998). It represents the custom or consensus of a group of people (Fourie, 1998). Bateson (1979) argues that mind is a process and is found in

communication networks. In other words, "the mind (meaning) is not in someone's head but, rather, in interaction" (Anderson & Goolishian, 1988, p. 378). Bateson saw communication, both verbal and non-verbal, as vital to comprehending human behaviour (Fourie, 1998; Prochaska & Norcross, 2003). Thus, an ecology of ideas comprises the shared linguistic discourse which influences how our actions are co-ordinated and co-created realities or meanings are derived (Anderson, Goolishian & Windermand, 1986). In short, "a co-constructed reality exists in the domain of shared meanings" (Fourie, 1998, p. 17). An ecology of ideas is continuously evolving (Fourie, 1998). It is a cybernetic system with a feedback structure and hence any difference introduced to the system may produce modified understandings of previous experiences or events (Bateson, 1979; Keeney, 1983). Therefore, context can be seen as "an ecology of ideas through time rather than a fixed entity" (Lifschitz & Fourie, 1990, p. 28).

Constructivism

Constructivism is central to second-order ecosystemic epistemology and represents a fundamental shift from the observed to the observing system (Fourie, 1998; Golann, 1987, 1988). Constructivism implies that it is impossible to assume that a fixed reality exists. People create their personalised views, or reality, out of the meanings they associate with what they observe (Erasmus, 2005; Goldenberg & Goldenberg, 2008; Meyer et al., 2003). Hence, what is observed does not have a separate objective meaning, but assumes the meaning that the observer ascribes to it (Meyer et al., 2003). The approach emphasises a person's "unique, subjective perspective or self-constructed narrative as contrasted with an 'objective' or consensual reality" (Prochaska & Norcross, 2003, pp. 458-459). The implication is that no real reality exists (Carpenter, 2001; Erasmus, 2005). Our own reality is constructed through the lens through which we see and it therefore represents a filtered reality (Meyer et al., 2003). Prochaska and Norcross (2003) explain: "Reality is not out there to be found; reality is constructed inside each of us. We cannot attain knowledge of how the world really is. All knowledge is relative to the construct, culture, language or theory that we apply to a particular phenomenon" (p. 459).

Constructivists argue that objective truths do not exist but are constructed by the observer in accordance with their own reality and there may not necessarily be consensus about an observation (Meyer et al., 2003). This perspective is known as radical constructivism and risks being described as solipsistic (Carpenter, 2001; Erasmus, 2005; Meyer et al., 2003). Solipsism is an 'anything goes' approach where reality is believed to exist in the mind of the observer, and the observation is not impacted by feedback from that which is observed (Fourie, 1998; Meyer et al., 2003). However,

constructivism that is anchored in second-order cybernetics presupposes that the observer is included in the system's recursive feedback loop thus refuting an 'anything goes' philosophy (Meyer et al., 2003). Fourie (1998) explains: "The reality which is co-constructed in a system cannot be just anything; it has to fit with the ideas which the participants have about themselves, each other, the problem and the world in general. Thus a co-constructed reality exists in the domain of shared meanings" (p.16).

This relates to Bateson's ecology of ideas (Fourie, 1998). People develop shared realities and meanings through communication (Anderson, 1997; O'Connor & Ammen, 1997). Hence, in this cognitively oriented approach, a co-construction of reality exists in the domain of language (or more accurately linguistic constructions) as this is the vehicle through which ideas and meanings can be communicated (Anderson & Goolishian, 1988; Goldenberg & Goldenberg, 2008). Human systems are seen as both language-generating and meaning-generating and, therefore, as linguistic or communicative systems (Anderson, 1997; Anderson & Goolishian, 1988).

Multiverses of reality. The belief that reality is a social construction implies that we exist in a "multiverse of worlds of description" (Anderson & Goolishian, 1988, p. 377). This conceptualisation directs us away from the pursuit of unique or objective truths and into a world where there are conflicting versions of reality (Anderson & Goolishian, 1988). There are "no 'facts' to be known, no systems to be 'understood', and no patterns and regularities to be 'discovered'" (Anderson & Goolishian, 1988, p. 378). Truth, then, is seen as relative and context dependent (Anderson & Goolishian, 1988; Goldenberg & Goldenberg, 2008). The constructions we make about our world are inevitably not true reality but subjective perceptions or points of view (Goldenberg & Goldenberg, 2008). Our understanding of the world is always a process and is never fully achieved (Anderson & Goolishian, 1988). Thus, the ecosystemic approach is a multiple level approach in which multiple realities are accepted and an absolute truth can never be known (Anderson & Goolishian, 1988; Visser & Moleko, 2003).

The implication for this research then is that the evolving ecology of ideas depends on the ideas and beliefs of both the participants and the researcher. The aim becomes to co-construct a reality through dialogue with the participants. A reality is constructed through the interaction of the observer and the observed (O'Connor & Ammen, 1997). Both the researcher and the participants conceptualise the process under investigation in terms of their own frame of reference and understanding of the system and the research results are "constructions or interpretations of the

phenomenon - there can be other interpretations as well" (Visser & Moleko, 2003, p. 63). There is no error in an ecosystemic thought system as the concept of error is based on the assumption of a single truth (Auerswald, 1987). The position of the expert knower is therefore abandoned and substituted with a continuing conversation (Anderson & Goolishian, 1988) through interviews and member checks. Each person involved offers a "partial glimpse of the whole picture" (Keeney, 1983, p. 3).

Optimal Environments

The cyclical feedback mechanisms discussed above allow individuals to search for optimal environments, a process called optimisation (Jasnoski, 1984). Optimal environments are those that address individuals' needs and allow them to accomplish their goals (Jasnoski, 1984). Hence, an ecosystemic definition of health is relational and focuses on the congruence or balance between diverse forms of experience and behaviour (Dallos & Draper, 2000; Jasnoski, 1984; Keeney, 1984): "The focus is the relationship between each level's demands and available resources, with the resources available and demands made from other levels" (Jasnoski, 1984, p. 49). Pathology would be characterised by the escalation or the constant repetition of the same sequence of behaviour, interaction or experience (Keeney, 1984). It is the inability of an ecosystem to connect between individual and social relationship levels (Keeney & Sprenkle, 1982). Problems are seen as an indication of an ecology of relationships, or a "collaborative problem definition" (Anderson & Goolishian, 1988, p. 388). Problems are considered social constructions in verbal and/or non-verbal language that arrange themselves around a "network of shared ideas concerning a specific theme" (Fourie, 1998, p. 68). As problems are linguistic events there can be as many definitions of the problem as there are members of the problem-organising system (Anderson & Goolishian, 1988). Health, on the other hand, is seen as ecosystemic specific for each individual and assessment must be based on the functional integrity of each unique human life (Jasnoski, 1984).

The earlier example of how slow negative feedback allowed HIV/AIDS to spread to pandemic proportions can be briefly elaborated here. Because of the virus' long incubation period people were oblivious to the repercussions of the disease and hence repeated their risky behaviour. While the virus was spreading rapidly, modifications in the resources at other ecosystemic levels lagged behind. Hence, once the impact of HIV/AIDS was realised, other systemic levels were unprepared for the unfolding crisis. For example, government had not planned for the medical crises, which resulted in the slow roll-out of antiretroviral (ARV) drugs. In the interim people became ill, with many

eventually dying. This, in turn, disrupted the supra-systems in which the individual was embedded. Thus, the inability of the individual to connect with the social relationship levels resulted in unbalanced ecosystems. In addressing the HIV/AIDS crisis the individual will need to reconnect with these wider systems, and vice versa.

CONCLUSION

This chapter highlighted pertinent aspects of the ecosystemic epistemological approach. The ecosystemic perspective represents a clear shift from an anticontextual, linear cause-and-effect paradigm to a focus on complexity, context and relationship. As seen in the literature review and the discussion in this chapter, understanding the issues that our young orphans face cannot be divorced from the complex interlinked relationships between the various systemic levels they inhabit. I believe that an ecosystemic paradigm provides a suitable lens through which to view these complexities. Ecosystemic principles offered a map that guided this research. The following chapter plots the route that the research followed.

CHAPTER 4

RESEARCH METHODOLOGY

Read the directions and directly you will be directed in the
right direction.

- *Disney, (1951) Alice in Wonderland*

INTRODUCTION

Research methods form the backbone of any study. This backbone is made up of numerous vertebrae, each of which contribute to the strength of the study's character. This chapter looks at each vertebra of the research design and how it contributed to strenthening the core of the study. An ecosystemic paradigm informed the questions that were asked in this research and prompted me to implement certain tools to answer these questions. A qualtitative research design was adopted, which, in turn, influenced the techniques used for sampling, data collection and data analysis. Each of these procedures is discussed in detail. The soundness of the study is then evaluated in terms of its credibility, transferability and dependability. The chapter ends with a discussion of the ethical issues that informed this study and how I responded to them.

RESEARCH DESIGN

A research design is "a strategic framework for action that serves as a bridge between the research questions and the execution or implementation of the research" (Durrheim, 2006, p. 34). The design should incorpate detailed information on the procedures that will be used in implementing the research, which include sampling, data collection and analysis (Durrheim, 2006). Durrheim (2006) lists four aspects that the researcher should bear in mind when generating a research design: (1) the objective of the research, (2) the theoretical paradigm behind the research, (3) the situation or context in which the research is performed and (4) the research methods employed to collect and analyse data. As was mentioned previously, little specific information exists on the psychosocial impact on very young orphans in the 2- to 5-year-old age group living in CHHs. Thus, the purpose of this research was to describe this topic by interviewing experts who work in the field with this population. I selected an ecosystemic paradigm to guide this research as it focuses on complexity, context and a reciprocally causal system of interaction and moves away from a linear cause-and-

effect model. I felt that there was a good fit between the ecosystemic approach and the research question. To me, the purpose of this research and the theoretical paradigm informing the study suggested that a qualitative research design should be adopted.

While quantitative research is concerned with objective facts, variables and statistical analysis, qualitative research focuses on the construction of social reality and cultural meaning, interactive processes, values and authenticity (Neuman, 2006). Quantitative researchers collect data by means of numbers and use statistics to analyse data, whereas qualitative researchers collect information through spoken or written language, or by observations that are recorded in language, and analyse the information by recognising and categorising themes (Durrheim, 2006). Qualitative research attempts to depict and ascertain meaning while the researcher is interacting with the data and is appropriate when attempting to understand social phenomena from the perspective of the participants (Hancock, 1998; Neuman, 2006; Struwig & Stead, 2001). Neuman (2006) states that qualitative researchers "borrow ideas from the people they study and place them within the context of a natural setting" (p. 157). Thus, qualitative research is holistic, naturalistic and inductive (Durrheim, 2006; Patton, 1990). My decision to adopt a qualitative methodology informed the research design decisions I made in terms of sampling, data collection and data analysis. I used qualitative methods by selecting a purposeful sample, collected data by means of interviews and, in turn, analysed the information by means of an interpretive analysis. Prior to finalising the themes from the interpretive analysis, feedback was obtained from the participants so that they could comment and recommend changes. This was done to enhance the validity of the findings. Before describing the specific design details a brief description of the paradigm informing the research is presented as "the first thing a researcher must outline is the paradigm that underpins the study" (Delport & Fouché, 2005, p. 261).

Ecosystemic Guidelines for Research

This research was informed by an ecosystemic paradigm. A paradigm promotes a series of assumptions about the nature of reality and hence serves as the lens through which we see life (Timm, 2003). The suppositions of a paradigm influence the questions that the researcher asks and how he or she approaches answering them (Timm, 2003). As the ecosystemic approach was discussed in detail in Chapter 3, only brief mention is made of it here in specific relation to research. Ecosystemic research takes place in a social setting where the focus is on dialogue, which consists of both verbal and/or non-verbal language (Fourie, 1998). It does not aim to prove anything and does

not regard one observation as more 'true' than another (Fourie, 1998). Rather, the research is descriptive - the goal is to describe a process of investigation and make sense of the total process (Fourie, 1998). Holistic thinking is central to an ecosystemic perspective; a system as a whole cannot be understood by analysis of separate parts (Patton, 1990). Synthetic thinking that focuses on function rather than structure is required. The focus is on why a system works in a certain way, not how it works (Patton, 1990).

Ecosystemic research is constructivistic (Fourie, 1998). The act of making sense is a cognitive function where the researcher purposefully constructs her appreciation and conclusions based on her acquired knowledge about the subject. It is impossible to think in a neutral way. Our thinking is directed by how we learned to think and this impacts how we interpret data. Ecosystemic research is also about constructing consensus. The researcher's meaning making must fit with existing knowledge and should consider prior research findings and the published positions of other researchers/theoreticians in the discipline (Fourie, 1998). Further, the evolving ecology of ideas relies on the ideas, beliefs and attributions of all the participants (Fourie, 1998). Fourie (1998) argues that it is important to understand the participant's "attributions of meaning" (p. 113) to the research situation as these impact the results and should be taken into account when interpreting the data. Fourie (1998) states that any research technique is acceptable in an ecosystemic approach as long as the researcher understands the assumptions on which the approach is based and how these assumptions impact on drawing conclusions: "Note that the emphasis is on a broadening of understanding and not on a reduction of complexity. The aim is to make sense of complexities and not to prove anything" (p. 114).

These factors all played a role in determining the design of this research. Approaching this research from an ecosystemic perspective influenced how data was collected, analysed and interpreted.

Participants

Sampling practices in a qualitative enquiry diverge from quantitative methods as random selection, representativeness and generalisability are not pivotal to qualitative research (Neuman, 2006; Smith & Osborn, 2008; Struwig & Stead, 2001). Typically, qualitative enquiries focus on the richness or depth of data with a relatively small sample, even a single case, selected purposefully, whereas quantitative methods depend on larger randomly selected samples (Durrheim, 2006; Patton, 1990; Struwig & Stead, 2001). Purposeful sampling is powerful in that it allows for the selection of

information-rich cases that can be studied in-depth, thereby illuminating the research questions (Durrheim, 2006; Patton, 1990; Struwig & Stead, 2001). Thus, samples used by qualitative researchers are nonprobability or nonrandom samples (Neuman, 2006). The sample size is seldom determined in advance and little is known about the wider group or population from which the sample is obtained (Neuman, 2006). Cases are selected gradually with the particular content of a case influencing whether or not it is chosen (Neuman, 2006).

Two NGOs who engage with young orphans living in CHHs to agreed to participate in this study. For ethical reasons, as discussed later in this chapter, I decided that caregivers and/or professionals working for these organisations would be interviewed rather than the children themselves. The two NGOs that participated in the study were Heartbeat: Centre for Community Development (Heartbeat) and Ikageng Itireleng AIDS Ministry (Ikageng). Heartbeat is a NGO that responds to the orphan challenges in South Africa and reaches over 11,000 OVC through direct and indirect interventions in 14 communities in 7 provinces (http://www.heartbeat.org.za). The Nellmapius branch in Pretoria was involved in this study. I was referred to a community-based social worker at Hearbeat, who served as a participant in the research as well as the gatekeeper to two caregivers who work directly with the children. A gatekeeper is "someone with the formal or informal authority to control access to a site" (Neuman, 2006, p. 387). The project director from Ikageng agreed to participate in the research. Ikageng is a community outreach project whose mission is to serve child- and child-assisted households in Soweto, Johannesburg (http://www.ikageng.org.za). Thus, a snowball sampling technique, a type of purposeful sampling (Patton, 1990; Struwig & Stead, 2001), was adopted in this research. Neuman (2006) describes snowball sampling as "a nonrandom sample in which the researcher begins with one case, and then based on information about interrelationships from that case, identifies other cases, and repeats the process again and again" (p. 223). Hence, it is a multistage technique that starts with a few people and extends out based on the associations with the primary cases (Neuman, 2006).

Four participants were interviewed in this study. There are no set rules for determining sample size in a qualitative study (Kelly, 2006; Patton, 1990; Smith & Osborn, 2008). Sample size depends on what you are researching, the goals of the study, the richness of the individual cases, how the findings will be used and what can be done with available time and resources (Kelly, 2006; Patton, 1990; Smith & Osborn, 2008; Struwig & Stead, 2001). Smith and Osborn (2008) indicate that the trend is to use a "very small number of participants" (p. 56) in an interpretive analysis, especially for novice researchers who may be overwhelmed by the extensive data generated in a qualitative study,

resulting in an insufficiently penetrative analysis. Four participants are adequate: "This allows sufficient in-depth engagement with each individual case but also allows a detailed examination of similarity and difference, convergence and divergence" (Smith & Osborn, 2008, p. 57). It has been proposed that sampling to redundancy, or until saturation is reached, is ideal in qualitative research (Durrheim, 2006; Greeff, 2005; Kelly, 2006; Patton, 1990). In other words, sampling is terminated once no new information is forthcoming from additional cases (Durrheim, 2006; Greeff, 2005; Kelly, 2006; Patton, 1990). In planning for this research I did not decide on the number of participants or the length of the interviews in advance. Taking the purpose and scope of this research and Smith and Osborn's (2008) advise into account, I knew the sample would be small. However, the quality of information obtained in the interviews determined the final number of participants and the length of the interviews. I made a decision to terminate sampling once I believed the topic had been sufficiently saturated and I had enough information to develop a thorough description of the issues.

Data Collection

In this research, I conducted individual face-to-face interviews with each of the participants. Prior to commencing with the interviews, all participants were informed of the nature of the study, that participation was voluntary and that they could withdraw from the study at any stage. Further details of informed consent are discussed later in this chapter. The interviews with the participants from Heartbeat were carried out in a private room at their community centre in Nellmapius. This centre serves as a meeting point for the Heartbeat child care workers who interact with OVC. The interview with the participant from Ikageng was conducted in the board room at their Soweto offices. A familiar location is important in making the participants feel comfortable during the interview (Smith & Osborn, 2008). Interviews were approximately 1 hour 30 minutes in length. This length is typical of semi-structured interviews, which generally last an hour or more (Smith & Osborn, 2008).

Interviews

In this study, data was collected by means of semi-structured, in-depth interviews, which were tape recorded. Interviewing is a principal means of collecting information in qualitative research and semi-structured interviews are popular (Eatough & Smith, 2008; Greeff, 2005; Kelly, 2006). The purpose of the research, though, should direct the researcher to select the most effective approach for collecting data (Greeff, 2005). I chose to interview participants as I believe that it was in keeping with the ecosystemic tone of the research where dialogue, and the conceptualisations and provenance of both the interviewer and interviewee play an important role in growing an ecology of ideas. I chose

individual interviews because of the sensitive nature of the subject matter. Interviews are a spontaneous way of interacting with individuals and facilitate rapport (Kelly, 2006; Smith & Osborn, 2008). Greeff (2005) states that "you interview because you are interested in other people's stories. Stories are a way of knowing…a meaning-making process…All interviews are interactional events and interviewers are deeply and unavoidably implicated in creating meanings that ostensibly reside within participants" (p. 287). The interview takes the shape of a conversation which "implies a discussion and captures the attitude of the interaction" (Greeff, 2005, p. 287) but simultaneously they are also "highly skilled performances" (Kelly, 2006, p. 297).

In semi-structured interviews the topic under investigation remains defined and questions or topics are planned in advance but the open-ended nature of the questions allows the interviewer and interviewee the flexibility to explore some topics in more detail (Berg, 2004; Eatough & Smith, 2008; Fox, 2006; Greeff, 2005; Hancock, 1998). Thus, the interviewer and interviewee are both actively involved in meaning-making (Eatough & Smith, 2008; Greeff, 2005). A semi-structured interview allows the researcher to conceptualise and formulate questions based on a focused literature study ensuring that the issues surrounding the construct are covered (Greeff, 2005).

Producing an interview schedule prior to the interview allows the researcher to contemplate the issues that might be encompassed in the interview and consider difficulties that may be encountered (Eatough & Smith, 2008; Greeff, 2005; Smith & Osborn, 2008). The schedule serves as a guide, allowing both parties to participate in directing the interview rather than being directed by it (Greeff, 2005; Smith & Osborn, 2008). Thus, in this study I prepared a series of open-ended questions (see Appendix A) around the psychosocial impact that living in CHHS has on young orphans. The formulation of the questions was guided by the literature I had read as well as the epistemological underpinning of the study. This allowed me the freedom to probe the interviewee to expand on a response or to reflect on a question in more detail. Similarly, the participants could elaborate on issues that they believed to be important. Leading from the qualitative and ecosystemic nature of the study, participants were considered the experts and although I had an interview guide at my disposal, the interviewee played a significant role in steering the direction of the interview.

The interviews in this study were tape recorded. Tape recording is preferential to note taking as it decreases the risk of interviewer bias and ensures that complete data is available for analysis (Greeff, 2005; Hancock, 1998). Tape recording enhances the flow of the interview in that the researcher is not distracted by detailed note-taking and can be more attentive to the participant

(Kelly, 2006; Patton, 1990; Smith & Osborn, 2008). Authors (De Vos, 2005; Patton, 1990; Smith & Osborn, 2008) warn that the interactive nature of the interview can be seriously compromised if the researcher attempts to take notes verbatim. On the other hand, Kelly (2006) cautions that the presence of a tape-recorder could "detract from the intimacy of the encounter, with both interviewee and interviewer in part performing for the…tape recorder rather than really talking to each other" (p. 298). Thus, in my interviews the tape recorder was used judiciously and unobtrusively so as not to inhibit the interview process. It is important to obtain consent to tape record an interview and the participant should be entitled to turn the recorder off at any stage and/or request the tape (Kelly, 2006; Patton, 1990). The participants were made aware of this prior to the interview during the discussion concerning consent.

Field and Process Notes

Patton (1990) highlights that the use of a tape recorder does not entirely eliminate the need for note taking. Throughout the interview notes should be jotted down that could assist the interviewer formulate new questions or to return to a point for clarification about something that was mentioned earlier in the interview (Patton, 1990). I took field notes throughout the interviews for this purpose. Further, Greeff (2005) advises the researcher to jot down their impressions immediately after the interview to assist with exploring the process of the interview. Greeff (2005) emphasises the importance of differentiating between the content and process of the interview. Content is the easiest component of the interview to study as it focuses on what has been said (Greeff, 2005). Process, on the other hand, is a "much more elusive, though powerful, component of the interview. It involves reading between the lines of what the participant says, and noticing *how* the participant talks and behaves during the interview" (Greeff, 2005, p. 291). The process can corroborate, enhance or even conflict with the content of what an interviewee says (Greeff, 2005). The process notes that I took after each interview served as an important source of information, particularly when interpreting the conversations.

Feedback Group

Because of the collaborative ambience of the research and the need to produce a dependable interpretation of our conversations (to be discussed later in this chapter), I gathered the participants together in the form of a feedback group to give them the opportunity to confirm the content of their own transcribed interview and to discuss the categories and themes which I had tentatively compiled during an initial data analysis. Thus, the feedback group met after I had categorised the interviews into preliminary themes. The participants were asked for input during this meeting and given the

opportunity to agree, disagree and elaborate on the identified themes. In giving each participant a copy of their own transcribed interview, I gave them the opportunity to confirm or disconfirm that this was in fact how the interview transpired. It was important to me that they felt like co-researchers throughout the process so that they could experience some ownership of the completed product and feel involved in developing an ecology of ideas. I believe that obtaining input enhanced the validity of the research and improved the chances of the material being taken seriously.

The Reasercher as the Research Instrument

The researcher is the main instrument in qualitative research in both collecting and analysing data and consequently the quality of the interview is largely dependent on their skill (Patton, 1990; Timm, 2003). In ecosystemic research specific demands are made on the researcher. Research becomes a collaborative and cooperative endeavour where meaning and understanding are co-constructed (Anderson, 1997; Barker, 2007; Golann, 1987; Goldenberg & Goldenberg, 2008). The meaning created is inter-subjective and based on an assumption of shared expertise (Anderson & Goolishian, 1988; Goldenberg & Goldenberg, 2008). The researcher relinquishes the role of director and approaches the research as a collaborative explorer (Anderson, 1997; Dallos & Draper, 2000) or 'non-blaming ecological detective' whose principal task is to situate the research problem in a contextual time-space (Auerswald, 1985). The participants are considered the experts, teachers or knowers in the research process, whereas the researcher is seen as a participant-observer and participant-manager whose responsibility is to co-construct meaning and understanding through conversations with the participants (Anderson & Goolishian, 1988; Barker, 2007; Goldenberg & Goldenberg, 2008; Hoffman, 1990). The researcher operates from the position of the learner in the process and operates from a position of not knowing (Anderson, 1997; Anderson & Goolishian, 1988; Goldenberg & Goldenberg, 2008). The observer is also required to step into a reflexive or self-referential stance (Becvar & Becvar, 2006). Chapter 7 has been dedicated to reflecting on my own influence on this research and how this research influenced me.

Data Analysis

Authors (De Vos, 2005; Patton, 1990; Struwig & Stead, 2001; Terre Blanche, Durrheim & Kelly, 2006; Tesch, 1990) agree that in a qualitative study there is no specific point where data collection stops and analysis begins – it is not a linear process. Analysis in qualitative research is recursive and inductive (Carruthers, 2007; Mertens, 2005). That is, "findings are generated and systematically built as successive pieces of data are gathered" (Mertens, 2005, p.420). Analysis takes place throughout

the data collection process; the researcher continually contemplates, for example, relationships, impressions, commonalities and patterns while they are still in the field (Carruthers, 2007; Mertens, 2005). The aim is to produce rich descriptions of phenomena and promote or develop new theory rather than to support a hypothesis (Carruthers, 2007). This is achieved by decreasing the amount of raw data, sorting trivia from the consequential, detecting patterns and building a context for conveying what the data shows (De Vos, 2005; Patton, 1990). Qualitative analysis is "a messy, ambiguous, time-consuming, creative and fascinating process" (De Vos, 2005, p. 333) where the researcher attempts to bring some structure and meaning to a massive amount of data (De Vos, 2005; Patton; 1990; Struwig & Stead, 2001). In analysing the data reflective activities should be included in note form. This provides a means of accountability and guides the process (Mertens, 2005; Tesch, 1990).

There is no consensus as to which methods are best in a qualitative analysis and thus there are few set procedures to direct the researcher (Timm, 2003). The analytical tool is "custom built" (Creswell, 1998, p.142) and qualitative researchers' "learn by doing" (Dey cited in Creswell, 1998, p.142). Patton (1990) states: "There are no absolute rules except to do the very best with your full intellect to fairly represent the data and communicate what the data reveal given the purpose of the study" (p. 372). However, Patton (1990) points out that the lack of rules does not imply that there are no guidelines. Although there are no characteristics universal to all methods of qualitative analysis, there are common features (Tesch, 1990; Timm, 2003). To start, familiarisation with the data is recommended (Timm, 2003). The words used by the participants are then analysed and reduced via the classification of information into themes by means of a coding system (Timm, 2003). These themes provide an interpretation of the participant's views or views identified in the literature. The derivation of themes requires that the researcher draw distinctions so as to form categories, establish the boundaries of each category and so on (Carruthers, 2007; Tesch, 1990). As was mentioned in the previous chapter, these distinctions are self-referential in that the researcher creates them based on her own frame of reference or epistemological stance. The aim of the analysis is to develop "some type of higher-level synthesis" (Tesch, 1990, p. 97). While much of the analytical work consists of reducing the data into smaller pieces, the ultimate goal is to present a composite picture of the phenomena (Tesch, 1990).

An interpretive analysis of the data was adopted in this research. The purpose of an interpretive analysis is to provide thick description, which can be defined as "a thorough description of the characteristics, processes, transactions, and contexts that constitute the phenomenon being studied,

couched in language not alien to the phenomenon, as well as an account of the researcher's role in constructing this description" (Terre Blanche et al., 2006, p. 321). The aim is not to collect bits and pieces of 'real life' but to describe them contextually (Terre Blanche et al., 2006). The steps listed by Terre Blanche et al. (2006) were used as a guide in this research. As was advised in the preceding paragraphs, I adapted and added to these steps to meet the particular requirements of this study. Although Terre Blanche et al. (2006) discuss these steps in sequence, they point out that in actuality an interpretive analysis seldom progresses in a systematic manner. This was true in this study where I continually had to return to the initial steps to check and re-check my analysis. Terre Blanche et al.'s (2006) steps are as follows:

Step 1: Familiarisation and Immersion

As mentioned previously, ideas and theories develop throughout the data collection process, from making contact with gatekeepers, interviewing the participants and writing field and process notes. Thus, once I started analysing the data I already had a preliminary understanding of the issues involved. Transcribing the interviews verbatim myself assisted in familiarising myself with the information. Authors (Patton, 1990; Smith & Osborn, 2008; Struwig & Stead, 2001) agree that it is important to transcribe interviews verbatim, including the pauses, laughs and so on. Struwig and Stead (2001) argue that if the raw data is rephrased or summarised "they no longer become the original data and this becomes methodologically problematic" (p. 169). This first step, however, requires one to return to one's interview transcripts and notes and totally immerse oneself in the material (Terre Blanche et al., 2006), which I did. I achieved this by reading the interview transcripts and my notes many times. I drew numerous mind maps which assisted in extricating what I believed to be important information from each interview and then linked this to important themes from interviews with the participants.

Step 2: Inducing Themes

Terre Blanche et al. (2006) describe induction as "inferring general rules or classes from specific instances" (p. 323). The researcher needs to identify recurring patterns but also be sensitive to fresh issues emerging as they work through the transcripts (Smith & Osborn, 2008). In this research, themes were induced from the gathered material by obtaining an understanding of the organising principles that lay beneath the material. My immersion in and familiarisation with the data assisted with this. Themes were not merely identified based on content, but processes, functions, ambiguities and tensions were also noted (Terre Blanche et al., 2006). Smith and Osborn (2008) point out that "one is aiming to respect convergences and divergences in the data - recognising ways in which

accounts from participants are similar but also different" (p. 73). According to the ecosystemic approach, the themes would be influenced by my own interpretation of the information and thus there could have been other interpretations as well. Terre Blanche et al. (2006) recommend that the language of the interviewees be used to label certain categories and I followed this advice wherever possible. For example, the term teacher is used throughout this document opposed to the more politically correct term educator as this is the word that the participants used. Further, they recommend that the researcher attempt to establish "an optimal level of complexity" (p. 324). Therefore, I organised the data into major themes each of which consisted of smaller sub-themes. This was accomplished via a trial-and-error process where I played around with the data for many hours in order to accomplish what I thought was the best fit. The themes that emerged from the interviews included: *why children live in child-headed households; issues surrounding the death of a parent; experiences of a young child living in a child-headed household; experience of living in a child-headed household; stigma; relationships with relatives; relationships with peers; relationships with crèches and teachers; relationships with the community; relationships with non-governmental organisations; and relationship to government and essential services.*

Step 3: Coding

This step ran concurrently with Step 2 (Terre Blanche et al., 2006). In order to uncover the themes, I coded all the data. I underlined words, phrases, sentences and paragraphs from each interview that I thought to be important. All the underlined information was then copied electronically from the original interview transcript and pasted into a separate document for each participant. The material from each individual case was then scrutinised to establish emergent themes. Smith and Osborn (2008) recommend an ideographic approach to analysis where each individual transcript is viewed in detail before moving on to the next case. Once each individual case had been viewed, common categories and themes across the interviews were highlighted, each in a different colour. Themes were formulated based on patterns of experiences noted in the transcribed interviews. Material that was coded the same colour was then copied and pasted into separate documents. From here the commonalities could be identified and appropriate names were created. The same applied for developing sub-themes. In reality this process was not as straight forward as this description implies. As codes and themes were not necessarily mutually exclusive, there was much arranging and re-arranging of the data.

Step 4: Feedback

This step is not included in Terre Blanche et al.'s (2006) process but I thought it was important taking into account the collaborative nature of the study. Participants were invitied to partake in a feedback group. As mentioned earlier, each participant was given a copy of their transcribed interview for verification as well as a copy of the preliminary themes and sub-themes, which were discussed. Being a student and having the advantage of working under a supervisor, I also submitted this information to my supervisor for comment. After obtaining the additional input I revisited the themes and categories, taking the feedback into account. The final themes were made available to the participants so that they could comment further.

Step 5: Elaboration

This step allows one to bring together data from sources which may initially seem distant and look at the data more closely (Terre Blanche et al., 2006). Once themes have been clustered together they can be elaborated. That is, one can identify the commonalities and differences within a theme as well as the different issues that this theme may expose. Terre Blanche et al. (2006) argue that the purpose of elaboration is to "capture the finer nuances of meaning not captured by your original, possibly quite crude, coding system" (p. 326). Further, they recommend that one should code, elaborate and re-code until no new insights are forthcoming from the data. I re-examined the material numerous times and reworked my coding system until I was satisfied that the material was positioned in the most suitable place.

Step 6: Interpreting and Checking

In this final step, a description of my interpretations was written in the form of Chapter 6 of this mini-dissertation. The themes and sub-themes identified in earlier steps, and their connectedness, served as compass points in the discussion. My interpretation was meticulously scrutinised for weak points, inconsistencies, contradictions and instances where I may have over-interpreted material. As the ecosystemic approach focuses on the whole rather than on parts, it was important that I re-contextualise the components or categories of information so that the phenomenon could be understood holistically. Hence, the ecosystemic analysis required that there be a focus on the dynamic interrelationships between the identified themes and systems so that a holistic and contextual picture could be obtained.

This final stage also requries one to reflect on one's own role in collecting and interpreting the information (Terre Blanche et al., 2006). This is presented in Chapter 7. The ecosystemic approach

emphasises a multitude of realities of which the researcher's is only one. Thus, another researcher conducting the same research may have interpreted the information differently or emphasised different aspects.

Ironically, becoming interested in a particular topic and analysing it in terms of themes is in essence isolating it from its context (Terre Blanche & Kelly, 1999). This appears to be contradictory to the ecosytemic approach. However, as Jasnoski's (1984) schematic in Chapter 3 shows, each layer of a system represents a boundary that offers a useful unit for analysis (Jasnoski, 1984; Meyer et al., 2003; Visser & Moleko, 2003). In research boundaries are conceptual or relative and can be altered according to the focus of the study (Visser & Moleko, 2003). For analysis sake, within the psychosocial environment, investigation may focus on the interpersonal, the family, the community or the cultural level (Jasnoski, 1984). Consequently, the person can be considered on numerous levels of analysis (Jasnoski, 1984). The approach allows the researcher to 'zoom in' on any level or subsystem and then to 'zoom out' again so that the ecosystem can be understood in its entirety (Jasnoski, 1984). Capra (1997) argues that a vital principle in systems thinking is the ability to swing one's interest between systems levels, thereby gaining significant insights. Once each level has been viewed, "information from all these different levels needs to be synthesised into a total ecosystemic picture if a fuller understanding of the individual human life is to be reached" (Jasnoski, 1984, p. 44). It is hoped that the final synthesis of information in this research offers an ecosystemic description of the psychosocial impact that living in CHHs has on young orphans.

RELIABILITY AND VALIDITY

While most qualitative researchers acknowledge the fundamental principles of reliability and validity, the words are seldom used due to their affiliation with quantitative research (Neuman, 2006). Further, in qualitative research the principles apply differently (Neuman, 2006). The traditional means of employing external and internal validity, reliability and objectivity to ascertain the trustworthiness of research findings are incompatible with the assumptions of a naturalist enquiry (Lincoln & Guba, 1985). Lincoln and Guba (1985) propose alternatives to these constructs which they believe more truthfully reflect the assumptions of the qualitative method. These alternatives are discussed below.

Credibility

Credibility provides an alternative to internal validity in postpositivist research (De Vos, 2005; Mertens, 2005). The test for credibility in qualitative research "asks if there is a correspondence between the way the respondents actually perceive social constructs and the way the researcher portrays their viewpoints" (Mertens, 2005, p. 254). There are numerous research techniques to improve credibility and Mertens (2005) argues that the researcher should attempt to use as many of these as possible. Only the techniques used in this research are mentioned below.

Prolonged and Substantial Engagement

The researcher should remain in the field until they are satisfied that no new information is emerging and that themes are repeating themselves (Mertens, 2005). Further, sufficient time should be invested so that certain purposes can be achieved: "Learning the 'culture,' testing for misinformation introduced by distortions either of the self or of the respondents, and building trust" (Lincoln & Guba, 1985, p. 301). I only concluded my interview sessions once I believed that no new information was forthcoming. In addition to the interviews, I had also spent a substantial amount of time in the field while completing my training as a Counselling Psychologist. Thus, I already had some introduction to the issues concerning this research prior to commencing.

Peer Debriefing

It is recommended that the researcher discuss the research findings and interpretation with other professionals (Lincoln & Guba, 1985; Mertens, 2005; Timm, 2003). This can serve as a corrective measure and establishes content validity (Timm, 2003). Mertens (2005) states: "The peer should pose searching questions to help the researcher confront his or her own values and to guide next steps in the study" (p. 254). In this study, my supervisor filled this role. Further, the findings were made available to the manager in charge of Research and Development at Heartbeat as well as the project director from Ikageng, for review and comment.

Progressive Subjectivity

This technique requires that the researcher monitors their own "developing constructions and document the process of change from the beginning of the study until it ends" (Mertens, 2005, p. 255). The researcher's beliefs can be shared with a peer who can challenge the researcher should they feel they have interpreted the information in terms of preconceived ideas. I maintained a journal with process notes throughout the research where I documented my own feelings and beliefs about

the research process. I remained open to be challenged by my supervisor about my beliefs so that I could keep an open mind and not be biased by previous experience.

<u>Member Checks</u>

Lincoln and Guba (1985) argue that the member check is the most essential criterion in determining credibility. Here, the researcher must verify the information collected with the participants (Timm, 2003). In this research copies of the transcribed interviews were given to the participants to ensure that they were satisfied with the content of their interview. Further, a member check requires that the themes constructed during data collection and analysis be confirmed with participants (Lincoln & Guba, 1985; Mertens, 2005). I allowed for this in this research by hosting a feedback group after I had categorised the data and identified themes. The participants had the opportunity to comment and recommend changes.

Transferability

Transferability is the qualitative alternative to external validity (De Vos, 2005; Lincoln & Guba, 1985). External validity is the extent to which results can be generalised to other situations (Mertens, 2005). Transferability of results in a qualitative analysis relies on the resemblance of the original context of the study to the context where the results are to be transferred (Lincoln & Guba, 1985). The onus is on the researcher who wants to transfer the information to prove transferability (Lincoln & Guba, 1985; Mertens, 2005; Timm, 2003). Transferability can be achieved by detailing a thick description in the study and by using multiple cases.

<u>Thick Description</u>

The responsibility of the qualitative researcher is to provide a thick description which includes an extensive and careful description of the time, place, context and culture (Lincoln & Guba, 1985; Mertens, 2005; Timm, 2003). Thick description will allow another researcher to make transferability judgments (Lincoln & Guba, 1985; Mertens, 2005; Timm, 2003). The small sample of 4 in this research allowed for the development of thick description as participants were interviewed in-depth. This was facilitated by meticulously detailing the research methodology, as laid out in this chapter.

<u>Multiple Cases</u>

The use of multiple cases can enhance the external validity of the results (Mertens, 2005). Four in-depth interviews were conducted in this research. Decisions about generalisability can also be made

by comparing each case to existing theories (Mertens, 2005). The findings of this research are linked to theory in the discussion section of this dissertation.

Dependability

Dependability is the qualitative alternative to reliability (De Vos, 2005; Mertens, 2005). In quantitative research reliability means stability over time (Mertens, 2005). This is in direct contrast to the qualitative supposition that change is to be expected and, therefore, the concept of replication is problematic in this approach (De Vos, 2005; Mertens, 2005). In qualitative research dependability is ensured by the researcher attempting "to account for changing conditions in the phenomenon chosen for study as well as changes in the design created by increasingly refined understanding of the setting" (De Vos, 2005, p. 346). This was done wherever necessary in this research.

ETHICAL CONSIDERATIONS

While there are numerous approaches to ethics, four philosophical principles are widely accepted (Wassenaar, 2006). The first of these requires respect for the autonomy and dignity of individuals and is usually fulfilled by the requirement for voluntary informed consent by participants (Wassenaar, 2006). The principle of nonmaleficence enhances the first principle and aims to ensure that research participants are not harmed or wronged as a direct or indirect effect of the research (Brinkmann & Kvale, 2008; Wassenaar, 2006). The principle of beneficence ecourages the researcher to maximise the benefits for the participants by providing, for example, better knowledge of the topic in question and better skills (Brinkmann & Kvale, 2008; Wassenaar, 2006). Finally, the complex philosophical principle of justice requires that participants are treated with fairness and equity throughout the research process. It also places the onus on the researcher to afford care and support for participants who may become distressed as a result of the study. This research was conducted with these philosophical principles in mind.

Ethical Issues in Working with Minors

Wassenaar (2006) points out that research with minors is "ethically and legally complex and should, as a rule, be done only with the consent of legal guardians and the assent of the minor if risks are acceptable" (pp. 72-73). Considering that this research centred on very young children who were orphaned and possibly not living with adult supervision, it was anticipated that obtaining consent

from legal guardians would prove problematic and obtaining assent from the child would not be ethical considering their age. Further, it has been shown that vertical transmissions from parent-to-child and sexual abuse or premature sexual activity are the two main routes through which children have been exposed to HIV infection (Brookes et al., 2004). As many orphans living in CHHs may be HIV-positive and/or have been sexually abused, the ethical and legal ramifications suggest that the children themselves should not be directly approached as participants. *The National Household HIV Prevalence and Risk Survey of South African Children* (Brookes et al., 2004) lists the challenges of working with children as including "age of consent and the capacity to give consent, confidentiality, legal obligations to report abuse against children, and secondary trauma associated with the research" (p. 12). This survey highlights the problems of "mandatory reporting and consequently breaking confidentiality assurances, the impact on a child and his/her family if cases were to be reported" (Brookes et al., 2004, p. 13) and any secondary trauma that the child may experience. It is mandatory in terms of the Child Care Act No. 74, 1983, to report child abuse if it is made known to you (Brookes et al., 2004), potentially resulting in tensions between child protection matters and confidentiality (Cluver & Gardner, 2007a). Thus, as a result of the various legal and ethical considerations and possible complications that may result from interviewing children directly, it was decided to interview specialists from NGOs who work with these children on a daily basis.

Informed Consent, Confidentiality and Availability of Information to Participants

Written informed consent (see Appendix B) was obtained from participants prior to commencing the interviews. Participants were informed about the study and were assured that participation was voluntary and that they could withdraw at any stage. Confidentiality for both the participant and any of the children that they discussed during the interview was guaranteed. The findings of the research were also offered to the participants on request.

Support for Participants

Research has shown that caregivers are also vulnerable to suffering from a post-traumatic stress syndrome (Ross & Deverell, 2004). Further, qualitative interviews carry potential for causing subjective distress in participants and this was a possibility in this research (Neuman, 2006; Wassenaar, 2006). Hence, participants were made aware that should they feel traumatised, or if emotional distress was evident to the researcher, as a result of participating in the research, the researcher would refer the participant to the counselling support structure within the organisation in

which they work. Should counselling support not be available from the organisation or if a participant does not want to disclose to their organisation, the researcher offered debriefing sessions where participants were afforded the opportunity to work through their experience.

Availability of Research to the Host Community

Wassenaar (2006) points out that there are escalating international concerns about the participants and communities on completion of research. Researchers are obliged to make their findings available to the host community so as to empower that community with the information accumulated (Wassenaar, 2006). Copies of the completed research project were given to both the organisations involved in this research and, as mentioned above, the findings were made available to individual participants on request.

CONCLUSION

The aim of this study was to expand and complexify, not to reduce and simplify, and this focus determined the tools used in the implementation of the study. A detailed account of the research design was offered in this chapter. The steps of the qualitative analysis conducted were discussed as well as the sampling technique and methods used for data collection. Factors pertaining to the reliability and validity of findings were discussed, as were ethical concerns. It is hoped that sufficient detail has been given to illuminate how themes emerged from my conversations with participants. The following chapter introduces these themes.

'What is the use of a book,' thought Alice, 'without any pictures
or conversations?'
-   Lewis Carroll, (1865/1994) Alice's Adventures in
Wonderland (p.11)

INTRODUCTION

This chapter presents the themes, as listed previously, that emerged from the interviews conducted during the course of the research. Themes and sub-themes emerged from immersing myself in the content of the interview transcripts and attempting to grasp the underlying assumptions contained in the interactions. Feedback regarding the themes and sub-themes was obtained from the participants as well as my research supervisor. Hence, the final themes were not predetermined but emerged as the ecology of ideas evolved during the research process. While the material has been presented in terms of themes and sub-themes, there is significant overlap and cross-referencing between themes and therefore the chapter should be read as a whole. Themes and sub-themes are not mutually exclusive but are all interwoven. A web of experiences is presented here. All of these experiences connect with one another and cannot be understood separately. Consequently, no theme is more important than another. In line with an ecosystemic approach to research, the aim in developing themes was to broaden an understanding of the research topic and not to reduce the complexity of the subject matter. Where possible, the words and experiences of the participants have been used to narrate this chapter. The chapter begins with an introduction of the participants, which provides some indication as to the lenses through which they approached the interviews.

INTRODUCTION TO PARTICIPANTS

As mentioned, 4 participants were interviewed for this study. All of the participants worked for NGOs in various capacities. Three participants worked for Heartbeat and were based in Nellmapius, Pretoria, and served that community. One of these participants was a social worker and 2 were trained child care workers who fulfilled various mentoring roles for the CHHs in their care. The other participant was the project director for Ikageng based in Soweto, Johannesburg. This participant

voluntarily gave me permission to disclose her identity (see Appendix C) and is identified as Participant 2. This enhanced the research in that important differences were found between the Soweto and Nellmapius communities which, in order to protect anonymity, I would not have been able to report on otherwise. Consequently, the development of thick description was improved as I could focus on contextual differences. Both organisations were founded in 2000 in response to orphan challenges in South Africa (http://www.heartbeat.org.za; http://www.ikageng.org.za). The participants offered a wealth of knowledge and experience, providing insights from different perspectives, which allowed a more holistic picture to develop. All 4 participants were involved in permanent work within their organisations and thus were able to draw on their own direct experiences of CHHs and on the experiences of their colleagues, who they either supervised or received supervision from regularly. The participants were all black women and the interviews were conducted in English, a second language to all participants. Consequently, dialogue was often not fluent but for ease of reading and to retain the integrity of the conversations, no editorial amendments have been made and the participants' words have been used. I would like to express my gratitude to the participants for accommodating me by speaking English in the interviews.

THEMES

THEME 1: Why Children Live in Child-headed Households

SUB-THEME 1: The Incidence of Child-headed Households

Participant 1 explained that "*normally there is someone to look after the child on the death of a parent.*" Family, particularly grandmothers, usually assume responsibility for the children: "*It's only a few that you find no-one and the children have to be alone*" (Participant 1). The participants did not agree as to what constituted a CHH. Ikageng considers a CHH to be a household headed by a child under 18 years of age. In the feedback group with the Nellmapius participants, it was clarified that Heartbeat considers a CHH to be a where the eldest child is 21 years of age or younger. However, some participants discussed households where the eldest child was over 21 years of age and yet it was clear they considered these to be CHHs. In these homes, the eldest child often has work commitments that take them out the house, leaving the younger teenage children to fulfil many household responsibilities. Participant 4 described a situation where the eldest child, who was in his mid-twenties, worked shifts in a restaurant and hence was not home most afternoons and evenings, thereby leaving his 15-year-old sister to run the household. She spoke of this family as if the household was child-headed. The incidence of CHH seems to be higher in Soweto. Participant 2,

from Soweto, criticised government research for claiming that Gauteng did not have many CHHs *"and yet we do."* Thus, the incidence and experience of CHHs may vary across communities. Further, although there are isolated cases, it is rare to find children in the 2- to 5-year-old age group living in a CHH: *"It's quite rare because then the relatives have to assist in that situation"* (Participant 1).

SUB-THEME 2: Reasons Why Children Live Alone

The reasons why children live alone vary. Often, on the death of a parent, children are originally placed with relatives but *"because of the fact that people are dying because of HIV and AIDS"* (Participant 2) there is eventually no-one left and they land up alone. Participant 2 explains as follows:

> *Before they...become into child-headed households...they have gone through such a series of deaths. Not only have they lost their parents to HIV and AIDS...They lose their mother and we take them to their uncle, the uncle passes on and they get removed again. They've been taken to their aunt somewhere, the aunt passes away as well and then finally when all of their family fibre has been taken away... they end up being on their own.*

Thus, *"most of the time, it's from the fact that they have lost everybody else"* (Participant 2). During the feedback group the participants from Nellmapius agreed with this description.

Although rare, some children are rejected by their relatives because of the stigma surrounding HIV/AIDS: *"We know of kids whose uncles and what's their names will never ever come near them because...they know the parents died due to HIV and AIDS related issues"* (Participant 2). Yet some children may reject the care of relatives because *"my mother told us not to have the relatives because they going to give us problems, kick us out the house...When we get our grant, he going to take our grant away"* (Participant 4). Accordingly, some children may prefer to live alone and manage their own grant money and their parents' assets. There were also cases where children would rather stay alone than be separated from their siblings (see Theme 1, Sub-theme 3).

In Soweto, some CHHs are a consequence of parents migrating to Johannesburg and then dying, leaving their children with no support structures:

> *Some kids in child-headed households would be kids whose parents are initially from Kwa Zulu Natal...Like we have most kids from Lesotho who are actually in our child-headed households and some of them come from Zimbabwe...and how do you get a*

family from all the way in Zimbabwe to come…Some of your child-headed households are actually saved from the fact that we managed to get some relative from Lesotho, or somebody else to come over and help us out with raising the kids. But there are other dire, very, very dire instances where there isn't anyone else who is actually coming over (Participant 2).

In the feedback group, the participants from Nellmapius stated they had not experienced this as most of the people in that community were local or from Mamelodi, a nearby township.

SUB-THEME 3: Other Possible Living Arrangements for Orphans

Children are most often placed with the maternal grandmother or, failing this, another relative. All the participants were opposed to CHHs, especially for very young children. All of them were in favour of trying to place very young children elsewhere but this often involved many dilemmas, most importantly involving the separation of siblings, which the children often resisted. This dilemma was evident in the participants' own contradictory comments: *"It works* [a CHH]*, but I would really prefer if children stay with their relatives…Even if it means splitting the siblings. As long as they will be under the supervision of an adult. For me, I think it's what we should be doing…instead of having children…in child-headed homes"* (Participant 1); *"The children want to be together…Almost in all cases they want to grow together. They want to stay together in the same place"* (Participant 1); *"This thing of the children younger than 5 years, it's painful for me 'cos the small child doesn't know nothing. It's better when you take them and leave the big ones in the household and take them to the place where they will get care"* (Participant 3); *"It's better when…they stay there, the bigger one's, the younger one's they take them to the home. When they growing they can come back"* (Participant 3); *"The brother and sister will go and visit them"* (Participant 3); *"Better to keep the children together"* (Participant 3); *"Adoption…When he got 13 years I can take him back to his sisters. Just to help them to raise him…so she can go to school"* (Participant 4); *"I think the whole child-headed household should just be erased because…it's not normal…for kids to be raising themselves"* (Participant 2); *"I don't think we should be allowing our kids to…be doing headed households"* (Participant 2). Participant 2 provided an example of a case where *"the 12-year-old is running the household and she has other siblings 3 and 2. We were scared that if we took them to social welfare that they would be split. The older girl would have to go to the social development and the other two would have to go to Johannesburg Child Welfare. And this little girl said: 'No ways. We're not going there.'"*

Other alternatives for child-placement that were discussed during the interviews included:

Granny-headed households. Grandmothers are the most common caregivers following the death of a parent and this seems to be the preferred choice: *"And they take very good care. You can see the granny is most important. When the mother passed away the granny is around"* (Participant 4); *"Mostly they are living with their grannies. So we have more granny-headed families than your child-headed families"* (Participant 1).

Relative-headed households and foster care. These two options have been placed together as they overlap. Relatives or non-relatives may foster children. The benefit of living in a foster home is that the child falls under the care of an adult, which the participants felt to be very important. Participant 3 stated that the benefit of living with a relative was that *"the relatives already...has a history of the family"* and thus the children grow up inheriting a legacy. Often one family cannot foster all the siblings and hence the arguments regarding splitting siblings, as discussed above, are also pertinent here. The participants identified two main problems with foster care. First, potential foster parents are often motivated to access grant money, or a Reconstruction and Development Plan (RDP) house, as opposed to providing adequate care for the child. Second, foster parents seem to favour their biological children over an orphaned child. These issues are addressed further in Theme 6 and Theme 11, Sub-theme 1.

Orphanages. Most participants were opposed to orphanages as a child care option. They have experienced logistical problems in placing children in homes: *"Most of the times orphanages are full"* (Participant 1); *"Another disadvantage of taking a child to a orphanage is that...they lose their cultural background, their values of who they really are and how they should go about doing things and in their society"* (Participant 1); *"You take them to a home...they will never know their history. Now they will change their lifestyle, and they will change their culture"* (Participant 3). Some thought it would be better to place the child in an orphanage under adult care, but then again the debate of splitting the siblings came into play: *"Even taking them to an orphanage, sometimes you have to split them"* (Participant 1).

Adoption. Although adoption is a potential living arrangement for some children, only one participant mentioned it. Participant 2 stated that it was easier to place children in the 2- to 5-year-old age group than older children: *"What we find as an organisation is that people would rather take kids who are at that age. We have a challenge with 18-year-olds, 17-, 15-year-olds."*

THEME 2: Issues Surrounding the Death of a Parent

SUB-THEME 1: The Child's Experience of Losing a Parent

Many children witness their terminally ill parent suffer and slowly die, an experience which the participants describe as deeply traumatic: *"I have the parents die in the hospital, sometime dying in the house. And the older one's they supposed to…watch them. The mother's sick. She must look after the mother before she go to school, make some food…When her mother passed away she got traumatised"* (Participant 4). The participants also shared the following examples:

> *Maybe the mother…was ill in front of the child…So the child all the time she hearing the mother, she's crying about the pain: 'I've got a pain!' Maybe they take nappies, take mother to the toilet and she's screaming in front of the child…When you find that kind of child, she's not happy at all. When you talk to her, that pain, she has too much stress* (Participant 3)

> *They've…nursed their parents to death. One girl child said to me 'I'm trying to feed my mum, and she won't open her mouth.' And she didn't know that her mother had already passed away* (Participant 2)

> *I've got the boy who was telling me the story of his mother. His mother was positive…It was the mother and the boy and the small girl. The boy was 12 years by that time. He used to wash his mother. The mother she was…just sleeping. When she want to go to the toilet, the boy must take the mother to the toilet. The boy must wash his mother. So that boy he told that story: 'You know I used to wash my mother, I used to feed my mother…And after that my mother passed away. They call my aunt, my mother's sister, to come and take care of the children.' The mother she passed away. The aunt now she's positive again. The small boy again must wash the aunt and give aunt the food. You see that boy he was crying when he told me those stories. He tells me he don't know what's going on in his life: 'I wash my mother, she passed away. Our aunt come to stay with us. My aunt she's positive again. Now I must take care of my aunt. Now my aunt she's passed away* (Participant 3).

When asked how this boy was coping now, Participant 3 replied: *"He stay at home and don't want to hear anything because his life now is mixed up and he is damaged here, his brain…He's not coping…he start to give up on life…He starts asking himself questions 'Why are these things*

happening in my life?' He's not happy at home" (Participant 3). Young children's responses to witnessing their parents in the terminal stages of their illness and after their death included excessive crying, acting out, regression in the form of bedwetting, nightmares and sadness: *"They cry, they cry"* (Participant 2); *"She's crying and she becomes confused...because the mother she's crying and the child now she's crying"* (Participant 3); *"The sister tells me they get nightmares. Wake up at night and crying...'He just cry at night and then he calling: 'Mum!' But now that time goes on, he sleep"* (Participant 4); *"Its bedwetting. It's about talking nice...just wearing this mask and yet they're hurting on the inside"* (Participant 2). Others become quiet: *"Yeah they change. Always quiet and they feel...very lonely. They are not talking. When you ask them he just look at you like this. He don't want to answer anything"* (Participant 4). Participant 2 stated that some children had witnessed the pain and suffering of many adults prior to their passing away and therefore *"some will just like ehhh...Especially when they've seen that before: 'You know what? I've seen this before and I couldn't matter any more.'"*

SUB-THEME 2: Traditions Around Discussing Death with Young Children and the Attendance of Funerals

Generally, participants believed that very young children were too young to understand death: *"They don't really understand that 'my mother's gone'"* (Participant 4); *"She don't understand because she will keep on asking, no matter you tell her, but she will keep on asking: 'Where's my mum? I want my mum'"* (Participant 3); *"Those ones who are less than 5 years, they don't really understand what you are talking about: 'Okay now my mother is an angel,' and all that. They don't really grasp, like understand, exactly what is going on"* (Participant 1); *"Under 5, they don't understand...See somebody is sad, that means something is not right"* (Participant 4).

Participants varied in their responses about how the death of a parent is communicated to children. Only one participant stated that the child was told directly about the death: *"Their relatives tell them...that this is what has happened and 'your parents have passed away, they're now angels.' Kind of talking to the children so that the children are aware that they are never going to see their parents again"* (Participant 1). The other three participants said the children were not told about their parent's death. One said that they lied to the children: *"Your mother has gone to God. Don't worry. But she'll be back soon"* (Participant 4). Two of the participants explained that it was their cultural tradition to whisper the news in the child's ear while they were asleep: *"In our culture, they used to tell them when they are sleeping at night but I don't think that's working"* (Participant 3); *"Normally*

people whisper. We whisper at night when somebody is asleep. You don't tell them. But the thing is how are they going to know if we whisper to them? If you don't tell them?" (Participant 2).

Participant 2 argued that *"our cultures have to change because…we are living in changing times…So should our communication to our kids…We should actually start telling our kids"* (Participant 2). Participants commented that children became angry when they were old enough to realise that they had been lied to or were not told about their parent's death:

> *When she grows up they're going to know you're lying: 'She's not coming back. I saw on the TV they put somebody in a coffin. Like that day I see you crying.' And it reminds him. He's going to ask you: 'It is like that day that you were crying. Who was in the coffin? 'Ja, get angry* (Participant 4);

"She saw the house being prepared, and she was surprised what was going on…But nobody said anything… Only when her mother's coffin came through that she said: 'This is serious, my mother has passed away.' And nobody said anything…And she wrote everything when she was 7: 'Nobody told me!'" Participant 2 shared an example from her support group for 13-year-old girls called *Tissue Issues*. The girls complained: *"You don't tell us the truth. You don't say my father died. We see the signs…I'm only realising now when I'm 11 when I'm going to the HIV/AIDS awareness at…school, this is what my father died from, this is what my mother died from. And I wasn't told!"* Participant 2 commented: *"When you've seen them go through series of counselling, and series of play therapy, they begin to rise and become girls again, which means that we have suppressed their feelings. We haven't told them the truth and they realise this…I think we should just become open about issues now."*

Participant 4 felt awkward when another child broke the news to a young orphan that their parent was deceased: *"'You know your mother's dead.' He comes home and he ask you: 'Is my mother dead?' and now I must tell him: 'Yes.'"* Participant 2 expressed concerns that *"because of our African culture"* boys are expected not to cry. She tells a story of an 8-year-old boy whose father died when he was 4 years old: *"'My uncle came to me and said 'Don't cry. If you cry you going to die like your Dad… 'But when he was 8 it actually manifested itself. 'You know, I never mourned my father's death. I was told we don't cry.' As a boy child you don't cry."* Participants agreed that very young children would attend the funeral even though they might not understand what they are seeing. Overall, participants believed that young children should be informed honestly about death and that support should be provided at this young age to avoid the development of anger and other emotional problems later.

THEME 3: Experience of a Young Child Living in a Child-headed Household

In interviewing the participants it was clear that they focused on the older children in the household, especially the eldest child. Conversations naturally steered toward issues and examples surrounding older children and I had to determinedly bring them back to the younger age group. Due to the young child's limited communication skills and the belief that they were too young to understand illness and death, on initial questioning most of the participants perceived young children to be coping. Comments included: *"It gets quite difficult for kids at that age to actually determine what's going on"* (Participant 2); *"The small child doesn't understand you see. You just see them lying there"* (Participant 3); *"I just feel like it's a very, very tender age that we tend to ignore"* (Participant 2); *"The small child doesn't know nothing"* (Participant 3); *"You don't even get much problems because of they don't talk"* (Participant 4). However, in questioning the participants in-depth during the interviews, specific issues relating to young children were identified which are described in the sub-themes below. While the perception was that generally these young children were coping, it became evident in the interviews that problems manifested later in the child's development, which could have had their origins during the early developmental period. These issues will be covered in Theme 4, Sub-theme 2.

SUB-THEME 1: Lack of Nurturing From an Adult

The participants acknowledged that young children in CHHs lack the nurturing attention and affection offered by an adult. While there was no doubt that their siblings love them, according to the participants, the young child misses the reassurance, cuddling and caring that only an adult, more specifically a mother, can provide: *"These children are not getting enough attention, enough love…because there's no mother, there's no father… so mostly they're lacking that being taken care of, being cuddled, being loved. They lack that"* (Participant 1); *"I cannot say they are able to establish… trust or that feeling of being loved…being special, you know your parents live here, you love your parents and your parents love you…You have everything when you have your parents. You have someone who takes care of you"* (Participant 1); *"A child of that age actually needs a mum or somebody who will be there cuddling them, caring for them, supporting them"* (Participant 2); *"The younger one she needs love. Parents love. There's no mother there"* (Participant 3); *"I think there's something missing. I miss somebody, like my mother maybe"* (Participant 4); *"They miss their mother: 'I hope my mother was alive.' I think they're always going to get something like that"* (Participant 4).

SUB-THEME 2: Withdrawal and/or Acting Out

Participants commented that withdrawal and/or acting out in the form of anger or aggression is one of the evident emotional consequences for some young children living in a CHH: *"In a lot of them it comes out as aggression, anger and some of them its withdrawal. Those children they don't want to participate in anything. They just want to be by themselves"* (Participant 1); *"They quiet…sometimes they become quiet and sleep…they don't want to talk"* (Participant 4); *"The thing that I realised to them, they are becoming angry because of the loss of their mother"* (Participant 3); *"They actually act their aggression out"* (Participant 2); *"That's when this anger manifests itself…they isolate themselves to other parts of their communities"* (Participant 2); *"The action will tell you that this child…because she don't talk but you can see the action. She realise that the mother that she's no more here"* (Participant 3); *"They don't talk most of the time, but you can see the anger when you talk to her…maybe you want to say: 'Don't do this… She will start, you see. She think that you don't love her and you try to show her the way. And then she will be angry for you"* (Participant 3); *"She's quiet…And aggressive"* (Participant 3); *"Violence. Ja, mainly its violence. You find that they like beating other children, bullying other children"* (Participant 1); *"Their behaviour is not good because they like to fight all the time. She got short temper"* (Participant 3); *"Angry and acting it out. I mean we have a, I think she's about 4½, she bangs everything when she's here. She bangs it. She pulls her hair, she bangs her head…and screams and cries"* (Participant 2). Participant 2 reported incidents of young children acting out sexually as a result of sexual abuse. She provided the following example of a boy who was molested when he was 4 years old: *"When he went to the crèche he wanted to do the same thing to other boys as well. We realised afterwards that he…was a case of molestation. So they act out their abuse as well, what happens at home and they want to do it to other siblings."*

SUB-THEME 3: Aloneness and a Sense of Being Different

A sense of isolation, loneliness, loss and a deep sense of being different emerged from my conversations with the participants: *"They are lonely and they think…there's nobody who loves them"* (Participant 3); *"Nobody take me out, I just stay at home"* (Participant 4); *"They ask themselves questions: 'Our mother is not here?' So they think that the people don't love them"* (Participant 3); *"They have too much stress now because when she's crying she knows that my mum she's here: 'I'll go to my mum, she'll comfort me. Now I'm alone. When I'm crying I must stay alone'…Those kinds of things, they stress the children"* (Participant 3). A caregiver from Nellmapius gave an example of how children may not be invited to friends' birthday parties because they had no transport to get there: *"The children they become stressed now because they say: 'Ooh, if my mother was alive… my*

mother would take us to the party…Now we are alone. We must stay in the house.' They become bored" (Participant 3). She continued: *"They are very isolated you see."* While stigma may be responsible for some of the isolation and loneliness that orphaned children feel, one gets the impression that there is also a deep sense of loss and aloneness apart from the issues attached to stigma. Stigma is discussed in Theme 5.

SUB-THEME 4: Neglect

Linked to this sense of isolation, was the impression of neglect. This was evident emotionally and in the child's physical appearance. However, all the participants emphasised the strong bond and love between siblings and how the older children really love their younger siblings: *"They love their siblings, really love their siblings. They love the young ones"* (Participant 3); *"That bonding, that's what keeps them together"* (Participant 2); *"I think that love is what makes them…rise above whatever that's happening"* (Participant 2); *"They love one another…they're close, close, close"* (Participant 4). Yet Participant 1 pointed out: *"Even though there is love, there are a lot of things that are lacking."*

Generally, it was believed that older children are overburdened with their schoolwork and the management of the household and thus were left with little time to provide adequate stimulation and attention to their young siblings: *"They usually fetch the children from the crèches and…when they reach home at that time in the afternoon they have their homework, they have to cook, they have to prepare the supper for the young children. So there isn't much interaction between the children"* (Participant 1); *"Because of the burden of care, sometimes they feel like 'It shouldn't be my problem.' Sometimes they come in here and tell us: 'I have so much else to do that I'm not able to deal with it'"* (Participant 2); *"The bigger one, she's suffering from the young one's because now she becomes a mother…And yet she's young…They stress the bigger one because it's an overload. She can't cope. It's the school, here she must be a mother…she must go attend the school meetings. It's a big stress now"* (Participant 3);

> There isn't any stimulation at all…because you can imagine…the girl child or the boy child in the child-headed home comes home from school and has to do household chores, make sure that there's meals. Then afterwards make sure that everybody is ready to go to school the next day and then by that time, he's tired. And they have to go to sleep (Participant 2).

When asked if she thought the young children were stimulated enough, Participant 3 responded: *"Ay! I don't think so."*

Participants stressed that the heads of households are still children and thus many of their own needs as children are not being fulfilled. Hence, they are not emotionally equipped to provide the kind of support that a young child requires. Although they do try, *"sometimes they just don't know what to do"* (Participant 1). Other comments included: *"As much as your girl child or your boy child who... is in a child-headed home will...try their utmost best to...be looking after themselves, but the fact is they're still just kids"* (Participant 2); *"They have to be responsible. It's more like you stop being a child and you become a parent"* (Participant 1); *"They do support each other. It's difficult because...you are a child at the end of the day and you miss being told what to do and being taught things...by someone who is an adult"* (Participant 1); *"Because I mean if I am 15 I will want to go and play and you're busy crying there, wanting this and that. I won't be able to take care of you"* (Participant 1); *"They have needs as 16-year-olds that somebody should...be taking care of them. And now you find the child who...has to head the household is burdened with care in the sense that they have to be so focused that she can actually begin to determine where the 5-year-olds are"* (Participant 2); *"Sometimes especially when she tells me: 'She* [the child] *didn't sleep...I must go to school. What can I do?'"* (Participant 4); *"It's not enough because they're young all of them. They're young. They need somebody to take care of them"* (Participant 3); *"A child can never take care of another child. The child herself she don't take care of herself, how can she take care of another child? Child is child. It's not an adult...She will never grow okay that child"* (Participant 3). Participant 3 continued:

> They love their siblings. It's just they're young, they don't have that power of the parents...They don't have the power of being a father or a mother. But they try. But the problem is they are children. All of them they are children. They need love from the parents. All of them. But they are trying to love themselves and their siblings.

Thus, while these young children may suffer from some form of emotional neglect, this is not intentional. Older siblings are doing what they can under extreme conditions.

Neglect was also evident in the physical appearance of orphaned children. All 4 participants commented on the clothing and dirtiness of some of their orphaned children, which often contributes to them standing apart from other children in their communities and adds to their sense of isolation. Examples included: *"The way they dress...because they have second hand clothing, and the child from that other home who has their designer clothes, and that again says a lot to this child who hardly has anything"* (Participant 2); *"The child is coming to the school and he didn't wash his body.*

She's dirty all the time" (Participant 3); *"You find that others they go to school with un-ironed clothes, dirty clothes"* (Participant 1);

> *The way they wear their clothes...they will not be the same like that one who's having a mother. Because this one, the orphan child, she'll be dirty. Because there's no-one who will wash their washings. And even their clothes you can see that sometimes she don't have the shoes. Ja, even the food...they're struggling. So you can see the difference that maybe this one, she's an orphan or she's a vulnerable child. Because they will never be the same with that one who's having a mother* (Participant 3).

Psychological problems that older siblings experience may render them emotionally unavailable to their younger siblings, which may also contribute to their neglect. Such issues are described in Theme 4, Sub-Theme 2.

SUB-THEME 5: Trust

Some of the participants highlighted how they had to work hard and be patient in order to establish trust with young children in the CHHs. They described their experiences as follows: *"To trust, they take a while. When you hold hand she just don't want you to. If you try she just look at you and go to the sister and hold her...but 2 to 3 months they come"* (Participant 4); *"They're afraid because they think there is no other person who can love them because they lost the person who were close to them... their mother"* (Participant 3); *"They take time to talk to you...when you talk to them they just say: 'Yes, no, yes'...They are not open for you. But when time goes on they become open. When they saw me in the street they say: 'Ha...sister M.' They are smiling now"* (Participant 3). Participant 1 reinforced this theme of lack of trust and stated the following regarding orphaned children:

> *They have problems...trusting people. They're afraid to...touch people because they have that mentality that these people will leave us eventually like our parents did or our granny did. They have that feeling... they don't want to touch or open up too much, to have people close to them, because they're not sure of how long this person's going to be around now.*

SUB-THEME 6: Signs of Psychosis

While no formal psychological evaluation had been performed on any children, 2 participants provided examples where it seems that the children were displaying signs of psychosis. Participant 3 described how a teacher called her concerning an orphaned child and reported that the child *"crawl like a snake down here and the other children get scared and they're screaming. I don't know what's*

going on with this child…When he starts that kind of things… I feel like crying in this class because I don't know what's going on with that boy." Similarly, Participant 2 reported children saying: "I'm seeing things…I'm seeing this, I'm seeing that." What disturbed Participant 2 was that people related this to traditional beliefs: "Maybe this child has to become a sangoma." Participant 2 argued: "It's not. It's psychological issues that are coming back because of the fact that we never dealt with them."

SUB-THEME 7: Sexual Abuse

The 3 participants from the Nellmapius community reported that they had not encountered a case of sexual abuse among children between the ages of 2 and 5. Participant 1 pointed out: "It's mostly…girls who are 9, 10, 11 and upwards and…then it is those…living with relatives that take advantage. In these homes they have back rooms where…people are renting and…they take advantage… They're left there the whole day. And obviously the guy will think of something to do with those children." While these three participants had no direct experience of sexual abuse of children in their care, they all feared it: "My fear is abuse" (Participant 3); "The criminals they rape them. They see the small child is secretive, he can take advantage of the small ones" (Participant 3). On the other hand, Participant 2 from Soweto had experienced sexual abuse among the children in her care. She argued that many cases of abuse were not identified "because with neglect she know that I have to cook, I have to do household chores and the needs of my 5-year-old or my 2-year-old are not just as necessary." Therefore, the older child is so overburdened that they "take sometime before they actually realise" (Participant 2) that a younger sibling is being abused, if they realise at all.

SUB-THEME 8: HIV-positive

Some young children, as well as their siblings, are HIV-positive themselves. Generally, very young children are not told about their HIV-status, as it is believed that, because of their age, "they don't understand" (Participant 2). Some children have enquired, though, as to "why do we go there and everybody's sick?" (Participant 2) but generally they are not told the reason: "Our psychologists start talking to them when they're 8 or 9 and tell them what's wrong" (Participant 2). Both organisations offer nutritional support, which seems to be the first line of defence against the virus: "Sometimes the signs…manifest themselves but we try good nutrition, but we do our utmost so that it doesn't show itself" (Participant 2); "We give her that porridge when she tell us the child is positive" (Participant 3). This is "energy porridge" (Participant 3). Children are also taken to clinics for regular check ups and have access to ARVs (see Theme 11, Sub-theme 2). Medication compliance is at times a problem as siblings "might even forget to give them their medication. It has become a problem" (Participant

1). Participant 2 reported that the incidence of mortality is high in the 2- to 5-year-old age group, as the mother *"may not have taken Neverapine at birth."* Neverapine is a drug that is effective in decreasing transmission from HIV-positive pregnant mothers to their babies.

SUB-THEME 9: Poor Concentration

Participant 2 pointed out that orphaned children *"don't have a high level of concentration."* Poor concentration could be linked to inadequate nutrition or emotional disturbance. Participant 2 stated: *"You must see what happens in Soweto. One of the teachers said to me: 'You teach in a class and half of the children fall asleep because they don't eat.'"* Participant 3 said that there was a change in children's ability to perform at school after the death of a parent and the stress of having to live in a CHH: *"The other's they change to be the slow learners. She was coping all the time, after that thing, she's become slow at school."* In the feedback group with the Nellmapius participants it was proposed that poor concentration could also be a result of *"secondary trauma due to multiple losses"* (Participant 1). They agreed that poor concentration affected children of all ages.

SUB-THEME 10: Hopelessness

A sense of hopelessness emerged from the interviews: *"Children loose...faith in life generally"* (Participant 1); *"It's a sense of helplessness and hopelessness"* (Participant 1); *"It's where they lose hope of life: 'Why am I still living? It's like I'm not existing'"* (Participant 3); *"They are not free...They don't have happiness"* (Participant 3); *"Now you can see he's hopeless, he don't have happiness"* (Participant 3). One teacher told Participant 2: *"She sleeps all the time. She's lost interest."* Participants believed that this sense of hopelessness was applicable to orphans across all age groups. Concerning older orphans, Participant 1 reported that many were *"not aspiring for better things"* and they *"don't have a vision, they don't have dreams."* She provided an example of a workshop she conducted where the children's vision for their future was explored: *"I was shocked 'cos I...saw a bunch of people who couldn't even say to me 'in 5 years time I see myself as a doctor, living in a mansion, driving an expensive car'...More like...'I'll be working, living...in my RDP house, staying there with my children, maybe if I'm married. If I'm not married, maybe I'll be like a single parent.'"*

THEME 4: The Experience of Living in a Child-headed Household

SUB-THEME 1: Relationships, Roles and Responsibilities

Theme 3, Sub-theme 4 showed how there is generally an abundance of love between siblings and that bonds between them are strong. It seems that children living in CHHs are doing their best under trying conditions. Participants commented that most of the household chores were divided amongst the siblings: *"In most families they do divide and play different roles, assist one another with the children"* (Participant 1); *"Some of them actually try to keep their homes clean…I've realised with all kids who…child-headed, if you teach them once, they'll…just pick up because they will know that there's no-one else who can…help them"* (Participant 2); *"Each and every one she know what they must do…They know their jobs"* (Participant 3). Little children are generally excused from household chores: *"The little ones they are not working, they're playing"* (Participant 3). However, Participant 2 expressed concern that because they do not fulfil any official role *"they actually have to go out to the street and we don't know who does what with them in the street."* This places young children at risk.

Opinions varied as to who would assume responsibility as the head of the household: *"I couldn't care whether the person who heads that household is a boy. Even if the boy is about 16 and the girl child is 11, guess what? The girl child will rise up and take over. It will be like gender inequalities actually"* (Participant 2). Participant 1 reiterated this sentiment: *"Its girls who are mostly looking after the children. You find the boys can't really cope with the situation and they end up using drugs, staying out all the time, not wanting to be in this house a lot."* However, Participant 3 stated that *"the older ones take charge"* irrespective of gender, and both boys and girls are under the same pressure: *"I don't think there's somebody who can cope better because the bigger one she's having the stress for this younger one."* My overall impression was that the children acted responsibly, working together, and that the head of the household adequately managed the finances. When referring to the management of finances Participant 3 said *"they managed alright."*

Although there was a sense of camaraderie between the siblings, two participants mentioned that levels of conflict were also high: *"They're fighting. This one she don't want to listen to the older one…Maybe the younger one she says: 'My sister all the time when she saw me she said go to the shop, after coming from the shop she say, sweep the floor, after…'"* (Participant 3); *"Eish! Fighting is a big problem. Because this one he say: 'You want to act like my father, you are not my father, you are a child.' The brother will say: 'I am bigger than you, you are young. You will listen to me.' Jooo!*

It's a big problem" (Participant 3); *"They fighting at the home"* (Participant 4). Thus, there are times when younger siblings resent the older sibling's attempts to fulfil a parental role.

SUB-THEME 2: Characteristics of Older Siblings

While participants agreed that signs of distress in very young children were not always obvious, the same was not true for older children and teenagers. Participants constantly discussed the older children in the interviews, offering valuable insights on how the quality of life of the very young child is impacted. Further, understanding the emotional climate of older children may pre-empt issues that young children could face as they grow older. Participants argued that while the problems with young children were not always overt between 2 and 5 years, they manifest later in the child's development, *"it manifests…when they about 9 years old"* (Participant 2), thereby bringing into question whether they are in fact coping as well as they portrayed when they are younger.

Participant 2 provided an example of 8-year-old P who, when she was 5 years old, *"in 4 months… had buried about seven members in her house."* Participant 2 stated: *"She wasn't given enough assistance at the time because…we felt like 'we are not going to tell her. We are just going to whisper to her at night-time.'"* P received sponsorship for private school tuition and one day, during class, the children were required to introduce themselves and their families. When it was P's turn *"she actually excused herself and went to the toilet."* She was provided the opportunity the next day where *"in her very, very broken English she said: 'My name is P. I stay in Soweto. Do you know that I lost everybody…I lost my uncle, I lost my mother, I lost my aunt, I lost, I lost, I lost. So I don't have anyone else."* P then *"sobbed and cried."* Participant 2 stated: *"That said to us that even at that age it actually gets recorded into their minds that there's loss, what is happening in the household."* Participant 2 implied that we could avoid having *"very traumatised teenagers who go into sexual issues rather than being able to deal with them when they are at that age."*

Many problems *"manifests itself when they go into the teenage years and begin to realise…there is so much that is missing in that child"* (Participant 2). Before reporting on the negative stories that emerged from the interviews, it is important to point out that success stories do exist. Some orphans who have been raised in CHHs are coping, have passed their Grade 12 exams and completed some form of tertiary education. Statements included: *"They're coping but it's not easy for them"* (Participant 3); *"We have had matriculants that have passed well"* (Participant 1); *"We as an organisation have kids who are at a tertiary level who are learning"* (Participant 2); *"There's one child-headed home that I'm so proud of. They divided roles, they're assisting one another and the*

older one's passed their matric very well. They went to nursing, they passed and this year those two are working so it's nice 'cos in other families they unite and work together" (Participant 1).

However, *"most of those children, they're not doing well. They're not coping at school. Mostly they're failing"* (Participant 1); *"She don't cope at school now she start changing"* (Participant 3). Participant 1 found that *"lots of our children pass well at school like our children in primary, they are very clever. It doesn't really impact. It's only when they're getting older. Ay, they're failing. Our, 15-, 16-year-olds, they don't pass well in school."* She attributed this to *"too much responsibility and it's more like you're realising 'I'm an orphan. This happened to me. This is my life and I have to cope with the situation.' Maybe it's kind of difficult for them to cope."* The problem of poor concentration, as discussed in Theme 3, Sub-theme 9, also impacts the children's ability to perform at school. Participants found that many children dropped out of school in their teenage years: *"A child will just leave school out of the blue. Just for no apparent reason"* (Participant 1); *"They going to drop out, getting pregnant. Bringing the boyfriend home just to get food"* (Participant 4).

Participant 1 believed that orphaned children *"become quite tough because of the situation"* and that *"its more like they have developed a way of living with this thing...more like a defence mechanism...You have to pretend... you have to learn some kind of role...a persona or something."* She found that *"there isn't emotion when that child responds"* and also found them to be dependent: *"The children in our programme they become very dependent and they think that Heartbeat will do almost everything for them."* Participant 3 stated: *"They are suffering emotionally. She can pretend, but really they are suffering."* Participant 2 felt that orphans lack confidence both in their demeanour and in their sense of security:

> *Confidence about the fact that they know their tomorrow, that 'I have a parent who is going to take me to school.' They know that 'I can rely on my parents for care and support and for some other things.' Now your child in your child-headed household won't be able to do that. But actually you see it by the way they portray themselves.*

Most participants described how boys become susceptible to drugs while girls often seek love from older men: *"It manifests itself in the form of drug abuse and teenage pregnancies"* (Participant 2). Participants said that boys use drugs as a means of escape: *"It's mainly drug abuse...They don't want to think anything because nobody really cares and no-one is there to listen to them"* (Participant 1); *"Most of the boys that we are looking after have...gone into drugs. There are boys who... have*

been raising kids alone…One boy said to me: 'I just want to get away from being mum and dad…I thought I was coping when I was using drugs and yet I didn't'" (Participant 2).

Girls seem to seek solace in the arms of men, especially older men, which often results in teenage pregnancies: *"Because the teenage… they like to go out, up and down with boys"* (Participant 3). Three participants mentioned the attraction young girls feel for 'sugar daddies'. That is, older men who provide girls with material possessions to win sexual favours. Participants' descriptions included: *"With girls it's more like they'll go out with older men…They want sugar daddies. They want airtime, cellphones and they want that special attention, someone to take you out, buying you clothes"* (Participant 1); *"Jooo! Money, money…It's for the love of money…'Sugar daddy he gave me R100. You must also get a sugar daddy'"* (Participant 4). Participant 1 explained that in the townships *"it's not taboo to go with a married man who's got a family. As long as that guy will take care of you…Even…children who have parents do it. They go out with guys with expensive car…because they want to be taken out, bought airtime and all those fancy things."* Participant 2 thought that the attraction to older men was about the

> *need to be loved…Kids in a child-headed household…begin to see sex as some form of being loved and wanted…Some of them…were being raised in single parent households where there wasn't this father figure. And now as soon the single mother passes away…this man who is older than the child will come in and pretend to be loving the child, buying the child things that the organisation cannot give that girl.*

This results in a high rate of teenage pregnancies and an increased chance of HIV infection: *"Most of them once they've had a child, they…don't want to go back to school"* (Participant 1); *"You see the rise in teenage pregnancies. Not because it is morally wrong. It's not about… morals. It's about the fact that being raised in a house that doesn't have a parent…poses itself to these challenges"* (Participant 2); *"If she like that man she don't care about HIV"* (Participant 4).

As discussed in Theme 3, Sub-theme 10, many older children feel hopeless. Participant 1 believed that some children suffer from depression: *"Normally they are depressed…because they don't know who to turn to."* Some older children express suicidal ideation and some of these children have committed suicide: *"Children loose their faith in life generally. 'If people keep on dying around us then why are we even alive?' Some of the children they…attempted to commit suicide…When you try find out the reasons its because maybe things are not going well at the house"* (Participant 1); *"If you are alone it will be difficult for you and you will think about the suicide…Others…tell us that 'I want to kill myself' because she doesn't talk to other people and hear other people's stories"*

(Participant 3). Participant 2 had experienced suicide in her organisation. She cited an example where a boy wrote in his suicide note: *"You know what? Nobody told me that I was doing amazing work by raising my siblings. Nobody told me that. And people just left me to do all these things alone and I'm tired of doing it."*

The content presented in this sub-theme could further contribute to the neglect experienced by young children living in CHHs, as discussed in Theme 3, Sub-theme 4. Poor psychosocial well-being in older siblings could negatively impact the development of their younger siblings.

SUB-THEME 3: Threats Children Living in Child-headed Households Face

Issues pertaining to this sub-theme are scattered throughout the other themes in this chapter. For example, neglect, absence of an adult caretaker and logistical problems in obtaining certification and grants, all serve as threats to the child in a CHH. Thus, the content of this sub-theme is not inclusive of all the threats children living in CHHs face.

Sexual abuse and threats to physical safety were seen as some of the biggest threats that children living in CHHs face. Participant 3 pointed out that *"rape is everywhere. They can rape you if you staying with your parents. They can rape you if you staying alone."* However, participants felt that children in CHHs were more vulnerable because *"some people actually abuse them for the fact that they actually have no other source of support except for themselves as children"* (Participant 2). Participant 3 admitted: *"My fear is abuse. The message you get is that they are not secure."* This same participant explained how she, as a single mother, was often afraid at night and asked: *"What about a child?...It's obvious that they scared...You see it's not safe for them."* These concerns were echoed by other participants: *"They're scared. They don't even want to go out at night"* (Participant 4); *"Your sense of security... Robbers and rapists go into homes...The vulnerability of...kids who are...in a child-headed household. What securities do we guarantee them that nothing will happen to them at night when something happens to somebody who has high walls? And most of them stay in shacks"* (Participant 2). Participant 4 organised *"at the policing forum I just tell them 'please, you have to patrol that child'... Now the police they go patrol at night."*

Young children and their older siblings are also threatened by HIV infection. This was mentioned in Theme 3, Sub-theme 8. Participant 3 described an incident where the head of household developed what was possibly an HIV-related dementia where she *"become crazy that girl. Then she become mad. Then they phone the granny to come take them 'cos now she want to burn the house."* Thus,

psychiatric symptoms related to HIV/AIDS may serve as a threat to all inhabitants of the household. Participant 2 provided an example where the eldest child succumbed to the pressure placed on him and resorted to physically assaulting his 7-year-old brother with an electrical cable because he constantly stayed out late in the streets: *"'You know what? I've just had enough. I've told you to come back home at 8 o'clock.' But by 8 o'clock he wouldn't be home. And 'this is what my mother would do if she was alive.' And he just beat the little boy."* Consequently, threats to children living in CHHs can be both internal and external.

Participant 2 mentioned other potential threats:

> *We have lost track somehow and some kids fall into the cracks…They turn to crime…Kids that are not recorded that we're losing to prostitution, that we're losing to drugs, that we're losing to crime because…we are not caring enough…If we don't look after them now, they're going to be our next robbers and there's a whole generation of them.*

SUB-THEME 4: Types of Dwellings

In the Nellmapius community most children in CHHs occupy RDP houses inherited from their parents. All the CHHs looked after by the two caregivers are accommodated in RDP houses. Participant 1 reported: *"They're living in the houses that their parents have left them. Others, they're in shacks."* On the other hand, Participant 2 from Ikageng, Soweto, said that they had been unsuccessful in accessing RDP houses for their orphans and thus most of them are living in shacks:

> *RDP houses is out because we have tried to go to the department of housing in a sense that kids have applied when parents are still alive, and it has been, I don't know because of the systems, I don't know what happens in there. Most of our kids they're in shacks. And some of them stay in like the back rooms, because of the fact that we want to make them feel like there will be somebody else whose helping out, looking after them. We put them in somebody else's back room. And some of them they actually using…those electricity homes that we used to have. But I think 80% of our kids who are in child-headed stay in shacks, back rooms. Few in their parent's homes.*

THEME 5: Stigma

Participants reported that there is still a significant amount of stigma associated with HIV/AIDS: *"There are other instances where there are adjustments from the community. I thought that by*

staying in an urban area that by now it would come down but it is not" (Participant 2). Participant 4 claimed: *"There's nothing like* [stigma]. *There's lovely people around here. They always know about HIV."* However, when questioned further she went on to say that one's status *"is still quite a secret in our community"* and that *"they don't trust you that much to tell you that."* Other statements about stigma included: *"There's a lot of denial and stigma associated with HIV and AIDS"* (Participant 1); *"Ay, it's kind of under wraps in most families if a parent has passed away. Maybe they don't even tell us why a parent has passed away, what are the reasons"* (Participant 1); *"Ja, they will stigmatise you. When you are coming sit, they will…run away from you. And when you are coughing, they will run away from you. They stigmatise too much here in the community"* (Participant 3); *"When the children they got sores all over the body you can see the teacher will isolate that child. It's hard for that children. Especially in the community, really they are suffering"* (Participant 3). An example was provided in Theme 1, Sub-theme 2, illustrating how some relatives are unlikely to foster children if they know that parental death was related to HIV/AIDS.

NGOs have established relationships with certain crèches where they prefer to send the children in their programmes. This is discussed further in Theme 8. Ikageng had approached the University of Johannesburg (UJ) t*o "train some of the teachers in the crèches…just to make them understand"* (Participant 2) the issues surrounding children orphaned by HIV/AIDS. The Nellmapius participants felt that teachers are generally well informed about such issues. Participant 2 admitted she was cautious about crèches she sent her children to and gave an example of discrimination that she had experienced:

> *One of the children came to me in the crèche and asked: 'Why are X's dishes washed differently from ours?' I said: 'What?' 'Ja. They wash them outside of our own dishes.' And that actually said to me 'No man, I shouldn't have told her.' And the other thing is you just don't even want to show up and say I'm this organisation that represent…Its few really…But in other instances when you go to crèches and you say this and all of a sudden your kids are being mistreated.*

She also expressed concern that instances of discrimination were under-reported as children were afraid that *"when we go back and tell them* [the teacher]*…we don't know how they're going to be mistreated."*

In order to protect the identity of their children, Ikageng transports them to clinics outside of their immediate neighbourhood. Their cars are branded with HIV/AIDS related logos as are some of the houses *"because everything of ours is written HIV"* (Participant 2) and thus the community are aware

that these children are affected by the disease. The organisation is attempting to raise awareness about the virus and decrease stigma and yet at the same time *"some kids were asking to take that out because when we leave...communities start gossiping about them"* (Participant 2). Participant 2 stated that children are sensitive to being identified as 'AIDS orphans' in their communities and claims they resist wearing clothing and designer shoes that have been donated as it identifies them as someone affected by HIV/AIDS: *"We have places like X* [a leading clothing retailer] *who gives us clothes but they are all the same. We have Y* [a sought after brand of trainers] *that gives us shoes that are the same...and the kids are scared to wear them."*

SUB-THEME 1: Denial

Participants reported that denial still existed around HIV/AIDS. Participant 1 explained that some people believe that *"hey its witchcraft or it's that, its cancer. They never want to say: 'No, I think you are positive. Go and test.'"* Participant 2 corroborated this sentiment: *"People feel like its not happening, and yet it is"* (Participant 2). Participant 1 was concerned that, because people were in denial, they were only tested *"when you see they are ill and that they don't know what's wrong with you. Then you start suspecting and testing at that time when it's more or less late and nothing like can be done at that point."* She added: *"People are dying because of HIV and AIDS because people don't test. They don't want to know their status. They are scared. They have this fear that if I'm told I'm positive that I'll die...So they go to late...Hence, nothing can be done when you are terminally ill"* (Participant 1). In the feedback group it was stated that people would rather die not knowing their status.

THEME 6: Relationships with Relatives

Most orphaned children, and children in the community generally, are being, or have been, raised by their single mothers: *"These daughters leave their children behind"* (Participant 1); *"When the single mothers pass away..."* (Participant 2). Many do not know their fathers and are thus considered orphaned on the death of their only parent: *"It's your single mothers. There aren't many families whereby it's a husband and a wife and a husband leaves children behind to be raised by grannies. You find that most of these children are being left by their single mothers"* (Participant 1).

On the death of a parent, most orphans are fostered by their extended families, with maternal grandmothers accommodating most of the orphaned grandchildren. Participants argued in favour of

the grandmother adopting the children, as was seen in Theme 1, Sub-theme 3. Participant 3 highlighted the benefits of children being fostered by a relative:

It's better because the relatives its part of that children's family. When they in these foster homes you will see just a person, but when you staying in your mother's house, the relatives take care of you. The relatives already…has a history of the family. Obviously you'll know your history because you are still in the house.

However, the general impression was that, with the exception of grandmothers, relatives were reluctant to get involved: "*The aunties don't want to take the children because the mother didn't have money: 'I've got my own children who are going to suffer. Who's going to take care of them?' But the lucky one's they take them*" (Participant 4). No doubt there are many admirable stories of successful foster placements, both relative and non-relative, but these are perhaps underrepresented in these interviews because of the NGOs' focus on vulnerable families. Participant 3 commented: "*Sometimes they* [relatives] *take them to visit them. Sometimes their relatives they come and see them.*" Further, some orphans in Soweto have family elsewhere in the country "*so what we do in our child-headed households is that we would make them stay alone…during the times when they are still at school, but December time or…the June holidays, send them back to their families to go and visit and come back again for the school purposes*" (Participant 2). Thus, relative involvement "*happens sometimes but…very rarely*" (Participant 2). On the whole though, the sentiments of the participants were encapsulated in Participant 4's statement: "*No, they don't like coming here…We have to take care of them.*"

One of the greatest problems with foster care, both relative and non-relative, is the motivation to access grant money or an RDP house, as opposed to providing adequate care for the child: "*There's so much neglect…There are some…people who, when they know that all the paperwork has been done and when they found out that there's money for the kids…they will take them all and say: 'No, we'll foster.' But as soon as the kids come to their home, the story…changes*" (Participant 2); "*Other's they want money for the grants. They don't want the children. They want their money. They eat their money*" (Participant 3); "*When a parent dies the uncle's…want to sell the house. They see the business now. They want to take the child out to the street and then they want to sell the house on…And the family they fighting for the house. Those kind of things, they disturb the children*" (Participant 3); "*Sometime the younger brother told me that 'my aunt came here, she wants to live with us now. I don't want family they going to make us not to stay…They want to take the house from us'*" (Participant 4); "*They're willing to take care of these children because most of them are looking at benefiting, like getting that house that parents has left behind. Your motive was getting this house*

not taking care of the children and some of the children are being abused by their relatives"
(Participant 1).

Participants believed that foster families tend to discriminate between their own children and an orphaned child. Stories of abuse and neglect were mentioned as well as the inability of some foster parents to love the orphaned child as much as their own children: *"You find that the child is being abused like psychologically, over worked, there's never enough time for the child to study"* (Participant 1); *"Then there's this person who's taking care of you who has her own children. I mean she can't portray that love onto you like she does onto her other children"* (Participant 1);

> *They will love their children and this orphan children...you can see it's not his child. The treatment will tell you that it's not his child. Their children they stay at home and these orphans must go up and down. 'Go and buy coke and bread, go and buy what, go and buy that.' It's raining, the weather's not good and the child he didn't wear a jersey and while his children are wearing well clothes* (Participant 3).

THEME 7: Relationships with Peers

On the whole, participants believed that young children did integrate with their peers: *"They the same. Ja, play a lot, just like other children"* (Participant 4); *"That young, they don't have a problem"* (Participant 4); *"They do* [integrate]. *And I think if we could learn the way that they communicate and make friendships at that age, and then...somehow take it to other levels of their lives as well. But kids of that age, they're fine"* (Participant 2). Participant 2 implied that it would be beneficial if children from other age groups could implement the social skills they learned when they were very young at future developmental levels. Participant 3 experienced young children as being able to make friends but then added that *"you can see when he's staying with friends he's lonely. His face is not happy. Don't have happy face, smiling face, sad. When you talk to her she just talk to you but you can see she's not happy"* (Participant 3). Participant 2, while acknowledging that young children make friends, claimed that *"their friends have got this whole world that's been built for them"* and *"a child from that house who has everything else would find it difficult to communicate with a child who comes from a house that hardly has anything because there aren't any parents in there. But the differences are just so...you know you see them."* Thus, there seems to be a deep sense of difference which reinforces feelings of isolation, as was discussed in Theme 3, Sub-theme 3. This theme also gave the example of children being excluded from peers' birthday parties because it was believed that they would not be able to attend. However, the participant from Soweto stated that they

would try and assist the child to attend birthday parties. When a child on their programme has a birthday *"we buy things"* (Participant 2) so that they can celebrate with their friends at crèche. They also have partnerships with a few restaurant outlets that will sponsor a party for the child.

Participant 3 described how she had experienced victimisation toward orphans in her care:

> *The other children in the street they realise that they are alone. Now they take advantage to them, they hit them, they swear them, and they don't have somebody that they can go and tell that person that 'you see that child is hitting me, that child is swearing me.' When you go to their place, you'll find them sitting. When you ask them what's wrong they say: 'The children in the street they fight us.' When we go to their parents* [the other children's parents] *they don't take our stories.*

As discussed in Theme 3, Sub-theme 2, participants acknowledged that young orphans could become angry and aggressive: *"They're fighting because they have anger"* (Participant 3).

Participant 2 stated that her organisation held camps for orphans around 10 years of age:

> *We…bring the friends to that camp and what happens is, maybe a child will come to the camp and say: "You know what Kim? Remember that my mother passed away and I've been scared of telling you that my mother died of AIDS and I wasn't told until now. So I hope that you'll still be my friend. When we go back home, I depend on you for friendship. I depend on you to walk along side me. My world is crumbling and I know that you have parents; you have that and that and that, that I don't have. And I just realised now. So are you still going to remain my friend?' So we will go through that process with the psychologist.*

THEME 8: Relationships with Crèches and Teachers

Most of the preschool children attend crèche during the day: *"Those who are younger than 5 they just go to crèche 'cos we also provide crèches, we pay for crèches for the children"* (Participant 1). The discussion of stigma in Theme 5 mentioned how NGOs had established relationships with many crèches and these serve as their preferred suppliers: *"We are using certain crèches…there are certain crèches that we don't use"* (Participant 2). It was evident that the crèches, schools and NGOs work together closely and that this relationship is reciprocal in nature. The caregivers ask for assistance on behalf of their children and similarly the school refers OVC to the NGO: *"But then you talk to the teachers at the crèche: "This child is like this, like this. Try to make him feel at home like*

the other children, please'" (Participant 4); *"Sometimes I just visit schools to say: 'I have kids in the schools, these are their names.' Just to bring back the self-esteem again"* (Participant 2); *"Schools they're playing a very huge role 'cos they help in identifying children who are orphans. They are able to refer children and say: 'Ay, I have a child here. I think this child has a serious problem, can you talk to the child?'"* (Participant 1);

> *The child is coming to the school and…she's dirty all the time. And now the teacher she's calling that child: 'Where's your mother?' When that teacher find the child is an orphan she refer to Heartbeat. They work together with our manager…they phone our manager, or they come here give us a list so we go to the house and check and see the child* (Participant 3).

Caregivers served as mother figures and represented the child's parent at parent-teacher meetings: *"So we have to be those mothers…to say: 'You know, I can stand on your behalf and become your mum'"* (Participant 2); *"When they say: 'Call all the parents.' Now I come around they say: 'Here is a letter. Are you going to go to the meeting?' I say: 'Okay, I'll go. Where is it?' Now they say: 'I also got my mother, she'll come to the meeting'"* (Participant 4);

> *Every child in this organisation calls me 'ma', mother, because you are actually saying to them and the world that 'I can protect her. I can be there, just like you in your own household.' So whenever there is a need that arises they will call and say: 'I need you to go with me to that place'* (Participant 2).

Two participants believed crèches play an important role in providing emotional support for the children and that *"the teachers know…they always teach them about HIV what what, this stuff"* (Participant 4). Other comments included: *"At the school it's better because the teacher's realise that they are alone. They try to talk to them"* (Participant 3); *"The teacher's they support because they know our orphan children. They know their problems. When they find an orphan child, they refer to Heartbeat"* (Participant 3). The other two participants believed that teachers are overburdened and do not have time to get involved in the emotional problems of the child: *"They're busy doing what's expected of them, like teaching…They don't…have time to get emotionally involved with the children in terms of assisting them and counselling them…'I see you have problems, what's wrong? And what's going on in your life?' They don't really get to talk to the children"* (Participant 1); *"There's a lot of children in crèche and these teachers they can't give each child enough attention. They're just going there, being around other children, learning things and then going home"* (Participant 1); *"In crèches you can't really give each child that attention and that love"* (Participant 1);

The teacher's are overburdened. There is a school here called A. The teacher cried whose running the HIV/AIDS. She said: 'You know what? I am more of a mother than the teacher…' Because one factor that a teacher is at school is because they need to go and teach, but we need to deploy other people who will actually be able to help. I don't think teachers are well equipped enough and that's why we went to UJ to say: 'Help us out in addressing issues of teachers' (Participant 2).

Participant 2 continued: *"The teacher's say it's too much: We can't. We have 50% of the kids in the crèche come from such households.'"*

Crèches play an important role in providing nutritional support for children as well as offering some of the stimulation that is lacking in the home environment. Participant 3 commented:

Eish…It's hard for the teacher because they see them in the class and everyday she see the stress on that child. It's very hard for the teachers but I can say to you every day at school they are working hard for the orphan children. 'Cos they giving them feeding scheme. Some of them they don't have lunchbox. They're struggling at school when its lunch. So at least they're cooking for them.

THEME 9: Relationships with the Community

With regard to community involvement, Participant 3 pointed out that *"neighbours are not the same. Others they help. Others they don't care. They say: 'It's difficult to teach my child. So what about the other person's child?' But others they take care of the children."* Participant 1 stated:

It's only a few who are assisting. Mostly other people they don't care. They wake up early in the morning, they go to work, they come back late. They don't care what's going on with those children. You find that. It's heartbreaking because…you can see your neighbour's children, they are still young, they need guidance, that parental guidance but you are there but you don't want to offer your support.

Participant 1 believed that there is poor community involvement with CHHs as *"most people are not working and if they are, they're earning little so they can't do anything…They need someone to tell them that 'it doesn't have to be money. You can offer your love, your support. Just be there for these children. Advise them. Do what you can.'"* Participant 2 put forward a similar argument:

Everybody, one way or another, is affected by the virus. So everybody is just busy taking care of whatever they have, that we actually overlook the child who is in a child-

headed household. Like one boy said to me: 'The minute I shut the doors of my house, everybody else does the same. They won't knock at night, find out what's going on. People just loose interest in you. Except for the organisations that look after us.'

Community members rarely volunteer to participate in programmes: *"Community doesn't get involved in programmes"* (Participant 4); *"There's no support from them"* (Participant 1); *"Unfortunately people are very individualistic these days. There's no humanity. Mostly they don't really care what's going on next door, whether those children are living alone or what. They don't care"* (Participant 1);

> *Let me…give you an example of what happens. We have about 51 volunteers who work with our kids on programmes. And all of the 51 volunteers that we have are from the white community. So I honestly don't know whether our kids are being rejected because of the fact that their parents died due to HIV/AIDS related issues or is it… that the communities are overburdened* (Participant 2).

However, Participant 1 mentioned that the community helped identify orphaned children and would refer them to the NGO: *"If there has been a funeral they are able to say they know these child care workers are staying around here: 'Okay in such and such a family the mother passed away and the children are alone there, what can you do?'"*

THEME 10: Relationships with Non-governmental Organisations

Based on my conversations with the participants, it became clear that NGOs were a critical support mechanism for OVC on many levels. Participants described how NGOs assist with nutritional support, educational support in the form of finance, homework assistance and providing uniforms and stationery, making sure documentation is obtained for the children, providing assistance in accessing grants, assisting with clinic visits, developing relationships with crèches and schools, partnering with the corporate sector to raise sponsorships and organising donations of clothes, toys and other items from the public: *"Heartbeat…they're giving them good things, quality things…We got social worker, we got food parcels for these children. We give them clothes, even clothes that they are wearing at home. We give them school uniforms…From the food garden they give them spinach, cabbage"* (Participant 3); *"We give everything that comes here like donations, if it's clothing, it's toys"* (Participant 1). These NGOs also offer a host of psychosocial interventions to OVC and their guardians, when guardians exist.

SUB-THEME 1: Child Care Workers

Many orphaned children are offered a parental figure in the form of care workers. For children in the 2- to 5-year-old age group in CHHs this is an important source of support: *"The younger ones get most of their support from the child care worker"* (Participant 1). Care workers are adults, mainly women, who serve as mentors to a number of households in their community. These households are normally child-headed or contain vulnerable children. Care workers *"assist them in house chores, teaching how to take care of themselves properly"* (Participant 1);

> The care workers play a very important role because in whatever decisions that the children have to make, they have to talk to the child care worker that 'this and this happened at school, and this is what they said I should do and what do you think?' Then the child maybe would decide on something and the child care worker would discourage it if it is not favourable to the child and the situation (Participant 1);

"We…talk to them…encourage them. We check their books, are they going to school or not…We show them how to wash their washing and clean the house and to take care of themselves. We… tell them to lock the house at night and they mustn't open the door" (Participant 3).

Some of the participants opened the doors of their own homes to children living in CHHs and occasionally they would include them in activities or take them on an outing: *"We…go with them to the zoo. They see the animals. They were happy. We buy a barrel of Kentucky and…rolls, we take a blanket and we sit down there and give them food. You know that day it was a good day, and the happiest day for them"* (Participant 3);

> You know you are around even if the children they tell you that sometimes have a problem. 'Come to my house and play with my children and we can get close together. We are not so far. Sometimes come weekends and…you can know me better with my family, my husband, my children. I must take you like my children.' And they came (Participant 4).

Caregivers provide important support to children living in CHHs. The high turnover of caregivers due to HIV/AIDS related deaths and burnout has been well documented. However, Participant 1 claimed that care workers *"they last. They're committed. Because we have child care workers who have been working with the same families for like 5 years."* Nonetheless, this participant had also *"heard by one of the social workers…saying there's 40% of our child minders that are positive…And not so long ago we lost one of our child care workers to HIV."* The loss of a caregiver could contribute to the problems associated with multiple losses, as was discussed in Theme 1, Sub-theme 2.

NGOs offer training to their care workers and provide them with supervision: *"Last year we did training on…child development. We trained them in child development and trauma counselling. I usually do counselling with them. Workshops and counselling."* Care workers refer problems that they feel they are not trained to deal with to the social worker: *"So as the caregivers we try our best to talk to them, even we take them to our social worker, to talk to them when you find they've got too much stress. Tell the social worker the problems. They become better"*; *"Any problem they give us we refer them to the social worker"*; *"If you've got that family problem…our manager goes to the house, the social worker too, to take care of their family."* (Participants are not been identified in this paragraph to protect their identity.)

SUB-THEME 2: Psychosocial Support

Play therapy and sport were used to identify problems with very young children: *"What we do is mostly play therapy, your toy library"* (Participant 1); *"When they play…and use toys, it is only then that we can…say 'You know what? There's something that's really disturbing to this child.' You know things aren't just okay at home. And we will…take whatever we have… established…to the social worker or…psychologist who works part-time with us"* (Participant 2); *"We would use the toy library most of the time. Where the kids come in and there's a guy whose been trained on how to use toys and then we will actually determine where the child is emotionally"* (Participant 2);

> *The other thing that we do, especially with the 5-year-olds, we use sport because it will be easier for a child to be involved in a sport activity rather than a child coming into a counselling session and then trying to find out what's wrong. And then immediately afterwards…there will be a coach that has been trained in looking into 'is the child…totally focused on the sport or is there something else actually disturbing here?' And then we will go back to their household and find out what is it that is actually making them to behave the way that they do* (Participant 2).

On the death of a parent, children are offered *"counselling, trauma counselling, whereby I talk to the children. I visit their place. We organise for the funeral. We assist where we can"* (Participant 1).

However, routinely organised support for children in the 2- to 5-year-old age group was rare because

> *we are thinking that they are small. There isn't as much help that is happening because even when we have support groups, very little do we have support groups of the kids between the ages of 2 and 5 because we feel they are kids, they are not recording and yet their minds are recording…And I think we are not educated on how the*

psychosocial support on those kinds of kids can actually be born so that we truly address them (Participant 2).

Generally, attention from NGOs seems to focus on older children, as they are perceived to need more assistance when compared to younger children, who are viewed as too young to understand. Participant 2 explained: *"We look more into your kids who are actually raising kids in the child-headed house and we place so much concentration on her – equipping her, skilling her you know that she will be able to cope. We give them coping mechanisms."* The rationale is that the benefits of supporting the older children will trickle down to the young child: *"I believe that a 5-year-old won't be in a very, very traumatic situation…if the eldest sibling is being taken care of. If the elder sibling has been skilled enough, it will be easier for them to look after their younger siblings as well"* (Participant 2). Participant 2 felt that more could be done for children in this young age group: *"I think there's so much more that needs to be done. I don't know what it is* [laughs] *but it needs to be done."* She followed this up by saying*:*

> So much more needs to be done for kids because between 8 and 13 there is so much. We have people that facilitate for them at that age, but there isn't …I just know that they can't read, they can't write…They still in their own little confused world but we need to straighten that out rather than getting it more confused.

The participants from Nellmapius echoed these sentiments in the feedback session.

Both NGOs that participated in this study reported offering camps to their children *"where we would have facilitators…who actually write us reports on whatever that they have found that is…as far as the child is concerned"* (Participant 2). Memory work is performed with the children at both organisations where they create memory boxes that contain items that remind them of their special person. Both NGOs also offer summer and winter schools during the school holidays *"to assist with challenging subjects like maths and science"* (Participant 1). Heartbeat offers this to children from primary school, whereas Ikageng also offers to *"the younger kids between 3 and 7 have their school as well … Because it lags because there actually isn't parental guidance, you know the way they speak, their English, which means some sort of extra support needs to be given"* (Participant 2).

Support groups are offered to older children and to guardians in homes where there are vulnerable children: *"They teach them about HIV, teenage pregnancy, those kind of things"* (Participant 3)*;*

> *Because that time when the teenagers are coming here…then they solve the problems amongst themselves. Maybe this one she was down and loose hope, and when she find the other one…she motivates the other one, now she can see 'I'm not alone.' She*

can stand, you see, because by hearing the words sometimes you can stand. Then you find somebody who was exactly in your situation and she tell you that 'for me to grow I was doing this and this and this.' And then you can see that I'm not alone (Participant 3).

To me, NGOs appear to function as extended family, providing a large safety net to catch these children:

Really the NGOs feed for these children because they learn at the centre. Because when the community's got the NGO they learn and they share ideas …That's why I tell you the NGOs I think they're making a big difference. Because NGO is like another hope for them…During the month she don't have food…they come here and we give them food. Because it's like their home this place. It's the last hope for them (Participant 3).

THEME 11: Relationship to Government and Essential Services

Participants from Nellmapius felt that government is taking issues surrounding HIV/AIDS seriously, as is evident in the financial support and grants they provide: *"Government is doing well"* (Participant 3); *"It is effective"* (Participant, 1). However, Participant 2 from Soweto perceived a lack of support and involvement from government:

I don't think they are doing enough. Sometimes it scares me because if government took this seriously then communities would…We need serious leadership at that level so that we, here, can be able to deal with the situations. When there is…strong words coming out from the Health to say: 'HIV is real. It's there you know. Do something about it.' And when that strong word comes out from leadership I think things could start to slow down.

She continued:

There's…so much that needs to be done. I…get tired because I…think so much responsibilities have been left…to NGOs. I could…give you a typical example. Government has about 300 kids in our programme that they are looking after and we still haven't received their uniforms and its March so can you imagine what would have happened to those kids if we did not make some other means of making sure that those kids have uniforms…Government should stop doing once off things. Christmas time

they do once off donations to child-headed households and then what happens again during the year?

Some participants saw the provisions of grants as the main area of government responsibility. Participants felt that government needs to focus on the alleviation of poverty: *"This thing is good of ARV, but poverty? Because you can never drink the tablets if you don't have food, you see. Because other tablets you must eat first, so where can you get the food?"* (Participant 3);

> *What could be done now is…creating more jobs for people so that whenever there is a family close to you and the parents have passed away and the children are there alone you can be able to assist those children. It would help so that neighbours would be able to be in a position to see when children are experiencing difficulties and get involved. It would sort of motivate them* (Participant 1).

Other suggestions on where government could improve included the provision of more orphanages (mentioned by two participants), changing certain policies and laws and the encouragement of programmes in crèches, schools and the workplace that deal with emotions: *"Not only in schools. At work like in factories where there would be debriefings, serious counselling, more of a therapy for the workers there so as to alert them to the different behaviours of children who are exposed to HIV and finally to the deaths of their parents"* (Participant 1); *"I think government if they can…change policy around the child, you know things that would…affect the child. We need to challenge government. We need to challenge the law-makers. But again they must change laws. How kids get documentation because it's not on, it's just not on"* (Participant 2).

SUB-THEME 1: Documentation and the Allocation of Grants

A foster care grant is available to each orphaned child. Often this grant money is the only source of income for a CHH. While it is an essential mechanism of support, there are often unintended consequences in providing this money. As has been mentioned previously, the grant money often motivates people to foster orphaned children but it seems rare that this money is used for the intended purposes: *"Ay, this thing of grants, it's a big problem"* (Participant 3); *"The relatives they difficult to come and stay when there's no grants. They want this money...they want to control this grants money for the children…If this money is finished 'I buying this for you. Don't ever ask me about the money.' They fighting for the money"* (Participant 3); *"Some grannies or relatives…do not use the money for the right purposes. Others…use the money for their own things, their own satisfaction. In this community… most people drink a lot so other buy alcohol and…this useless stuff*

instead of buying school uniforms for the children, investing money for further education" (Participant 1).

> *The other challenge is when somebody has to be assigned to the child, like a foster somebody, who can actually monitor the money. Most of the time it doesn't end up feeding that child or looking after the child. It ends up being used for some other things. When someone's actually been appointed as a foster parent would end up using the money for their own means* (Participant 2).

The ability to access grants is hampered by the lack of documentation of the child and logistical problems at the Department of Home Affairs. Without all the necessary documentation children cannot access their grants. Many children are never registered at birth and thus do not have birth certificates, which disqualifies them from obtaining grants and impacts hugely on their financial status. Locating a parent's death certificate also poses problems in accessing grants: *"Your parent's death certificates. Sometimes we don't even know where they are. And some of the things that they have to get before they get into the social care grant. That's the other challenge"* (Participant 2); *"That is a bit of a challenge. You find a mother has passed away, she didn't have an ID* [identity document] *book and then it's difficult to get certificates for the children…and in most cases there isn't even a death certificate then it becomes more or less complicated"* (Participant 1).

Both NGOs involved in this study work actively to obtain the necessary documentation for children: *"Our…community developer, he's the one who works directly with Home Affairs…and arrange for our children to get…documents, those certificates and ID books…He registers them there and eventually they do get their ID books and they do get their certificates"* (Participant 1). Participant 2 mentioned the difficult situation of foreign children left orphaned in South Africa without any documentation:

> *When parents are not born here, there is no ways that a child can be a South African citizen…Most of them are born here, and your challenges of ID's and everything else, where it becomes difficult. I mean we had some who we wanted to send back to Lesotho but they were arrested at the border gate because they didn't have any documentation at all. So we had to bring them back here and start with them.*

Part of the problem is that:

> *Government is in the backlog. We have had kids that have started with us when they were 13, they are actually doing their tertiary and they still helping us with the money. Okay we have had other kids, where the kids they've had the foster care grants, but the*

other challenge has been, because of the paper and admin, you know, because of what
is required of the child to have, before they have access to that (Participant 2).

SUB-THEME 2: Clinics

Participants were generally satisfied that children have adequate access to health care and medication: *"They're getting ARVs, counselling as well…They are getting medication. As long as you have your identity book or your certificate, then they give you medication"* (Participant 1). Most HIV-positive children are placed on a multivitamin and once their *"CD4 count is below 200 at whatever age, then they will get the ARVs"* (Participant 2). Panado (a brand-name for paracetamol, a mild analgesic drug) was also offered and medication for diarrhoea when necessary. Once again, it seems that the NGOs have developed relationships with clinics: *"When we go there we don't go in the queue, we just go to the sisters and she know"* (Participant 4). The participant from Soweto mentioned that there were certain clinics that they would never take their children to, whereas the participants from Nellmapius said they had no choice of clinics, as there was only one clinic available to them. Medication was available to children who were HIV-positive. Participant 2 said:

Something has to be done to our health systems. You know X and Y clinics are just one
of the best clinics as far as child care is concerned. But other one's we just get scared. I
won't take any of the kids to casualty at Z at night time. I'd rather wait until the morning
and then take them to X or Y.

CONCLUSION

This chapter introduced the reader to the participants who were interviewed during the study. The data obtained from the interviews was conceptually grouped into themes and sub-themes. These themes and sub-themes were co-constructed by the researcher and the participants and input was also obtained from the project supervisor. Accordingly, the final themes presented in this chapter were decided collaboratively. The participants were considered the experts throughout this process. The following chapter offers a discussion of the themes within an ecosystemic framework.

CHAPTER 6

THICK DESCRIPTION

*The chief difficulty Alice found at first was in managing her flamingo:
she succeeded in getting its body tucked away, comfortably enough,
under her arm with its legs hanging down, but generally, just as she
got its neck nicely straightened out, and was going to give the
hedgehog a blow with its head, it WOULD twist itself round and look
up in her face, with such a puzzled expression that she could not
help bursting out laughing: and when she had got its head down, and
was going to begin again, it was very provoking to find that the
hedgehog had unrolled itself, and was in the act of crawling away:
besides all this, there was generally a ridge or furrow in the way
wherever she wanted to send the hedgehog to, and as the doubled-
up soldiers were always getting up and walking off to other parts of
the ground, Alice soon came to the conclusion that it was a very
difficult game indeed.*

- *Lewis Carroll, (1865/1994) Alice's Adventures in
Wonderland (pp.98-99)*

INTRODUCTION

In line with the ecosystemic approach, the aim of this chapter is not to prove or solve anything but to describe, discuss and provide thick description. This chapter elaborates on the qualitative enquiry presented in Chapter 5. The data is presented in two chapters so that an ecosytemic description can be adequately developed. Combining the data in one chapter risked becoming cumbersome. In this chapter, I also adapt Jasnoski's (1984) schematic, as presented in Chapter 3, to illustrate some of the psychosocial and systemic factors influencing the young child living in a CHH. The chapter journeys through each thread of the web and then elevates above the web, to observe a more panoramic or holistic view of the network. Some statements made by participants' in Chapter 5 are repeated here to illustrate the ecosystemic principles.

THE ECOSYSTEM OF A YOUNG CHILD LIVING IN A CHILD-HEADED HOME

Some of the central themes that emerged in this research are visually summarised in Figure 6.1. The diagram provides a framework for the discussion in this chapter. The figure represents an adaptation of Jasnoski's (1984) schematic that was presented and discussed in Chapter 3. All the ecosystemic principles discussed in that chapter should be kept in mind during this discussion. The figure is also influenced by Donald et al.'s (2006) adaptation of Bronfenbrenner's model of nested systems. Figure 6.1 portrays the very young child as nested within various supra-systems. The Sibling system has replaced the family system. This level represents the child's home environment. The Interpersonal Community level reflects individuals or institutions that the child interacts with on a face-to-face basis. These include the peer group, crèche/teachers, the extended family, NGOs, neighbours and clinics. At the level of the Wider Community are those attitudes, beliefs, traditions and community characteristics that influence a community and the individuals living in it. The young child and all other aspects of the ecosystem are impacted by the governance practices, laws and policies that exist at a Wider Society level.

As discussed in Chapter 4, the conceptual boundaries in the diagram allow the researcher to consider a multilevel ecosystemic portrait of a child living in a CHH. Hence, the researcher can zoom in on any level for a more in-depth understanding of that level and then zoom out again and view the total picture. The diagram could be misleading in that it suggests that each theme exists independently. In actuality the themes exist in interaction with each other and are not mutually exclusive. Thus, the headings and sub-headings in this chapter simply serve to assist with the organisation of the data. In terms of ecosystemic thinking no aspect is more important than the next. Neither the figure nor the discussion is exhaustive in its description of the research problem. It is merely my ecological exploration of what Auerswald (1985) calls an event-shape in time-space. It is a snapshot of certain situations at a specific time. The landscape of the research problem is in constant flux requiring any researcher to constantly re-focus their photographic lens. I agree with Keeney (1984) that the systems and sub-systems that I have highlighted here are merely "arbitrary punctuations" (p. 34) and reflect only the systems that I chose to see. The discussion in this chapter reflects the main ideas presented in the previous chapter as I feel that some of the themes and sub-themes were covered in sufficient detail and do not warrant repeating here.

The Child

The impression that I received during the interviews was one of uncertainty concerning the specific issues relating to very young children living in CHHs. There are a few possible explanations for this uncertainty. Firstly, according to the statistics cited in the literature review, the actual incidence of children in this age group living in CHHs is very low. The participants corroborated this and described such situations as "*quite rare*" (Participant 1). Thus, the participants' exposure to and experience of this age group may be limited. Secondly, even when exposed to very young children, participants generally believed that, because of their developmental level and their inability to communicate, "*the small child doesn't understand you see*" (Participant 3) or "*you don't get much problems because they don't talk*" (Participant 4). However, Howard et al. (2006) cite a survey on orphan caregivers who were asked how they would identify a depressed child: "Many caregivers cited withdrawal (73%) and sadness (62%), but only 9% mentioned anxiety/irritability/anger, and less than 4% mentioned other documented indices of depression, such as inability to concentrate, lack of appetite, headache or stomach problems, insomnia or fatigue" (p. 80). One participant in this study stated that they were "*not educated on the psychosocial support on those kinds of kids*" (Participant 2). Accordingly, caregivers may be ignorant to the subtleties of distress in young children. Participants seemed more *au fait* with issues pertaining to the older children and I would repeatedly have to ask if their comments were also true for the younger children. Finally, and linked to the previous point, the literature emphasises that specific concern for very young children in the context of HIV/AIDS "remains striking in its invisibility" (Swift & Maher, 2008, p. xi). Swift and Maher (2008) point out that young children "are invisible not only to sections of government, some service providers, donors, charities, medical professionals and others, but also in many cases to their own caregivers" (p. 13). It was evident in this research that no special interventions were targeted at the very young child. It seems true that there is a general lack of awareness and information surrounding this age group.

As was seen in the summary of early childhood development in Chapter 2, the young child's healthy development is strongly influenced by external factors. This is a critical developmental period in terms of cognitive and emotional development as well as the development of the concept of self. Most of these developmental tasks occur naturally in the context of the family (REPSSI, 2007; Richter et al., 2006). Thus, attachment relationships are important for the child's optimal

development. Despite many of these factors being compromised for the orphaned child living in a CHH, participants were generally of the opinion that they were *"just like other children"* (Participant 4) and that *"they're fine"* (Participant 2). I got the impression that on the whole participants believed that these children were on a developmental par with their peers. However, Participant 2, despite mentioning that these young children were *"fine,"* went on to comment that 3- to 7-year-old children were included in their holiday camps as developmentally *"it lags because there actually isn't parental guidance, you know the way they speak, their English, which means that some sort of extra support needs to be given."* Participants also commented that becoming orphaned affected the child's school performance. Yet Participant 1 pointed out that *"lots of our children pass well at school like our children in primary they are very clever. It doesn't really impact. It's when they're getting older. Ay, they're failing. Our 15-, 16-year-olds, they don't pass well in school."* However, poor academic performance and high levels of school drop out seem to be problems in poor communities generally and are not limited to the orphaned population. Parikh et al. (2007) found income level a better predictor for school enrolment than orphaning.

Despite the above comments, when participants were interviewed in-depth various themes emerged indicating difficulties experienced by some young orphans. These included the lack of a nurturing attachment to an adult, withdrawal and/or acting out such as anger or aggression, a sense of loss, isolation, neglect, problems with trust, signs of psychosis, a vulnerability to sexual abuse, HIV infection, poor concentration and a sense of hopelessness. These themes were discussed in detail in Chapter 5, Theme 3. These problems were identified in the reviewed literature, although it was not always clear to which age group the literature refers.

While participants seemed to believe that these young children were coping, concern was expressed that problems manifested themselves later in the child's development, suggesting that they may not have been coping as well as what was initially assumed: "*It manifests itself when they about 9 years old*" (Participant 2); "*It manifests itself when they go into the teenage years*" (Participant 2). Donald et al. (2006) support this and argue that most psychosocial problems have their roots in the interpersonal developmental encounters of infancy and early childhood and only reveal themselves as problems during late childhood and the teenage years. This makes it extremely difficult to recognise the link between the stressful event and the behavioural response (Daniel, 2005). However, to suggest that all these children will go on to develop significant psychosocial problems in response to their circumstances would be incorrect. Although there is little empirical evidence on the relationship between psychological problems and AIDS related orphanhood, the literature suggests

that most orphans, despite their high-risk status, do not exhibit considerable mental health problems (Cluver & Gardner, 2007b; Cluver et al., 2007; Howard et al., 2006; Li et al., 2008; New et al., 2007; Tolfree, 2006). This is discussed further later in this chapter.

Siblings

Participants and the literature generally agree that once a parent becomes ill there is a reversal of roles, or parentification. A child, usually the eldest sibling, nurses their dying parent and takes over the role of caring for the younger siblings. Stories documenting how young children have to care for their ill and dying parents were given in Theme 2, Sub-theme 1. As was mentioned in the literature reviewed, assuming a parental role can result in internalising, social and behavioural problems, including depression, eating disorders, anxiety and low self-esteem (Wenar & Kerig, 2005). Many of these problems were expressed in the interviews in this study and were reported in Theme 4, Sub-theme 2. In summary, participants reported that older siblings experienced poor concentration, lack of confidence, dependency, hopelessness, depression and suicidal ideation. Participant 1 described how many orphaned children *"don't have a vision, they don't have dreams."* Donald and Clacherty (2005) reached a similar conclusion in their research comparing children living in CHHs and AHHs. They found children living in CHHs to have difficulty describing long-term goals and concluded they had a lower internal locus of control (or a lower sense of control over outcomes) and less confidence than those children living in AHHs. A participant also mentioned that orphaned children appear tough but she believed this was a defence mechanism.

In terms of ecosystemic theory, in CHHs the sibling subsystem has come to replace the parental subsystem: "*It's more like you stop being a child and you become a parent*" (Participant 1). Thus, traditional rules and boundaries of family organisation have been disrupted in the face of HIV/AIDS. Empirical research indicates that the effects of HIV/AIDS are challenging the concepts of childhood and youth in many African communities (Germann, 2003). As was seen in Chapter 3, rules and boundaries play a role in defining the autonomy of a system and delineate the behaviours, roles and values of family members. Clear boundaries in the family system allow each family member to meet their developmental needs (Wenar & Kerig, 2005). However, in the context of the HIV/AIDS orphan crisis, older siblings have had to take over parental roles and responsibilities in order to retain some autonomy in the family system, thereby ensuring its survival. The disruption of roles, rules and boundaries within the family system impacts on a child's ability to meet their own developmental needs. Participants reported how teenage children generally were battling at school and that school

drop out was high: *"They're not coping at school. Mostly they are failing"* (Participant 1). Although this age group was not the focus of this study, in the literature reviewed it was highlighted that school played an essential role in facilitating peer relationships, which serve as an important source of support to the bereaved child in this environment (Li et al., 2008). Thus, in taking over the parental role the teenage child is often denied an education and the establishment of friendships, both of which serve as important protective mechanisms for the child. Participants also highlighted that boys were turning to drugs as a means to cope and girls to older men to fulfil the need to be loved and supported financially, which often resulted in pregnancy: *"Most of the boys that we are looking after have actually gone into drugs…One boy said to me: 'I just want to get away from being mum and dad…I thought I was coping when I was using drugs and yet I didn't"* (Participant 2); *"With girls its more like they'll go out with older men…They want sugar daddies"* (Participant 1).

The teenage child who is attempting to attain their own developmental milestones and who now has the additional burden of parental responsibilities has little time to attend to the developmental needs of their young siblings. The overloading of the child head of household was emphasised during the interviews. Participants agreed that they had their own needs as children and thus were not equipped to meet the needs of their younger siblings, even though there were clearly strong bonds and lots of love between them: *"And the sister…she's suffering from the young ones because now she becomes a mother…And yet she's young"* (Participant 3). They are robbed of their childhood and in the process many of their rights are violated (Germann, 2003). Two participants reported high levels of conflict between the siblings, where younger children often expressed resentment toward their older siblings for taking on the parental role: *"You want to act like my father. You are not my father. You are a child"* (Participant 3). While sibling rivalry and family conflict are likely to occur in all households, Donald and Clacherty (2005) found that siblings living in a CHH were actually more empathic in providing emotional support to each other and were more sensitive to detecting emotional distress when compared to children living in AHHs. Orphans in CHHs also reported that they were able to resolve arguments among themselves. Participants in this study agreed that there was cooperation between siblings in dividing household chores: *"Each and every one she know what they must do…They know their jobs"* (Participant 3). However, on the whole it appears that the social, emotional and cognitive development of a young child living in a CHH is compromised in that they live with a caregiver, an older sibling, who is not in a position to fulfil their needs for attachment, nurturance and stimulation.

Participants mentioned success stories where children had educated themselves and seemed to cope admirably in the face of the challenges of living in a CHH. To understand how children display resilience in the face of hardship, one needs to investigate the risk and protective factors on an individual, family and social level (Donald et al., 2006). In their study comparing children living in CHHs to those living in AHHs in impoverished communities, Donald and Clacherty (2005) found that children living in a CHH did significantly better on a written language test compared to children living in an AHH, although scores in both groups were well below the norm. They hypothesised that this unexpected result reflected children in CHHs "determination to stay in school despite severe difficulties and their generally serious attitude towards homework" (p. 27). Reports of effective money management and division of household responsibilities in the present research were echoed in Donald and Clacherty's (2005) study. Thus, children do show resilience in this situation and, particularly adolescents, demonstrate effective coping mechanisms, responsibility and nurturing skills (De Witt & Lessing, 2005). Participants' comments concerning their experiences of children living in CHHs are documented in various Sub-themes under Theme 4.

Interpersonal Community

I have placed structures that the child living in a CHH may interact with on an interpersonal, or face-to-face, basis on this systemic level. The research showed that these elements include the extended family, the crèche and teachers, the peer group, NGO's, the child's immediate neighbourhood and clinics.

<u>The Extended Family</u>

As stated in Chapter 2, the current state of the South African family in the context of HIV/AIDS cannot be understood without taking into account the country's historical and socio-economic environment (Goldblatt & Liebenberg, 2003). While informal child fostering has been, and remains, common practice in Africa, what has changed is the family's ability to cope in the face of the increasing number of HIV/AIDS related deaths and subsequent lack of resources (Schenk et al., 2008; Swift & Maher, 2008; Urassa et al., 1997). Unlike other epidemics HIV/AIDS typically preys on the productive and caregiving segment of a community and mortality is highest in the 30- to 50-year-old age groups (Germann, 2003; Snipstad et al., 2005). The conversations in this research (see Theme 6) confirmed much of what has been identified in other literature and research. Participants stated that most children were being cared for by their extended families, particularly their grandmothers. Participants also agreed that *"before they actually become into child-headed*

households that they have gone through such a series of deaths…then finally when all of their family fibre has been taken away…they end up being on their own" (Participant 2). Some children preferred to live alone as it enabled siblings to remain together and allowed the children to protect their parental home. Arguments were presented in the literature review as to why the CHH should not be summarily dismissed as a placement option for orphaned children. However, the participants in this research were unanimous in their belief that very young children should not be allowed to live in CHHs.

Participants agreed that when relatives other than the grandmother fostered orphaned children, often the motivation was to obtain the parental home or land along with the money available from foster care grants and not necessarily to ensure the emotional well-being of the child. Stigma occasionally played a role in the extended family's decision to foster orphaned children but this did not seem to be common. Freeman and Nkomo (2006) found that distantly related adults were more likely than close family members to be influenced by a child's HIV status and this may also ring true for children affected by the disease. Participants expressed concern that when children were fostered by relatives they were susceptible to abuse and neglect and that a mother *"can't portray that love onto you like she does onto her own children"* (Participant 1). Literature (Richter et al., 2006; Swift & Maher, 2008) suggests that because of the high geographic concentration of HIV/AIDS in poor areas, caregivers may be overburdened to the detriment of themselves and the children they care for. When children did come to live in a CHH, participants agreed that the extended family offered assistance "*sometimes but…very rarely*" (Participant 2). Relatives only visit occasionally and one participant reported that some of their orphans lived alone during the school term and then visited relatives elsewhere during their holidays. According to the participants the relatives' unwillingness to either foster or offer assistance to children living in CHHs was largely related to economic conditions. In a context of poverty many do not have the resources to extend to orphaned children: *"I've got my own children who are going to suffer"* (Participant 4). Thus, multiple deaths in the family along with increased poverty has destabilised the traditional ecosystemic balance of the extended family. To ensure its survival as an autonomous system, some family units may have had to discard the traditional concept of *ubuntu* in order to ensure their own survival.

The Neighbourhood

I have differentiated between the neighbourhood and the Wider Community as the former deals with face-to-face relationships with members in the community, or neighbours, and the latter refers to the broader attitudes, beliefs, traditions and resources of the community. Much of what has been said

about the extended family is also applicable to relationships with community members. Participants agreed that while there were some community members who assisted children living in CHHs, this was rare. Participants' comments concerning the relationship between children living in CHHs and community members and neighbours are documented in Theme 9. Like the family, the members of the community are burdened by economic demands: *"Everybody, one way or another, is affected by the virus. So everybody is just busy taking care of whatever they have"* (Participant 2). Participants claimed that community members rarely volunteer to assist their organisations and the participant from Soweto stated that all her volunteers were from the white community. This led Participant 2 to wonder if *"our kids are being rejected because…their parents died due to HIV/AIDS related issues or is it…that the communities are overburdened."* Thus, the traditional customs, values and beliefs of the wider community are being challenged on an interpersonal level. This seems to support arguments presented in the literature review that state that as financial resources are compromised adherence to traditional and cultural norms is also compromised.

Crèche and Teachers

The participants in this research agreed that the crèche played an important supportive role for the young child living in a CHH (see Theme 8). Most of the young children in Heartbeat and Ikageng's programmes attend crèche during the day. These NGOs assist the children by paying for their school fees, school uniforms, stationery and other school expenses for older children. Caregivers fulfil an important parental role for orphaned children by attending parent meetings at the school, allowing children to say *"I also got a mother, she'll come to the meeting"* (Participant 4). The participants in this study reported that the NGOs that they worked for had coupled with certain crèches and had established reciprocal relationships with them: *"This child is like this, like this. Try to make him feel at home like the other children, please"* (Participant 4). In turn, crèches and schools serve an important role in referring OVC to NGOs for assistance: *"Schools are playing a very huge role 'cos they help in identifying children who are orphans"* (Participant 1). Further, Ikageng has approached the University of Johannesburg to get involved in training teachers on HIV/AIDS related issues.

Crèches offer important nutritional support in that meals are provided daily. It is evident from the research conducted and the literature reviewed that attendance at crèche ensures that the child is cared for during the day as opposed to possibly being left at home unattended, leaving them vulnerable to abuse, or an older sibling having to quit school to care for them. In the light of disrupted family relationships and the stressful home environment, crèche and the interaction with peers offers crucial support for the young child. Participants believed that because older siblings were

overburdened and not fully developed emotionally, they were not able to adequately stimulate their younger siblings. Crèche provides an opportunity to fill this gap. As mentioned in the literature review, in the case of older orphaned children, school was where they felt happiest (Howard et al., 2006). School was a place where children could escape from the "negative feelings and emotions of grieving" (Li et al., 2008, p. 153) and gave them the opportunity to socialise.

It has been argued that the school will become a critical centre of care and support as a result of the impact of HIV/AIDS and the consequent orphan crisis (De Witt & Lessing, 2005; Van Vuuren, 2004). With this growing ecosystemic calamity and the increased pressure that is placed on overburdened caregivers, it is anticipated that the management of school performance in affected individuals will increasingly be left to the teacher (De Witt & Lessing, 2005; Van Vuuren, 2004). Van Vuuren (2004) claims that morale in the classroom is expected to diminish as a result of increased suffering and multiple deaths, and thus the schools will need to offer psychosocial support to both teachers and learners. Berry and Rudolph (2006) argue that teachers are critical in the learning process and in the context of HIV/AIDS it is essential that teachers are aware of a child's unique circumstances and are equipped to provide care and support. This is expected to challenge the school system as teacher to learner ratios are high. These difficulties are exacerbated by the absence of teachers due to their personal struggles with HIV/AIDS (Berry & Rudolph, 2006). Participants had mixed opinions regarding the role of the teacher in the context of HIV/AIDS (see Theme 8). Two of the participants believed that teachers provided an important source of emotional support while the other two participants felt that teachers were overburdened and did not have the capacity to support children. Participant 2 commented: "*Because one factor that a teacher is at school is because they need to go and teach, but we need to deploy other people who will actually be able to help. I don't think teachers are well equipped enough.*"

The Peer Group

On the whole participants agreed that young orphaned children living in a CHH integrated well with their peers. Participants' experiences are presented in Theme 7. One participant reported instances of victimisation where children were bullied and sworn at in the streets. Two participants sensed that orphaned children felt different from their peers who had parents, perhaps contributing to their sense of loneliness and isolation, which was discussed in Theme 3, Sub-theme 3. Participants also mentioned that some children would act out, become aggressive or withdraw, but this interactional style was not necessarily exclusively in relation to peers. This was explained in Theme 3, Sub-theme 2. As mentioned above, the crèche serves as an important space for peer interaction. Louw and

Louw (2007) point out that developing friendships with peers is one of the most significant aspects of a young child's social development. The skill of interacting is developed through increased self-awareness, which allows them to communicate more effectively and be more understanding of the feelings and thoughts of others (Louw & Louw, 2007). Play is an important part of the young child's development. In play young children "share affection, offer approval and make demands on one another, providing valuable learning opportunities in social interaction" (Louw & Louw, 2007, p. 197). Play offers children the opportunity to practice new skills and is thus essential to the child's cognitive development (Louw & Louw, 2007). Much of this is accomplished in the context of peer relationships and often in the crèche environment.

Non-governmental Organisations

During this research it became evident that NGOs are fulfilling essential functions across all ecosystemic levels in relation to the needs of OVC. They have coupled with numerous systems from the individual child and their siblings in terms of nutritional, educational and psychosocial support, to offering essential support to the community and the extended family. Reciprocal relationships have been established with schools and crèches; they assist children with access to health care and liaise with government departments in terms of obtaining personal documentation, which allows children, with their help, to access their grant money. They also provide a caregiver who serves as a mother figure to children in CHHs and hence provide an adult attachment figure. The services offered by NGOs were described in detail in Theme 10 and will not be repeated here. Under conditions of extreme adversity NGOs have managed to fill or partially fill some of the gaping holes created by the onslaught of the HIV virus. Although NGOs experience enormous challenges, I believe that they serve as a crucial corrective mechanism in our society.

In terms of an ecosystemic approach the role fulfilled by the NGO is that of a negative feedback loop which attempts to maintain the status quo and stabilise the whole system by restoring some balance. The HIV pandemic has served as a positive feedback loop at every level in the ecosystem. It has introduced change to, for example, family organisation and functioning, community beliefs and traditions and has impacted the workforce. These rapid changes result in instability in the ecosystem. It was explained in Chapter 3 how because of the long incubation period of the virus, the disease was able to spiral out of control before corrective measures could be implemented. Because of the imbalance between positive and negative feedback mechanisms, a social disaster has been unfolding. NGOs serve as a corrective mechanism for the ecosystem. They reduce the digressions from the preferred equilibrium in the services that they offer. For example, in providing nutritional

support they are able to restore balance to the physiological system of a child who otherwise would be starving. A caregiver is offered as an attachment figure to an orphaned child and restores some balance in a household that has been disrupted in terms of rules and boundaries.

<u>Clinics</u>

Discussions with the participants about clinics and health care were brief and the relevant content was presented in Theme 11, Sub-theme 2. It is sufficient to say here that participants, on the whole, were able to access health care for the children in their programmes and, while one participant commented that services varied between clinics, they were able to source facilities that they found suitable: *"As long as you have your identity book or your certificate, then they give you medication"* (Participant 1). Adequate health care is obviously essential for the holistic development and well-being of the child.

Wider Community

The Wider Community functions at a metalevel that allows us to understand how individuals in a community make sense of their reality. Communities at this level of analysis differ in terms of their resources, values, beliefs and traditions. In the context of this research, relevant factors to be discussed include the effects of poverty, traditional beliefs, practices and attitudes within the community.

<u>Poverty</u>

The level of resources in a community impacts the psychological and physiological functioning of the members of that community (Louw & Louw, 2007). Richter et al. (2006) point out that in conditions of poverty a child's development is negatively impacted in the form of limited access to services, unfavourable environmental circumstances, scarce provisions, social volatility and discouraged and overburdened caregivers. We saw in the literature review how HIV/AIDS and poverty are related to each other in a circular manner. The one feeds the other and it is a cycle that is difficult to break. Both the communities that were involved in this research could be described as poor communities. Participant 1 described the Nellmapius community as *"a very poor community. Let us say it is the poor of the poor."* Participant 2 described the Sowetan community as *"poverty stricken."* Both communities experienced the problems described by Richter et al. (2006), leaving many children in the community vulnerable, not only orphans living in CHHs.

Numerous social problems are affiliated with poverty such as higher rates of teenage pregnancy, crime, drug and alcohol abuse, sexual abuse and physical violence (Donald et al., 2006). Participants in this research acknowledged that dropping out of school, teenage pregnancies, drug abuse and girls relying on sugar daddies for financial support were common among children in their communities generally and were not limited to orphans. As mentioned, participants reported drug abuse to be common among boys whereas girls were likely to get involved in sexual relations for financial or material rewards. Participant 1 explained that *"here it is not taboo to go with a married man who's got a family. As long as that guy will take care of you...Even with children who have parents they do it."* However, Participant 2 believed that girls being raised by single mothers and those living in CHHs came to equate *"sex as some form of being loved and wanted"* because of a lack of a father figure. Participant 2 explained that teenage pregnancies were *"not about their morals. It's about the fact that...being raised in a house that doesn't have a parent...You go outside your home to get the love and attention and somebody just gives that to you and find that they give it to you with a price tag on it."* This sexual activity often led to higher rates of HIV infection and teenage pregnancies with subsequent school drop-out. While all children in impoverished communities are at risk, research suggests that orphaned adolescents and children living in CHHs are more likely to engage in risky sexual behaviour because of their increased psychosocial problems and financial hardship. They were also deceived more easily into seeing sex as a sign of protection and love which assisted them in coping (Nyamukapa et al., 2008; REPSSI, 2006; Schenk et al., 2008). Sexual abuse of very young orphans because of their vulnerability was of concern to all participants although none of the participants from Nellmapius had experienced this directly. The participant from Soweto had encountered sexual abuse and expressed concern that it was under-reported because child heads of households were too preoccupied to detect the signs in their younger siblings. The elusiveness of abuse in young children was confirmed in the literature reviewed but, as reported in Chapter 2, orphans living in CHHs seem particularly vulnerable because of their isolation and financial and emotional vulnerability.

All the participants in this study highlighted the negative effects that poverty had on their community generally. One example presented showed how interventions offered by the wider society were impaired because of the effects of poverty. While government was providing ARVs, Participant 3 pointed out that *"you can never drink the tablets until you have food."* This illustrates how, in planning interventions, one needs to take factors across the entire ecosystem into account. Some participants highlighted the importance of job creation, believing that an increased flow of capital would increase people's willingness to assist young children living in CHHs. As seen in the

discussion on the extended family, many people were unwilling to take care of orphaned children because fostering would further threaten the already fragile economic situation of their own family unit. Consequently, poverty and its exacerbated effects in the context of HIV/AIDS has impacted on the traditional organisation of family life and the concept of community in many African communities. This was evident in the literature reviewed and confirmed by the participants in this study.

Ubuntu

The spirit or customary value of *ubuntu* has traditionally played an important role in African culture. *Ubuntu* was described in Chapter 2 as a sense of community or collectiveness, often expressed in the idea that "your child is my child" (Swift & Maher, 2008, p. 5). While participants agreed that most orphaned children are cared for by their extended families, all the participants stated either explicitly or implicitly that the custom of *ubuntu* seemed threatened. Freeman and Nkomo (2004) argue that traditional and cultural norms will be contested as the financial resources of a community are challenged. This was confirmed by the research cited in the literature review and by participants in this study: "*When we should actually be practicing ubuntu, where your child is my child, where you actually take this village to raise a child, and you see that not happening at all*" (Participant 2). This participant explained that as an NGO they were "*depending on that village that surrounds a child to help us out. And sometimes that village… is…fading away; being eaten away from HIV/AIDS…Because…everybody else is poverty stricken or one way or another HIV and AIDS has…eaten up the whole…dynamics of families…and the fibre of society as well.*" Other comments suggesting the demise of *ubuntu* are quoted in Theme 9. Conversations with the participants seem to confirm Freeman and Nkomo's (2004) prediction that people's 'in principle' willingness to help orphaned children would be jeopardised in the light of economic and social constraints.

Economic factors are not the only explanations that have been offered regarding the breakdown of community spirit. It is possible that the dissolution of collective norms within communities is influenced by the infiltration of individualistic Western values (Snipstad et al., 2005): "*People are very individualistic these days*" (Participant 1). As stated in Chapter 2, Roalkvam (2005) found "unresolved *lobola* issues" (p. 217) to be responsible for the isolation of some children living in CHHs. This was not mentioned by any of the participants in this study but may warrant further investigation. The spirit of *ubuntu* may also be jeopardised by the high mobility between communities. Roalkvam (2005) observed that families may not have had time to establish relationships within a community at the time of parental death and therefore a neighbourly sense of obligation and social support toward new arrivals may be diminished. Participant 2 from Soweto

highlighted that she was experiencing increasing numbers of children being left orphaned and isolated as a result of migration from other areas in South Africa as well as from neighbouring states. Hence, these children may not have established social networks on which they can depend. In light of the current xenophobic attacks, it is possible that foreign orphans are even more vulnerable to hostility from the community.

<u>Stigma and Denial</u>

I battled to decide on which level stigma should be represented, as stigma is pervasive throughout the entire ecosystem of a young child living in a CHH. In accordance with the definition of stigma given in Chapter 2, I eventually decided to place it at the level of the wider community where attitudes and beliefs may differ. Participant 2, however, would probably argue that stigma would be more appropriately placed at a governmental level in the wider society: *"If government took this seriously then communities would…When there is…strong words coming out from the Health to say: 'HIV is real. It's there, you know. Do something about it.' And when that strong word comes out from leadership I think things could start to slow down."* The South African government, under the leadership of Thabo Mbeki, was infamously slow in responding to the unfolding HIV/AIDS crisis and it is possible that this attitude of denial, which is reinforced by stigma (Swift & Maher, 2008), seeped through to other areas of society. Participant 2 reported that she had experienced instances *"where there are adjustments in the community."* However, she had anticipated that because of the prevalence of the disease in urban areas that stigma *"would come down but it is not."* Stigma is a problem that affects the entire ecosystem. In systemic terms, stigma and denial influence the escalation of positive feedback cycles in that people do not utilise corrective measures that would restore balance to the system, even when such measures are available. For example, by being unaware of one's HIV status people delay treatment until *"you start suspecting and testing at that time when it's more or less late and nothing…can be done at that point"* (Participant 1).

Participants agreed that stigma, as discussed in Theme 5, was still evident in their communities in the form of secrecy, discrimination, victimisation, gossiping and isolation. Other research confirmed participants' concerns that stigma may serve to marginalise and isolate children from their peers and from neighbourly support (Donald et al., 2006; REPSSI, 2007; Swift & Maher, 2008) and decrease the likelihood that they would seek out psychosocial and medical support (Ross & Deverell, 2004). Further, the ostracism, gossiping and teasing may result in them dropping out of school, robbing them of a critical mechanism of support (Chitiyo et al., 2008; Cluver & Gardner, 2007b; Freeman, 2004; Louw & Louw, 2007). Participant 2 gave examples of how she tried to protect the children in

her care by only using schools that she had relationships with as well as transporting children to clinics outside of their immediate neighbourhood in order to decrease identification by community members and hence decrease possible gossiping and discrimination. Thus, stigma has obstructed an effectual public response to HIV/AIDS and has imposed suffering on people both infected and/or affected by the disease (Dias et al., 2006).

Attitudes Toward Bereavement and Death

Research suggests that, as a result of the deterioration of parenting skills and anticipatory grief, children are most affected by parental HIV/AIDS before the death of a parent (Foster, 2006; Pelton & Forehand, 2005). The interviews contained heartbreaking stories about young children having to nurse their dying parents. Some of these stories were documented in Theme 2, Sub-theme 1. It was evident during the interviews and in the literature and research reviewed that African children generally, and specifically very young African children, are inadequately prepared for their parent's imminent death. This lack of preparation is entrenched in cultural traditions surrounding the role of the child. As mentioned in the literature review African adults do no not traditionally concern themselves with the inner life or feelings of the child (Swift & Maher, 2008). Very little, if any, support or communication was offered before or after the death of a parent. Only one participant in this research claimed that children were informed honestly about their parent's death. One participant stated that they lied to the child and told the child that the parent would be coming back while the other two participants stated that they whispered the news in the child's ear while they were sleeping. This lack of communication coupled with the belief that preschool children are too young to understand death or experience grief, as discussed in Theme 2, Sub-theme 2, means that issues relating to death are cloaked in secrecy and silence, which research (REPSSI, 2007) suggests may exacerbate feelings of insecurity. However, signs described by participants such as excessive crying, acting out, regression in the form of bedwetting, nightmares and sadness show that young children do experience a sense of loss. These non-verbal signs, amongst others, were confirmed in the literature.

In contrast to the beliefs and practices mentioned above, research suggests that because of their total dependency on a caregiver to meet their needs, young children may experience death or separation as extremely painful and frightening (REPSSI, 2007). Although not explored in detail in this research, other findings show that very young children are most likely to be moved between households on the death of a parent. This can exacerbate a sense of instability at a time when routine and familiar relationships are most important to young children (Richter et al., 2006).

Participant 2 confirmed that most children had moved on numerous occasions prior to living in a CHH but the effects of this on young children were not elaborated. Research suggests that children may feel insecure with new living arrangements and possibly develop anxious attachments to caregivers, expressed in excessive clinging (Chitiyo et al., 2008; Howard et al., 2006; Louw & Louw, 2007). We have seen in this research how over-burdened older siblings are compromised in their ability to meet these needs, which, according to some literature (REPSSI, 2007), leaves young children vulnerable to lasting developmental problems. Li et al. (2008) argue that because of their developmental level children are more likely to experience unresolved or complicated bereavement. It is therefore important that age appropriate interventions are available to these youngsters.

Some participants admitted that there were negative consequences to not being open and honest regarding the death of a parent. Many children expressed anger once they were old enough to understand what had happened. Further, some participants believed that children had not coped as well as they had initially thought as problems that seemed to be related to the death of a parent manifested later. As the general view is that children do not understand the concept of death, NGOs do not provide programmes specifically for them. Despite these beliefs, Swift and Maher (2008) point out that the impact of bereavement may be worse for children if they are not assisted in coming to terms with their loss. Howard et al. (2006) argue that assisting a grieving child comprehend the loss is one of the most important things one can do for them. Research (Howard et al., 2006) suggests that memorial and grieving activities serve as protective factors for the child. Participants from each organisation mentioned that they do memory work with their young children prior to the death of the parents but this was not explored in detail. While they mentioned support groups for children from middle childhood, no programmes are targeted at very young children. Support offered to young children appears to be more reactive than preventative – if a child displays problems then they are assisted by a social worker. As most of these children have experienced multiple losses prior to living in a CHH psychosocial support becomes even more important as the psychological impact is likely to be greater and the support from grieving adults is likely to be diminished (Li et al., 2008).

Snipstad et al. (2005) point out that funerals have been made more visible to children with the onset of HIV/AIDS and yet "ways of caring and communicating with children on life-and-death issues may not have changed accordingly" (p. 192). Participants expressed similar concerns about cultural adjustments. Participant 2 argued that *"our cultures have to change because...we are living in changing times...So should our communication to our kids...We should...start telling our kids."* In addition to concerns expressed about poor communication and support around death, Participant 2

was troubled about young boys being discouraged from expressing their emotions owing to cultural traditions: "*As a boy child, you don't cry.*" On the whole participants agreed that cultural beliefs needed to be challenged so that children can more effectively cope with the losses experienced as a result of HIV/AIDS.

Community Characteristics

In conducting this research I sensed differences between the Nellmapius and Sowetan communities that could lead to different outcomes for children living in CHHs. Nellmapius appeared to be a much smaller community, comprised mainly of local people or people that had moved there from the nearby township of Mamelodi. Thus, it is a relatively homogenous group. Nellmapius is divided into extensions and caregivers are dispersed between these extensions. One participant mentioned that there are a few newer sections that Heartbeat does not have a foothold in yet but on the whole they seem to be visible to the community. If a community member identifies an OVC they refer them to Heartbeat. My impression was that most of the OVC in Nellmapius have been caught by Heartbeat, who is offering them a safety net. On the whole, although Nellmapius is a poor community my impression was that they did not experience poverty to the same extent as certain areas in Soweto. In Nellmapius most children in CHHs live in RDP houses, whereas their counterparts in Soweto live in shacks and back rooms, thereby increasing their vulnerability. In Soweto, the situation seems more chaotic. While the NGO I worked with there does a phenomenal job in assisting children living in CHHs, I felt that the situation in Soweto is not as contained. Soweto is more of a heterogeneous community, accommodating foreigners as well as migrants from other areas in South Africa. The population in Soweto is also much larger, which left that participant, and myself, concerned that "*we have lost track somehow and some kids fall into the cracks…They turn to crime…Kids that are not recorded that we're losing to prostitution, that we're losing to drugs…because of the fact that we are not caring enough*" (Participant 2). In a larger, less homogenous community like Soweto, I believe it can be anticipated that the level of social capital, as discussed in Chapter 2, is decreased and thus impairs their ability to cope with the orphan crisis. Landry et al. (2007) support this finding. They found the unity of the extended family to be better preserved in smaller rural communities where traditional values are maintained as opposed to urbanised communities where traditional values may be challenged. Consequently, the circumstances of OVC vary by context, and reactions need to be centred on situation appraisals so as to mirror local realities and reflect local needs (UNAIDS, 2006).

Wider Society

To understand any social problem, it is necessary to understand the whole society in relation to the effects that it has on each of the other systemic levels (Donald et al., 2006). Changes that occur at this widest level have the potential to have a ripple effect through the entire ecosystem (Donald et al., 2006). Policies, laws and governance practices of the state may be included at this level (Donald et al., 2006). Richter et al. (2006) point out that government plays a critical role in dealing with the orphan crisis, particularly in the provision of health and social services as well as in providing education. They also play an important role in developing policies that encourage the holistic well-being of the child and the stability and competence of families (Richter et al., 2006). The participants in this research differed in their opinions on the South African government's effectiveness in addressing the orphan crisis and HIV/AIDS issues generally (see Theme 11). Differences were aligned in accordance with the community the participant belonged to. The participants from Nellmapius generally believed that government *"is effective"* (Participant 1) in addressing the HIV/AIDS crisis as was evident in their financial provisions in terms of grants, health care and medical support. Participant 2 from Soweto, on the other hand, stated that *"I don't think they are doing enough"* and believed that government did not take HIV/AIDS seriously. She argued that government should *"change policy around the child"* and *"they must change laws."* These different responses may reflect characteristics at the Wider Community level, as was mentioned under the heading *Community Characteristics*, in terms of, for example, the size of the community. While policies may be made at the wider level of society their successful implementation may depend on factors at the Wider Community level.

Donald and Clacherty (2005) found that child heads of households had little awareness of the nature and availability of grants and how to access them. They also found low ownership of birth certificates among children living in CHHs as they were either lost or births had never been registered. All the participants stated that while grants were critical in addressing the orphan crisis, there was often a problem in accessing them because of a lack of documentation for the child. This documentation is often difficult to obtain because *"you find a mother has passed away, she didn't have an ID book and then it's difficult to get certificates for the children…and in most cases there isn't even a death certificate then it becomes more or less complicated"* (Participant 1). Further, government is *"in the backlog"* (Participant 2) which delays access to grant money. Both NGOs assist children in obtaining the necessary documentation and grants. Participant 2 claimed that government needs to challenge laws about how *"kids get documentation because it's not on."* Participants also argued in favour of

government's role in job creation, poverty alleviation, education around and emotional support for those affected by HIV/AIDS and two participants argued in favour of the provision of more orphanages.

ZOOMING OUT

In striving to offer a holistic ecosystemic picture of the psychosocial dynamics of young children living in CHHs it is important to step back from the individual segments discussed above and look at the interactive or interlinked relationships between the parts. When one looks at the complexities of the OVC crisis it becomes clear that the whole is indeed more than the sum of its parts. This ecosystemic picture can be likened to the baking of a cake. Each ingredient, or system, contributes uniquely to the end product. If any one of the ingredients is substituted or eliminated it alters the final creation. It is the interaction of different ingredients that gives a cake its unique flavour. Likewise, it is the interaction of many factors, some of which have been discussed in this and the preceding chapters, which contribute to the picture of young children living in CHHs presented here. The interaction between each theme and sub-theme presented in this dissertation, as well as issues that are not covered here, contribute to the unique outcome for each individual child.

Keeney and Sprenkle (1982) highlight the importance of understanding how systems are coupled to each other as this reinforces or generates the epistemological foundation upon which people mould their ideas and behaviours. They argue that pathology or problems in a system develop when the parts are not united amicably to the whole. As seen in Chapter 4, an ecosystemic approach sees pathology as the inability of the individual and social relationship levels to connect within the ecosystem. Problems arise when there is incongruence or imbalance between systemic levels – there is an imbalanced relationship between demands and available resources within the systemic levels. Keeney and Sprenkle (1982) cite Bateson's example of Alice's difficult game of croquet, as quoted in the heading of this chapter, where she couples with a "Flamingo mallet," which couples with a "hedgehog ball." Bateson argued: "Alice's difficulty arises from the fact that she does not 'understand' the Flamingo, i.e., she does not have systemic information about the 'system' which confronts her. Similarly, the flamingo does not understand Alice. They are at 'cross purposes'" (cited in Keeney & Sprenkle, 1982, p. 9). In terms of this conceptualisation of health, coupled with the literature reviewed and the information uncovered in conversations with participants in this research, I believe it is evident that the ecosystem in which the young child living in a CHH exists is severely distressed. The escalation of positive feedback in the ecosystem has immobilised individuals,

communities and even the society and prevented them from seeking optimal environments. Like Alice and the flamingo, systemic levels seem to be discordant and unable to support each other. At a time when systemic support is critical, people affected by HIV/AIDS are often disconnected from their environment. This is particularly true for young children, as is evidenced by their recurring invisibility and especially for those young children living in CHHs who are often isolated from other societal structures because of, for example, stigma and a lack of resources.

Authors (for example, REPSSI, 2007; Richter et al., 2006) have proposed a 'circles of care' model, similar to the schematics presented in this dissertation, to support the well-being of infants and young children. REPSSI (2007) explains the logic as follows:

> When the immediate care-giving circle is broken, extended families need to fill the gap. If this cannot be done, community initiatives need to provide the necessary care. And if this community circle of care is broken, external agencies need to take over. A strong and continuous circle of support provided by government and legislation should embrace all efforts. (p. 6)

In theory this seems like a useful model to strive toward but I believe it is evident that there has been ecosystemic disintegration to such an extent in many impoverished, HIV/AIDS affected communities in South Africa that these circles of care are no longer functioning. In this journey, we have seen how the family and community may no longer be able to integrate the increasing number of orphans and how traditional beliefs and practices have been challenged. We have seen that support from government is questionable. It was suggested earlier that the school should increasingly provide care and support for children affected by HIV/AIDS. However, a South African Human Rights Commission report stated that "school was the 'single most common' site of crimes such as assault and robbery against pupils and that more than one fifth of sexual assaults of young people occurred while they were at school" (Swift & Maher, 2008, p. 21). The Commission also reported that of the 1227 female students who had been sexually assaulted, 8.6% were assaulted by teachers. External agencies, such as NGOs, are offering invaluable support but it is debatable whether they are equipped or able to contain the crisis. They are also dependent on other structures for their sustainability and success. My fear in this current global economic crisis is that the ability of NGOs to maintain and develop their services may be compromised as the availability of international and local aid is threatened. Indeed, while writing this chapter, the *Sunday Times* ran a front-page article with the following headline: "Charities going bust as recession hits: Suffer, little children" (Philip, 2009). The article reports: "Charity organisations, which represent 30% of social services in the country,

would have R3-billion less to spend on crucial causes because of the recession" (Philip, 2009, p. 1). With a decrease in foreign, corporate and private donors, many organisations, as well as the individuals that they assist, face an uncertain future.

In terms of ecosystemic theory, a child raised in the environment described in this dissertation would be at high risk of developing psychosocial problems. Many authors, as cited in Chapter 2, concur with this belief. However, as mentioned previously, research has found that although important psychosocial needs can be identified, most children do not develop considerable mental health problems or disorders. I think that the participants from this research would agree with this statement. Research (De Witt & Lessing, 2005; Richter, 2003) highlights a child's ability to show resilience despite severe adversity. Richter (2003) argues that this is because of "the intrinsic biological processes which drive child development where children actively seek out these formative experiences even in conditions of extreme difficulty" (p. 12). Freeman (2004) compares the current HIV/AIDS situation with the political upheaval in South Africa in the 1980's and 1990's, which was characterised by considerable violence and turmoil. Concern was expressed about the 'marginalised youth' and 'lost generation' and yet he reports that comprehensive research suggests that the concerns for the psychological health of the youth were exaggerated. Similarly, in their review of international and southern African research, Cluver and Gardner (2007b) established that "fears of orphaned children as 'unsocialised', 'juvenile delinquents' and 'potential rebels'" (p. 9) could be challenged. Thus, it is important to view both the strengths and weaknesses in an ecosystem so as to avoid a deficit-only orientation (Donald & Clacherty, 2005).

Wild (2001) concludes that "there is no definitive answer to the question of whether losing a parent to AIDS places children at risk for psychological adjustment difficulties" (p. 16). As mentioned in Chapter 2, a child's resilience will depend on the balance between protective factors and specific risks which may include the previous, present and future characteristics of the child, their family and wider social environment. Earls et al. (2008) caution that "risk and protective factors seldom function as main effects; rather, they should be seen as interacting components of a system" (p. 301). The ecosystemic concepts of equifinality and multifinality should be kept in mind. However, what has emerged in current research may not be mirrored in research 5 or 10 years from now. The picture presented in this research is not static but is continually developing, changing and evolving: "Through social interaction, cultural values, beliefs, practices, and ways of understanding the world constantly change and evolve" (Donald et al., 2006, p. 46). Freeman (2004) paints a frightening picture of the possible cumulative micro and macro effects that HIV/AIDS as a whole could have on a

society in terms of "overgrieving" (p. 153), psychological problems, crime and a loss of productive individuals. Although the implications are serious, UNAIDS (2006) argues that with concerted efforts governments, international agencies, NGOs and community organisations can change the direction of the response. I would like to add that I believe that for these agencies to be effective they need to act concomitantly and target systemic levels simultaneously.

CONCLUSION

This chapter reflected on some of the themes that emerged in Chapter 5 and attempted to thicken the description of these themes. A figure summarising some of the central themes of the research served as a guideline for the discussion. Each aspect of the figure was discussed separately and then the discussion stepped back from the parts to offer a brief overview of the ecosystemic picture as a whole. My experience of writing the chapter can be likened to Bateson's ecology of ideas. Each theme could have evolved into something much larger than presented here but due to the scope of this mini-dissertation the discussion needed to be contained. Unfortunately, I had to let some of the hedgehogs crawl away. In reality, the themes and sub-themes are interdependent and the headings offered serve a purely organisational purpose. Accordingly, how to present the themes was a tricky task. I could relate to Alice's experience with the flamingo – each time I thought I had encapsulated a theme the flamingo would twist its head and look me in the face, suggesting new ideas. Thus, along with Alice I concluded that this "was a very difficult game indeed" (Carroll, 1865/1994, p. 99).

IN THE LOOKING GLASS

I wonder if I've been changed in the night? Let me think: was I the same when I got up this morning? I almost think I can remember feeling a little different. But if I'm not the same, the next question is 'Who in the world am I?' Ah, that's the great puzzle!

- *Lewis Carroll, (1865/1994) Alice's Adventures in Wonderland (p.24)*

Dear Reader

The final stage of an interpretive analysis requires one to contemplate one's own role in accumulating and illuminating the data. This coincides with the ecosystemic emphasis on acknowledging one's epistemological influence on the research process. The purpose of an ecosystemic enquiry is not to obtain objectivity, but to be reflective, to examine personal feelings, values, expectations, desires and perceptions (Anderson & Goolishian, 1988; Dallos & Draper, 2000). In this letter I offer you a glimpse behind-the-scenes of this research and offer some insight into my personal aspirations, emotions and experiences. It is an observation of my observations.

Keeney and Sprenkle (1982) believe that a researcher should speak of her work in terms of "a journey or pilgrimage" (p. 2) in which concern with her own growth is included. Like many pilgrims, the journey travelled over the last three years has traversed many pinnacles and laboured through many troughs. My relationship with this research problem began in the middle of 2006 when, as an aspiring psychology masters student, I was required to submit a research proposal as part of the selection process for that degree. The plight of young children in South Africa has been close to my heart for many years. My initial involvement with research concerning very young children was as an anthropology student in 1988, and as CHHs are an area of increasing concern, I decided to focus my attention in that direction. As I have always been an ethnographer at heart, I was motivated to work with a culture or community other than my own. I am a thirty-something-year-old white woman who has lived her life behind the protective walls of suburbia.

While I had this compelling desire to work in this field, I first had to address my fear of voyaging into the townships around Gauteng, which are perceived by many as being dangerous. This was

important because, as Maturana emphasised, the individual structure of the researcher and participants, which includes their emotional equilibrium and state of health during the conversation, influences how they conceptualise or make sense of their conversations (Fourie, 1988). It impacts on how they couple with each other. Had I been unsettled during the interviews it could have impacted on the fluency of conversations and my ability to establish rapport with the participants, ultimately impacting on the quality of information gathered. Anderson and Goolishian (1988) suggest that the researcher engages in a dialogical conversation with herself and be willing to set aside her prejudices. Although this leaves her vulnerable to having her prejudices exposed, challenged and changed, it should also be seen as an opportunity to spark curiosity and explore alternative meanings. I decided in favour of challenging my pre-judgments and exposing myself to this opportunity. I alleviated my fears by interacting with other white women who work in these communities and also took a companion on my initial visits to enhance my sense of security and help me navigate. Even so we got lost on entering both communities, allowing me to experience the kindness and humanity in a context that I had previously feared. Retrospectively, the opportunity to work in the townships was probably the most liberating experience for me. A wall was broken down between my world and an unknown that I always felt curious about but was afraid to enter. A mental shackle was removed and I now find myself encouraging colleagues, family and friends to face their fears and become more active in these communities.

An ecosystemic approach argues that what we observe and the distinctions that we make are based on our own frame of reference (Becvar & Becvar, 2006). In observing we draw distinctions and in order to describe what we observe we draw further distinctions and thus "one's epistemological slip is always showing" (Keeney, 1983, p. 22). Although an attempt was made to co-construct meaning, the distinctions made in this research nonetheless reflect my epistemological stance. Hence, this research represents a description of what I observed and, although I collaborated with other parties, ultimately I decided what was to be included or excluded in this document. While cues were taken from the participants during the interviews, my semi-structured interview schedule, based on what I thought was important to cover, undoubtedly influenced the direction that the interview took. The choice of research topic, my motivation for which is mentioned above, as well as the choices I made concerning paradigm and research method are in themselves self-referential. I chose a theoretical paradigm and research methodology that aligned with my worldview. I like to think of myself as a person who sees the world in shades of grey as opposed to black and white and thus the ecosystemic approach and a qualitative methodology resonated with me. Being allowed to explore and elaborate in a 'yes, but what about' way, as opposed to searching for cause-and-effect, in the

most part made me feel invigorated. I would have felt stifled had I adopted a quantitative methodology. The content of this dissertation could have been wholly different had I approached the research from an alternative theoretical perspective or methodology. Fourie (1998) explains that the ecologies of ideas may be entirely different although the presenting problem may be alike.

Dallos and Draper (2000) point out that what we hear in a particular communiqué is influenced by what we expect to hear. Similarly, Whitehead (cited in Keeney, 1983) elaborates: "The trouble is not with what the author does say, but what he does not say. Also it is not with what he knows he has assumed, but with what he has unconsciously assumed. We do not doubt the author's honesty. It is his perspicacity which we are criticising" (p. 22). Thus, it is important to acknowledge my expectations on commencing this research. Anderson and Goolishian (1988) stress the importance of the researcher's awareness of her own map so as to avoid steering the conversation toward her prejudged ideas but rather facilitate the elaboration of multiple realities about the topic. Prior to commencing this research I had a very negative picture of the orphan situation and did not expect to hear uplifting stories. I had assumed that the aid, both economic and psychosocial, that they were receiving was far less than was the case. While I still believe that the situation is very bleak, as the research progressed I realised that there was an admirable side to this problem in terms of the work that NGOs and individual caregivers were performing and that many children living in CHHs were not totally destitute. I was surprised by stories of remarkable resilience shown by some orphaned children and impressed to learn of some of their strengths in terms of, for example, their organisational and empathic abilities, which some reported to exceed those of children living in AHHs. I had a very negative view on government's contribution to HIV/AIDS and experienced some dissonance on hearing the Nellmapius participants' praise of government's efforts. I had to remind myself of the importance of acquiring the ability to contemplate multiple views, as purported by Anderson and Goolishian (1988), so that no one idea would dominate thinking, leaving all views tentative and thus open to negotiation and change. I hope that I have adequately been able to communicate the more optimistic elements that emerged in this research.

Because the interviews were conducted in a second language for all the participants, I felt more vulnerable to interpreting what they were saying according to my map. Anderson and Goolishian (1988) warn against approaching research with an "overarching map of psychological and social theory regarding human nature and…difficulties, a map on which to fit the…data" (p. 384). I had to be cautious to not try to assist them when they were battling to express themselves. If I had assisted I would have run the risk of stating or interpreting the subject matter according to my frame of

reference and thus misrepresenting what they actually wanted to say. It was essential that the participants' words be used. Similarly, because of the poor English of some of the participants I was susceptible to misinterpreting some statements. In approaching this research, I was guided by the philosophy that the only way in which a researcher can familiarise herself with a system is to interact with it in a spirit of mutuality, respect and modesty (Anderson & Goolishian, 1988; Keeney, 1979). Thus, it was important to me that the participants' views were not misrepresented. I believe the follow-up sessions where participants were provided the opportunity to confirm the content of my preliminary analysis were essential in ensuring that their opinions were actually relayed.

The emotional aspect of this journey has been incredibly tough for me. I anticipated it would be a poignant topic to work with but I was not prepared for the intensity of emotion that I would experience. My feelings oscillated from being impressed by the extraordinary work that NGOs and their caregivers perform in their communities to a deep sense of sadness and despair about the overall position of orphaned children. At times I felt confident, especially in Nellmapius, that there was some containment of the situation and that there were positive influences in these children's lives. I am in awe of the phenomenal women who participated in this research. Their philanthropic natures forced me to constantly reflect on my own life and I could not help but compare how much more they were doing than me despite how much less they had both materially and in terms of support. One participant was a single mother with tremendous responsibilities and yet still showed the capacity to love altruistically. I am grateful to them for sharing their experiences with me and each of them has become a role model. I was constantly unsettled by the introspection that this research required of me. At times I felt a sense of urgency to participate in work in this field as well as frustration that I was not interacting with the children directly. At other times I felt relieved that I had my by suburban wall to hide behind. I have come to understand that to be involved in this type of work one must have a real long term commitment otherwise one runs the risk of becoming yet another member on an orphaned child's list of losses.

Interacting with the stories told by participants and case studies relayed in other research, was profoundly unsettling for me. On occasion I found myself resisting working with the material and realised it was not because of the fatigue experienced in completing a dissertation but because I felt traumatised by these experiences and hopeless. At times I had to acknowledge the distress, helplessness and anger I was experiencing and allow myself to cry before I could continue writing this document. I was horrified by stories of, for example, a child unknowingly trying to feed her dead mother, visualising a 12-year-old boy nursing his dying mother and aunt through the terminal stages

of their disease and a 13-year-old orphan girl being taken advantage of sexually by a district politician, with the tacit consent of her family, as was the case in Yamba's (2005) narrative of Loveness. As a mother of two young girls, a 10- and an 8-year-old, the reality of young orphaned children was probably made more real to me. I could not help but place my children in the situation of orphaned children in townships and informal settlements wondering how they would cope yet knowing full well that they would not. Through my own children, I believe I could experience more compassion toward orphaned children and experience greater empathy for them. This of course left me vulnerable to exaggerating the plight of orphaned children. Yamba (2005) reported being "torn between the demands of academic disinterest and…moral involvement" (p. 207) and I could relate to this comment. While writing this document, at times I felt I had to refrain from the temptation of vociferously promoting an agenda for orphaned children.

I leave this research feeling little sense of resolution. Although I appreciated that my ideas were given the scope to mushroom in this research and I feel that I have explored the research problem extensively, I cannot help but feel that I have only touched the tip of the iceberg. This truly is an ecosystemic circular problem where I feel there is no beginning and there is no end in sight. During this research I have at times felt despondent as to the impact that one individual can make in this context and then I am reminded by the words of Participant 1: "*It doesn't have to be money. You can offer your love, your support. Just be there for these children. Advise them. Do what you can.*" I also feel this is the beginning of a journey for me rather than the end. I feel motivated to answer the call of the Department of Health quoted in the justification in Chapter 1 "for all possible available structures and people to be mobilised to nurture children, who are the future of this country" (cited in Van Vuuren, 2004, p. 207).

In concluding this research, I find the words of Gilda Radner resonating with me:

> I wanted a perfect ending. Now I've learned, the hard way, that some poems don't rhyme, and some stories don't have a clear beginning, middle, and end. Life is about not knowing, having to change, taking the moment and making the best of it, without knowing what's going to happen next. Delicious Ambiguity.

Best Wishes

Kim

BRINGING IT HOME

Oh my ears and whiskers, how late it's getting.
- *Lewis Carroll, (1865/1994) Alice's Adventures in*
Wonderland (p.142)

INTRODUCTION

At the beginning of Chapter 1, the introduction to this research, I quoted from Lewis Carroll's (1865/1994) *Alice's Adventures in Wonderland*: "'Begin at the beginning,' the King said, very gravely, 'and go on till you come to the end: then stop'" (p.142). I realised early in this research that there was no beginning and there is no end in attempting to offer an ecosystemic description of the psychosocial implications for young children living in CHHs. Rather, this dissertation captures a mere moment in time, an event-shape in time-space. Meaning was created in the conversations that were held with participants. However, meaning was also created in terms of the distinctions that I made. Certain discussions or themes were punctuated at the expense of others. This chapter looks at some of the limitations of the study and humbly offers some thoughts concerning future research in this field.

EVALUATION

The theoretical orientation and other aspects of this study present with certain limitations, some of which are discussed below.

Evaluation of the Ecosystemic Approach

Briefly, higher order ecosytemic thinking is a demanding level at which to live, work and think (Ashdown, 2006). It is demanding on the creativity of the researcher as it requires constant "sensitivity to ideas and meanings verbally and/or non-verbally expressed" (Fourie, 1998, p. 64). Its critics, such as Falzer (1986), argue that this higher order perspective is not useful because it cannot be established to be a valid approach as rigorous methods are not clearly defined. The approach does not offer the (false) security of an objective truth and thus it is neither true nor false but a point

of view (Fourie, 1998). Golann (1988) argues that "constructivism and the observing-system stance have not yet led to a substantially less intrusive or hierarchical family therapy practice" (p. 56). Although he acknowledges positive contributions, he warns that the introduction of new information into a system is an act of power that may be performed openly and with tact or in a way that is deceptive or intrusive: "Power obscured eventually emerges – a therapeutic wolf clad as a second-order sheep" (Golann, 1988, p. 56). Similarly, although constructivism is considered an important starting point, some warn of the perils of taking it to the extreme where the existence of an external reality is totally denied (Meyer et al., 2003). However, Ashdown (2006) points out that, because it is informed by second-order cybernetics and constructivism, the approach is often misunderstood. The approaches' focal point is admitting to power discrepancies, assisting with mutual decision making, dividing responsibility and promoting action. O'Connor and Ammen (1997) argue that validity from an ecosytemic perspective should rather be appraised in terms of its general efficiency and its efficacy in altering the experiences of participants in a positive direction. Despite the critics, Fourie (1988) claims that the lack of definite structure can be very exciting: "There are many 'Aha!' experiences and surprises" (p. 64). The approach may be particularly valuable in a context like South Africa where most people's needs cannot be attended to on an individual level (Meyer et al., 2003). Wider solutions can be sought and different perspectives viewed alongside each other with none of them representing the 'truth'. Thus, new realities can be created "even if the process is sometimes long and exhausting" (Meyer et al., 2003, p. 495).

Generalisability

The generalisability of this data is limited for various reasons. A nonrandom sample of 4 participants was selected from two different organisations and two different communities. Firstly, the views expressed by these four ladies cannot be said to represent the larger population of caregivers. Further, this research acknowledges that, in line with the ecosystemic approach, findings are context specific. It was evident that participants' experiences were influenced by their context, both the organisation and community, in which they work. Additionally, participants were selected from NGOs, whose focus is on vulnerable children. It is possible that there are many more orphans out there who are coping and have been under-represented in this research because they do not fall under the care of a NGO. Thus, this research cannot be generalisable to all orphans or communities in South Africa. Indeed, in terms of the ecosystemic concepts of equifinality and multifinality, it is difficult to generalise about the experiences of orphans as the approach emphasises the uniqueness of each child and their context.

Not Interviewing Children Directly

Although it was not ethically possible to interview older orphans about their own and their younger siblings' experiences of living in a CHH, there are certain inherent shortcomings in relying on information supplied by adults. Research that tries to appreciate issues from the children's standpoint is limited (Donald & Clacherty, 2005). However, Snipstad et al. (2005) cite studies that assert that adults are likely to underestimate children's reactions thereby providing a skewed portrait of their circumstances. Adults believe that children worry about peer relations and personal matters whereas children report that they are concerned about more serious issues and events. Similarly, Cluver and Gardner (2007a) found that caregivers are prone to underestimate children's internalising problems whereas children are more inclined to under-report externalising problems. Snipstad et al. (2005) argue that "children have been found to be reliable informants of their inner states" and that "they should be granted the right to be listened to and to be active participants in the ongoing research and debate about how they, as children, may best be supported" (p. 184). Consequently, one needs to consider that the adults interviewed in this research may have presented a slightly distorted picture.

Orphans Versus Orphans and Vulnerable Children

Some researchers (for example, Richter & Desmond, 2008; Richter et al., 2006; Schenk et al., 2008; Sherr et al., 2008) may criticise my decision to focus solely on orphaned children in this study to the exclusion of other vulnerable children. There is a trend in the field to broaden the focus to vulnerable children generally, a group that may include orphans. Richter and Desmond (2008) cite studies that found "few differences between orphans and equally poor and disadvantaged children with living parents" (p. 1019) and point out that "it has long been known that membership of unidimensional categories does not predict children's developmental course, even with respect to seemingly robust biological and/or socioeconomic factors" (p. 1020). Further, they highlight that by focusing solely on orphans, one runs the risk of further stigmatising them, leaving them vulnerable to victimisation, as they are singled out for assistance (Richter & Desmond, 2008; Richter et al., 2006; Sherr et al., 2008). On the other side of the coin some research, much of which has been cited in earlier chapters, has found differences between the responses of orphaned and non-orphaned children as well as orphans living in AHHs and CHHs. Earls et al. (2008) state: "Increasingly sophisticated studies support earlier findings that social and psychological functioning, educational achievements and economic well-being of children who lose parents to AIDS are worse than that of other children"

(295). Nyamukapa et al. (2008) found that orphans experienced more psychosocial distress than non-orphans. Cluver and Gardner (2007b) advocate: "We need to distinguish which factors are specific to HIV/AIDS orphanhood, or to poverty more generally" (p. 324). Cluver et al. (2007) report "the need for a much larger study of psychological well-being of AIDS-orphaned children, compared both to children orphaned by non-AIDS causes, and to non-orphans" (p. 756).

Based on the limited scope of this research project, and taking the previous limitation regarding generalisability into account, I felt that to interview 4 participants on the experiences of OVC generally or even orphans only, would produce vague information and thus jeopardise the usefulness of this study. This, as well as the evident lack of research on the experiences of very young children in CHHs, reinforced my decision to focus on a more specific population. Further, as I concentrated on caregivers in NGOs, I did not compromise any orphaned children directly, thereby avoiding ethical infringements.

Participants Presenting a Favourable Picture

As a manager was used as a gatekeeper to participants at Heartbeat, participants may have been tempted to depict their experiences in a more positive light. Even though confidentiality was ensured, the small number of participants made total anonymity difficult. Similarly, as participants were aware that their organisations would be mentioned in the research, they may have presented their organisation and the work they perform in a more favourable manner.

SUGGESTIONS

I believe that to propose a set of recommendations and conclusions in this research would elevate me to a position of power, to that of the detached expert or knower, who has access to an absolute truth. This would go against what a second-order ecosytemic approach requires of me. The purpose of this research was to be descriptive and not prescriptive. This research does not claim to have objective meaning. It acknowledges that the descriptions are context specific and thus specific recommendations may not be relevant across situations. Thus, I choose to humbly offer some broad suggestions for future research.

I agree with the comments of Cluver and Gardner (2007b) and Cluver et al. (2007) quoted above, which highlight a need for research, both qualitative and quantitative, that compares "AIDS-affected

subgroups" (Cluver & Gardner, 2007b, p. 323). I also believe that more research needs to be conducted specifically around CHHs, especially as they are being considered as a model of care for children. Research is quick to point out the negative effects of, for example, the institutionalisation of children but no research could be found comparing the developmental impacts of being raised in an institution and in a CHH. How do we really know whether or not children are better off in a CHH than in residential care? Further, research needs to focus on specific age groups or developmental levels. As pointed out previously, the term children is often used to encompass children from birth to 18 years of age, which is misleading. Children of different developmental levels have different needs and thus any interventions offered need to be age-appropriate. This research has highlighted the invisibility of very young children and thus I propose that further attention be focused on this age group. Finally, the remarkable resilience shown by children has also been emphasised in this and other research. Some children are coping admirably and thus may be able to teach us how to help other children cope or adapt in these adverse circumstances. Research should review the adaptive strategies adopted by those children in CHHs who are succeeding and establish how these traits can be developed in those children that may not be coping as well.

Prior to concluding, I believe that it is important that the findings of any community research should ultimately aim to provide feedback to that community as well as to agencies that may be able to impact the community positively. Yamba (2005) offers the following statement with which I agree: "The researcher who conducts research on children without becoming an advocate for them embarks on a course that makes research futile" (p. 209). Consequently, it is essential that the findings of our research do not sit on the shelves of libraries but find their way to the appropriate agencies to advise on programming content as well as to challenge policies, laws and governance practices.

CONCLUSION

The aim of this research was not to solve or prove anything. Rather, working from a position of not knowing, an ecology of ideas was allowed to evolve. An extensive psychosocial description of the issues surrounding young children living in CHHs was offered. An ecosytemic framework was adopted to guide the research, which ultimately impacted on the questions that were asked and the description of the findings. The research was conducted in the qualitative tradition where participants were interviewed in a semi-structured format. The conversations were then subjected to an interpretive analysis where, in collaboration with the participants, central themes were identified and

discussed in detail. As part of this interpretive analysis and in line with an ecosystemic epistemology, a reflection of my personal experiences while conducting the research was presented. Finally, an evaluation of the research and some suggestions for future research were put forward in this chapter.

In concluding, I leave the reader with the words of Participant 2:

And I say that there's something that we missing...We should go back to when we still had Apartheid, how the ANC formed street committees and people could actually be able to know what the enemy was doing...We face a greater enemy here. All societies should actually be looking into what is it that we can do to protect this child. Because if we don't as society... I think we have the answers in each and every community. But the thing is, I don't know what it is about HIV and AIDS that make people so scared...of coming together and saying "You know what, we can." And the thing is it is a silent enemy, not like Apartheid that we saw.

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APPENDIX A: INTERVIEW GUIDE

o What are your roles and responsibilities in relation to the children?

o What are your general impressions on the impact that living in a child-headed home has on a child in the 2- to 5-year-old age range?

o How does a child in the 2- to 5-year-old age range living in a child-headed home differ from other children raised in the community?

o What are the psychological and social needs of these children?

o What are the unique psychological and social challenges that children in the 2- to 5-year-old age range face as a result of living in a child-headed home?

o How did these young children come to live in a child-headed home as opposed to, for example, living with relatives, foster care, etc?

o Describe how the households generally operate, e.g., what are the various roles and who fulfils them? What usually happens to the 2- to 5-year-olds in this set up?

o What roles does the extended family fulfil in assisting these children? What more, if anything, do you think the extended family could do to assist the children?

o What roles do schools fulfil in assisting these children? What more, if anything, do you think schools could do?

o What roles does the community fulfil with young children living in child-headed homes? What more, if anything, do you think the community should be doing?

o What roles does the government fulfil with young children in child-headed homes? What more, if anything, do you think the government should be doing?

o Is there anything else that we have not discussed that you think is important to mention about 2- to 5-year-old children living in child-headed homes?

APPENDIX B: INFORMED CONSENT

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Department of Psychology
23 February 2009.

Dear Sir / Madam,

RE: Informed Consent

Research title:	A psychosocial description of young orphans living in child-headed homes
Principal researcher:	Kim Korevaar
Department:	Department of Psychology, University of Pretoria
Telephone number:	0829003163

We appreciate your willingness to be interviewed for this research project. The researcher will contact you to arrange a time

for the interview to take place.

- Your involvement in this study is voluntary, you are not obliged to divulge information that you would prefer to remain private, and you may withdraw from the study at any time.
- The researcher will treat the information you provide as confidential. You will not be identified in any document, including the interview transcripts and the research report, by your surname, first name, or by any information. You will be referred to in the documents under a code name. No one, other than the project team, will be informed that you participated in this research.
- The interviews will be tape-recorded but will only be referred to by the principal researcher and her supervisor.
- The names of any children that you discuss in the course of the interviews will not be identified in any document, including the interview transcripts and the research report. The children may be referred to in the documents under a code name.
- The research findings will be made available to you should you request them.
- The data will be securely stored for 15 years for archiving and possible further research purposes.
- Should you have any queries about the research, now or in the future, you are welcome to contact the researcher on the above contact number.
- We appreciate your willingness to be involved in this research project.

I understand the contents of this document and agree to participate in this research.

_____   _____

Signature   Date

_____

Name

11th Floor, Room 11 – 14, Lynnwood Road, Pretoria, 0002 | Republic of South Africa
Telephone: +27 12 420 2329 | Facsimile: +27 12 420 3479
Website: www.up.ac.za

APPENDIX C: PARTICIPANT CONSENT FOR DISCLOSURE OF IDENTITY

IKAGENG ITIRELENG
A I D S   M I N I S T R Y

Physical Address:
8299 Cnr. Sisulu/Mahalefele Road,
Department of Social Services (Peoples
Centre),
Orlando West
P.O. Dube / P.O. Box 218,
Soweto. Johannesburg, South Africa.
1800

Attention: Kim Korevaar
Fax:
                    0114470229
Date:
                    23 March 2009.

Dear Kim

PERMISSION TO REVEAL IDENTITY IN RESEARCH

I hereby grant you permission to reveal my identity in the research that you are conducting as part of your Masters degree in Counseling Psychology. You may reveal my name, company and my position within the company in your dissertation.

Regards,
Carol Dyantyi

Founder and Project Director
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