The experiences of children carrying responsibility for child-headed households as a result of parental death due to HIV/AIDS

by

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Summary

Much has been written in the media about the plight of children in child-headed households. However, little is known about the psychological experiences of children carrying responsibility for households as a result of parental death due to HIV/AIDS. Most of the research that has been done has utilised quantitative approaches to investigate the social and economic challenges confronted by children affected by HIV/AIDS.

The aim of the present study was to explore, using a qualitative approach, the challenges, psychological experiences and perceptions of children carrying responsibility for child-headed households as a result of parental death due to HIV/AIDS. A total of fourteen semi-structured interviews were conducted with children carrying responsibility for households in Gauteng and Kwa Zulu Natal provinces of South Africa. The Interpretative Phenomenological Analysis (IPA) approach was used to guide the data analysis process (Smith & Osborn, 2003).

The findings from the study highlight the devastating consequences of living and coping with parental illness, bereavement as well as carrying the responsibility for a household. Illness and bereavement-related themes that emerged from the study include reversal of roles, living with parental illness, denial and fear of the impending reality, grief and sense of loss, and the apportioning of blame.

The dominant post-bereavement experiences were: lost childhood and self; sense of obligation to family, abandonment and neglect; concern over basic survival needs, grappling with conflicting demands, and feelings of helplessness, vulnerability and uncertainty. Significantly, the study found that experiences in the community as well as personal dispositional factors both mediated and aggravated psychological adjustment. Although the children interviewed in this study are faced with very difficult challenges they, nevertheless, appear to be quite resilient. The study highlights the importance of providing care and support to these children before, during and after the death of a parent or parents. Implications and limitations of the study are also critically discussed.

Key words: HIV/AIDS; illness; grief; child-headed; psychosocial consequences; social support; adjustment; resilience

Chapter One: Introduction

> "It has been said a day is coming when the progress of nations will not be judged by their economic power or military prowess, or by the splendour of their capital cities and public buildings. Instead, the measure of a nation's humanity, and the strength of its civilisation, will be based upon the provision it made for its vulnerable and disadvantaged people and the protection it afforded to the growing minds and bodies of its children" (Tutu in Foster, Levine & Williamson, 2005, p. vii)

1.1 Background

HIV/AIDS is without a doubt the most widely discussed and pressing public health challenge internationally. This attention is certainly justified, considering the multifaceted and pervasive effects of this pandemic. Some health experts are already saying that HIV/AIDS is transforming the world as we used to know it. Preventing and managing the spread of the virus has been the source of many debates, with calls being made for interventions informed by multiple perspectives. Although the virus has left no country untouched or unscathed, the advent of HIV/AIDS has been most unrelenting and severe in sub-Saharan Africa.

Ever since its formal recognition in 1981, AIDS has been responsible for the deaths of more than 25 million people worldwide (UNAIDS, 2006). UNAIDS (2006) also estimates that 38.6 million people globally are living with HIV/AIDS. Three quarters of these cases are located in sub-Saharan Africa. In this region alone, there were roughly two million AIDS-related deaths in 2005 (UNAIDS, 2006).

South Africa has the fastest growing rate of the HIV/AIDS epidemic in the world (UNAIDS, 2006). By the end of 2005, approximately 18.8% of adult South Africans between the ages of 15 to 49 years old were living with HIV (UNAIDS, 2006). An increasing mortality rate in the 15 to 49 year old age group is recognised as fuelling the orphan crisis world-wide.

To date, 12.3 million children have lost a parent to HIV/AIDS in sub-Saharan Africa, (UNICEF, 2004). This figure is projected to increase to 20 million by 2010. Sub-Saharan

Africa has the highest proportion of children orphaned by HIV/AIDS in the world (UNICEF, 2004).

The Southern African region is the hardest hit, with future predictions painting what some consider to be 'alarmist' scenarios. Unless life-prolonging treatment is made widely available, between 60 - 85% of all children in Southern Africa younger than 18 years are expected to be orphaned as a result of HIV/AIDS by 2010 (Ghosh & Kalipeni, 2004).

South Africa is facing an escalation in the number of children made vulnerable or orphaned by the pandemic (Bradshaw, Johnson, Schneider, Bourne & Dorrington, 2002). More than 800 000 children under the age of 18 years have lost a mother, in the majority of cases, to HIV and AIDS (Bradshaw et al., 2002).

The problem of an increasing orphan population as a result of HIV/AIDS is fast gaining public and academic attention both locally and internationally. One of the other considerations for extending anti-retroviral treatment to everyone in need in the South African context is the possibility of prolonging lives, thus curtailing the number of children orphaned and compromised by the pandemic.

A considerable amount of research in the area of HIV/AIDS has been conducted and much has been written and televised on the plight of children in child-headed households. It appears as if in the eyes of the public, these groups of children best symbolise the devastation and destruction wrought by HIV/AIDS on families. However, despite all the attention and focus on child-headed households, there is a conspicuous absence of qualitative studies on the subject. In particular, little attention has been paid to the experiences of South African children carrying responsibility for households as a result of parental death due to HIV/AIDS.

There are a number of indications that the extended family will in future be unable to continue absorbing orphaned and vulnerable children (Foster, Makufa, Drew & Kralovec, 1997a; Nyamukapa & Gregson, 2005). Traditional family and community structures are disintegrating as families are forced to restructure. This trend has no precedent. In addition, many of these structures are reaching absorptive levels, with their capacity to cope having been exhausted by the extent of the pandemic (Foster et al., 1997a). The vexing question as to what will become of the children that cannot be accommodated by existing traditional coping mechanisms, requires practical and realistic solutions.

Foster (2000) identifies the following reasons for the appearance of child-headed households:

- increasing HIV/AIDS-related parental bereavement;
- relatives being unwilling or unable to accommodate additional children in their households due to economic constraints;
- the death or illness of a relative, for a example, an elderly caregiver, who had previously taken charge of the children concerned;
- the lack of contact and the distance between the relatives and the remaining children;
- the presence of older children willing and able to provide care to younger siblings; and
- possibly related to the previous point, the surviving children inheriting the family home.

Children also become heads of households when siblings are unwilling to move in with relatives or foster parents, and in the process risk separation (UNICEF, 2004).

Despite what is currently known about the factors that result in children assuming the burden of responsibility for households, little information is known about the scale and magnitude of these households in countries with high HIV prevalence rates, such as South Africa (Gow, Desmond & Ewing, 2002).

In South Africa, the Nelson Mandela/Human Sciences Research Council (HSRC) study on HIV/AIDS found that 3% of children aged 12 to 18 years were heads of households (Brookes, Shisana & Richter, 2004). This percentage was, however, revised at a later stage because not all households have children in this age group. Furthermore, some of the children interviewed stemmed from the same households. Correction of the above factors resulted in the 3% being reduced to 1.5%.

However, the questions remain: What do these figures mean to those concerned? What kind of lives are children in child-headed households exposed to? How do children in these situations go about living their daily lives? More specifically, what is it like being a child responsible for such a household?

In my view, the best way to address these questions is not by reverting to percentages and numbers but rather through an in-depth and qualitative exploration of the lives of these children through their own perspectives.

1.2 Motivation for the study

A review of existing literature reveals that children orphaned and rendered vulnerable by HIV/AIDS exhibit high levels of depression, emotional distress and conduct problems (Sengendo & Nambi, 1997; Malinga, 2002; Rotheram-Borus, Weiss, Alber & Lester, 2005). These psychosocial adjustment difficulties appear to be higher for children orphaned by HIV/AIDS compared to children orphaned by other causes or children whose parents are still alive (Sengendo & Nambi, 1997). Makame, Ani and MacGregor (2002) compared the psychological wellbeing of 41 orphans to that of 41 matched non-orphans. Compared to the non-orphans, the orphans revealed higher internalising problems, which included emotions of anger, resentment, hopelessness and depression.

In a study conducted in New York, parents/guardians reported increased conduct problems (e.g. truancy), among youths in their care affected by HIV/AIDS (Hudis, 1995). The death of a parent may even lead to reduced self-esteem and self-confidence (Rotheram-Borus et al., 2005).

In many developing countries ravaged by HIV/AIDS, orphaned children and adolescents also have to contend with familial, economic and social difficulties (Foster & Williamson, 2000; Malinga, 2002). Some of these challenges may include HIV-related stigma, social ostracism, and the availability of resources (monetary or otherwise), as well as lack of social support (Hunter, 1990). In addition, these orphans also face the possibility of their education being disrupted (Ankrah, 1993; Foster, 2000).

In the next chapter, the issues highlighted in the preceding paragraph are discussed in detail. At this stage it is, however, sufficient to point out that most of the studies cited above were aimed at finding general patterns, and they have what is generally called a nomothetic focus (i.e. they pay attention to the general dimensions on which persons vary) (Ashworth, 2003).

As such, these studies do not provide in-depth insight into how these children perceive and make sense of their experiences.

An important point that is often overlooked is that children orphaned and rendered vulnerable by HIV/AIDS are not homogenous. The experiences of children affected by HIV/AIDS may differ as a function of age, socio-economic background and, especially, by the type and nature of post-parental death placement and care. There is thus a need for studies focusing on specific sub-groups within the wider group.

A growing body of studies has sought to determine the experiences of orphans being looked after by different caregivers. A substantial body of literature is available on the effect of terminal illness on children (Siegel et al., 1992), children and grief (Catalan, 1995; Sherr, 1995) as well as the effect of parental death on children of different age groups (Zayas & Romano, 1994). However, most of these studies were conducted in developed countries.

There is a dearth of literature in which an interpretative approach is employed. To the best of the author's knowledge, there is also an absence of idiographic studies in this area. Although there may be a number of similarities in the experiences of children that have lost or face the prospect of loosing a parent in general, it is suggested that HIV/AIDS has a heightened impact on children. The associated stigma may lead to unique challenges and responses in affected children (Ruland et al., 2005). Understandably, some authors have protested (e.g. Foster, 2006) against distinguishing between 'AIDS orphans' and other vulnerable children in resource constrained communities. These views are motivated by a need to reduce stigma directed at children affected by HIV/AIDS. Singling out this group of children could result in further stigmatisation.

There is, however, a need to focus on, in particular, the special effects among those groups in communities devastated by HIV/AIDS. From a socio-economic point of view, there may be no differences between children from child-headed households and other children from the same communities where the general poverty levels are exceedingly high. Yet, having to nurse and care for a parent debilitated by the complications of HIV/AIDS as well as siblings before and after the death of a parent could have serious psychological consequences. It is in this context that a study focusing on children responsible for a household as a result of parental death due to HIV/AIDS was conceptualised.

Freeman (2004) identifies five categories in which people left behind following AIDS-related deaths feature. HIV/AIDS is likely to affect these individuals' mental health in a destructive manner. While some research has been conducted on the mental health/HIV interface, especially in developed countries, the mental health impact of HIV/AIDS in countries with high HIV prevalence rates remains largely unknown. More research on the relationship between HIV and mental health, and particularly on mental health and the wellbeing of children affected by AIDS-related illnesses and death is thus needed (Freeman, 2004).

Literature on child-headed households is minimal, while literature on the psychological impact of this phenomenon is almost non-existent. Although the psychosocial effects of HIV/AIDS on children have been researched extensively in the developed world, studies emanating from the developing world are limited (Foster, 2002).

Furthermore, a review of the relevant literature suggests that a substantial amount of research on the subject pays more attention to the socio-economic effects of HIV/AIDS on children, which consequently shadows the psychosocial impacts (Fox, 2001; Foster, 2002). Although the psychosocial effects are often less visible than the economic (or even health consequences), they are nonetheless just as important (Ebersohn & Eloff, 2002). According to Foster (2002), it is understandable that the former appear to need more urgent attention than the latter, as the former are easier to identify, while the psychosocial consequences are harder to recognise. For example, a Ugandan study found that HIV positive parents' concern for their children's future was mostly geared towards economic prospects as opposed to psychological wellbeing. Approximately, only 10% of HIV positive parents expressed concern for their children's psychological and emotional welfare (Gilborn, Nyonyintono, Kabumbuli & Jagwe-Wadda, 2001).

1.3 Aim and objectives of the study

The present study aims to explore, describe and analyse the experiences of children carrying responsibility for households as a result of parental death due to HIV/AIDS. The study has three main objectives:

- examining the major challenges confronted by South African children in this situation as well as how they deal with/find solutions to the challenges;
- ascertaining the psychosocial needs of South African children carrying the responsibility for child-headed households and the extent to which these needs are met within the context in which they live; and
- examining the nature of the children's perceptions of their situation and the extent to which these perceptions influence the decisions they make with regards to their fears and aspirations.

In most studies on children from child-headed households affected by HIV/AIDS, the emphasis is all too often on the effects after the parent's death. However, evidence suggest that the most damaging impacts occur before the death of a parent or parents (Gilborn et al., 2001). Other related studies on the effects prior to bereavement are explored in detail in Chapter 2. It is, however, important to note that children would already have experienced the devastating effects of illness and death of a parent from HIV and AIDS before being forced to assume the responsibility for the household.

The above objectives are explored in terms of pre - and post-parental death experiences and adjustment. Due to the exploratory nature of the study, it was impossible to determine the nature of the expected results. It was thus deemed inappropriate to formulate any specific hypothesis or adopt any particular theoretical perspective to inform the study. To ensure the validity of any theory, the theory has to be qualitatively grounded (Strauss & Corbin, 1990). The investigation of 'insider' views thus becomes important for the formulation and development of a theory.

1.4 Definition of terms

1.4.1 Child-headed household

Before providing a definition of a child-headed household, it is crucial that the meaning of a child is conceptualised and contextualised both legally and socially. Various definitions of the concept are available in different countries and communities (Skinner et al., 2004). Section 28 (1) of the South African Constitution (1996) defines a child as any person under the age of 18. A child becomes a major upon reaching the age of 18 years. In line with the constitutional definition, **a child-headed household can thus be defined as any household where a child up to or under the age of 18 is called upon to carry care-giving responsibilities** (Sloth-Nielsen, 2004).

According to Skinner et al. (2004), childhood may be extended for various reasons, for instance, the period of dependency. Skinner et al. (2004) also argue that in African communities, a person may remain a child beyond the legally defined timeframe. Anecdotal information in the media suggests that in a number of community settings in South Africa, even youngsters not much older than 18 are also regarded as child-heads. Consequently, any attempt to define a child-headed household will have to incorporate both the legal as well as contextual definition. For the purposes of this research, the age of 18 largely informed the recruitment of research interviewees. The researcher did, however, accommodate community or situational understandings and definitions of a child or children. This allowed for children slightly over the age of 18 years to be included in the study.

It is useful to note that some of the existing literature refers to child-headed households as youth-headed households (Horizons, 2005). Unlike child-headed households, the term youth-headed households allows for the inclusion of youngsters over the age of 18. For the purpose of the current study, the author has, however, chosen to incorporate only the later concept, i.e. child-headed households. A child-headed household, as opposed to a youth-headed household, is a more common term and most people, including both the general public as well as the researchers, are more familiar with this concept.

1.4.2 Orphan

As in the case of the definition of a child, the definitions for the term ‘orphan’ vary from country to country and from one community to another (Skinner et al., 2004). In most instances, the difference is related to the specific emphasis. For example, in Namibia an orphan is any child under 18 years that has lost a mother, a father, or both as a result of death (Smart, 2003). The definition also includes a child in need of care. In Ethiopia, the definition relates to any child under 18 who has lost both parents, irrespective of how the parents died. The definition of an orphan in Botswana includes children that have lost a single parent or both parents where the biological or adoptive parents are married (Smart, 2003).

Other definitions are influenced by cultural modes of understanding. For example, among the Shona-peaking group in Zimbabwe, isolated child-headed households and children residing in city streets are regarded as orphans because their needs may often not be met (Roalkvam, 2005). According to this definition, a child or children cannot be labelled as orphans for as long as their needs are met, regardless of whether their parents are alive, ill, dying or deceased.

In South Africa, **an orphan is defined as a child that has no surviving parent caring for him or her after one of the parents has died** (Draft Children's Bill, 2002). In most countries, children that have either lost one or both parents are generally recognised as orphans. The definition as outlined in section 28 (1) of the South African Constitution (1996) will, however, be used for this research.

1.4.3 Child affected by HIV/AIDS

The South African Draft Children's Bill of 2002 defines a child affected by HIV/AIDS as:

- part of a household in which a member suffers from the complications of HIV/AIDS;
- abandoned or orphaned as a result of HIV/AIDS; or
- him/herself HIV positive or ill because of HIV/AIDS.

Some children fall into more than one of the aforementioned categories. For example, a child can be both part of a household where a member is infected with HIV while suffering from the infection him/herself.

This research will employ the term 'child or children affected by HIV/AIDS' to encapsulate the various ways in which children may be affected by the HIV/AIDS pandemic.

1.4.4 Grief

Grief is the emotional reaction resulting from longing for someone or something that is no longer there (Sherr, 1995). The term, however, is often used in connection with the death of a person. In the literature, grief is usually described in terms of stages or phases. For example, Bowlby (1980) defines grief in terms of the following phases: numbness; yearning and anger; disorganisation and despair; and reorganisation.

It is widely recognised that children do not experience these phases in the same way as adults do (Sherr, 1995). In the case of adolescents, emotions predominant during this developmental stage are intensified by the loss of a parent (Ruland et al., 2005).

In a general sense, the term grief refers to "the dysphoric feeling or affective response to the death of a loved one" (Clark, Pynoos & Goebel, 1994, p.101). This definition will also be used for the purposes of this research.

1.4.5 Mourning

According to Kubler-Ross (1969), mourning comprises the following stages: denial and isolation; anger; bargaining; depression; and acceptance. These stages are, however, not inevitable or rigid in their occurrence. In broad terms, mourning "describes the internal process of adaptation to death that culminates in an appropriate or maladaptive adjustment. Mourning also includes social rituals and other expressions of grief" (Clark et al., 1994, p.101).

Sherr (1995) cautions that even though the phases and stages expounded by the various theorists in the literature on both grief and mourning are helpful and useful in describing the emotions and experiences common for people going through these processes, they can never capture the nuances of each individual experience.

1.4.6 Bereavement

Bereavement is thought to be "… an umbrella term encompassing both the feelings of grief and the process of mourning – it represents the social process of coping with an emotional response due to death" (Clark et al., 1994, p.101).

Due to the meaning and stigma attached, a certain amount of doubt exists as to the applicability of the definitions, stages and processes discussed in the literature on grief, mourning and bereavement in the HIV/AIDS scenario (Sherr, 1995). For the purposes of the present study, these definitions are, however, sufficient.

1.5 Conclusion

At present, the issue of child-headed households is receiving increasing attention. The plight of children in child-headed households presents difficult and vexing questions that require practical and realistic solutions. In the next chapter, the author examines the literature on children affected by HIV/AIDS.

Chapter Two: Literature Review

2.1 Introduction

This chapter reviews the literature on the experiences of children orphaned and rendered vulnerable by HIV/AIDS, including children in child-headed families. This review provides a broader context within which findings regarding the experiences of children responsible for households as a result of parental death due to HIV/AIDS can be presented and discussed. These children would also have experienced the illness of a parent or parents as a result of HIV and AIDS in the process of becoming responsible for households. In most instances where children have become heads of households, the process would have begun while the parent or parents were still alive. As the illness from HIV/AIDS takes its toll on the parent or parents, the older child will, in most instances, begin assuming parental responsibilities around the house even before the death of a parent or parents. It is consequently also necessary to review the literature on children who have been through such an experience.

It should be kept in mind that children responsible for households are also orphans and may therefore share many similar psychosocial effects as other orphaned children, particularly children orphaned by HIV and AIDS. It is thus also necessary to include literature on orphaned children who are not necessarily heads of households in this review.

According to the WHO/UNICEF (1995), children affected by HIV and AIDS experience problems in the following six main areas: subsistence; health; psychosocial wellbeing; shelter; education and training; and inheritance. Although these problem areas were expounded on more than a decade ago, they remain relevant to this day. Although this chapter explorers these problem areas, special attention is given to the psychosocial ramifications of being an orphan.

In terms of the review structure itself, the author starts out by scrutinising the implications of HIV/AIDS-related parental illness and impending death on children, followed by the effects of HIV/AIDS-related parental bereavement on children and the youth. The author continues by exploring post-bereavement experiences, focussing specifically on children in child-headed households. The protective and coping strategies for children in child-headed households and other children living in adverse circumstances are also reviewed.

Since most child-heads are adolescents, the chapter also discusses the developmental implications of AIDS-related bereavement for adolescents. The last section provides an integrated and synthesised overview of the issues that emerged in the chapter and the implications for children carrying the responsibility for households.

It is important to point out that where possible and appropriate, quotations from the studies reviewed are incorporated to enhance and enrich this review. This particular approach is consistent with the study's qualitative interpretative approach.

2.2 Grappling with parental illness and the prospects of impending death and loss

This section addresses the following questions:

- what are the experiences of children providing care to parents made ill by HIV/AIDS, who at the same time have to care for younger siblings?
- what constitutes the worlds of young people grappling with not only parental illness but also the prospect of impending death?

Before dealing with these questions it is important to discuss briefly how children find out about parental HIV sero-positive status.

Disclosing HIV status to children can be very complex and challenging. A predominantly quantitative study conducted among parents living with HIV in Belgium indicated that rates of disclosure were extremely low (Nostlinger et al., 2004). The study also found that HIV among the families included in the study was clouded in secrecy.

Due to the stigma and discrimination that so often surrounds HIV/AIDS, children are often not aware of a parent's HIV positive status. Some children, particularly the older ones, may be suspicious in the event of the onset HIV-related or AIDS-defining illnesses, based on their knowledge of the subject. Another common scenario that often transpires is that children are informed of a positive status, but discouraged from sharing the information with others outside and sometimes within the family. Younger siblings in the household may even be 'protected' from the knowledge that a parent is living with HIV/AIDS.

A study based on qualitative interviews conducted in the United States of America amongst 35 women and 19 children between the ages of 10 to 18 years indicated that a child's developmental and maturity levels, among others, play a significant role in the decision to disclose the parent's status (Vallerand, Hough, Pittiglio & Marvicsin, 2005). Unlike the younger children, older children have a higher capability of understanding the implications of a parent's illness from HIV.

Another important determinant of disclosure is the nature of the relationship between parent and child. The closer and more open the relationship, the greater the likelihood of disclosure. In this scenario, such a disclosure can result in misery for the child involved. One study found that maternal disclosure of HIV status is significantly related to a daughter's increased emotional distress (Lee, Lester & Rotheram-Borus, 2002). Disclosure can generate fear, uncertainty and behavioural changes in children (Lee et al., 2002).

Conversely, Lee et al. (2002) found that a number of positive benefits could accrue from disclosure, such as an open, honest and close relationship between infected mothers and children. The following evocative illustration from Zayas & Romano (1994) serves as an example:

> "Paula, a 17 year old, was initially required to keep her mother's HIV status a secret from her siblings and the rest of the family. Fortunately for her, however, her mother began to speak out courageously about AIDS discrimination in her community when Paula was 15 and her mother was a year into her drug recovery. Her mother's courage released Paula of her burden to keep quiet, and now she has a choice about whether or not to reveal her mother's HIV status. Now, according to her mother, they discuss the advisability of new disclosures, but the decision is entirely up to Paula. 'I'm proud of my mother', Paula says, 'and keeping the secret made me feel that I had something to be ashamed about. Not being ashamed makes us stronger as a family" (p.64)

According to Strode and Barret-Grant (2001), stigma associated with children and youth affected and infected by HIV and AIDS arises when children and youth that are HIV positive, are perceived to be HIV positive or associated with HIV/AIDS are treated negatively. This manifests when children infected and affected by HIV/AIDS are discriminated against at schools or in the community. These children may, for example, be denied access to schools as well as being shunned or called derogatory names. To date, few, if any, studies have examined the extent of stigma and discrimination against children affected by HIV and AIDS (Strode & Barret-Grant, 2001). The only available information is inconclusive and at best, anecdotal.

The relationship between disclosure and stigma is unclear. Contrary to most people's expectations, a study conducted in the United States of America found that stigma, either imagined or actual, had only a minor influence on disclosure for HIV infected women with children aged five to 18 years (Ostrom, Serovich, Lim, & Mason, 2006). This finding demonstrates that "women are interested in taking the lead role in disclosing to their children and make the decision based on the child's ability to cope with the information…on perceived child maturity and emotional stability" (p.63). It appears as if parents consider a number of factors other than stigma when making the decision to disclose their status.

Apart from the issues surrounding disclosure and stigma, HIV/AIDS-related parental illness and possible impending death has a number of other implications. Evidence suggests that the above factors may lead to a decline in socio-economic status in affected households, additional household responsibilities for the children caring for chronically ill parents/caregivers as well as psychosocial difficulties. A growing number of children in sub-Saharan Africa are forced to care for terminally ill parents, a situation that is in many instances exacerbated by conditions of dire poverty and need (Foster, 2002). Chatterji et al. (2005) found that children living with a persistently ill parent in Zambia and Rwanda perform poorly on a number of socio-economic indicators (e.g. ownership of blankets, shoes, clothes and food as well as access to healthcare and education.)

As stated previously, a number of children, in most instances, the older adolescent children, more often than not take on additional responsibilities in the household when a parent is gravely ill (Stein, Riedel & Rotheram-Borus, 1999). These responsibilities include household chores, such as cooking, washing, cleaning, feeding, bathing, toileting, administering medication and accompanying parents to treatments (Foster & Williamson, 2000). For older children in particular, these responsibilities also include caring for younger siblings, some of whom are infants and may be infected with HIV themselves (Foster, 2002). As a result, these children are cheated of their childhood, as the additional responsibilities leave very little time for developmentally appropriate activities, such as playing, forming friendships and participation in other social and recreational activities (Cree, Kay, Tisdall & Wallace, 2006).

The additional responsibilities also result in a decline in school attendance and an increased involvement in activities geared towards income-generation (Foster & Williamson, 2000). Cree et al. (2006) interviewed 28 children in Scotland with infected parents. The research indicated that a substantial number of the interviewees' learning was affected negatively as a result of their staying at home to look after sick parents or through weariness in the classroom. A number of participants, especially those who indicated that they did not want their teachers to know about their parent's HIV positive status, also reported that they felt isolated and lacked the support they needed at school.

Other aspects that exacerbated these children and young people's experiences include the focus on HIV prevention and sex education (Cree et al., 2006). The reasons cited by these children for the aforesaid include fear and concern about other children finding out that they know more about HIV because they have a parent or parents who are living with it. The children reported that the attention afforded to HIV prevention at schools inadvertently reinforces the wrong message: "only foolish people indulge in risky behaviour" (Cree et al., 2006, p.74).

The study also yielded that participants reported to feel better at school, as this environment serves as a refuge from the concerns at home (Cree et al., 2006). It would thus appear that school serves as both a source of comfort as well as consternation.

Studies on the effect of parental illness conducted in other parts of the world, for instance, sub-Saharan Africa and Asia, yielded similar findings as those illustrated by Cree et al., (2006) (Malinga 2002; Safman, 2004). The following excerpt taken from Malinga (2002) is illustrative:

> "I lost my father and stopped schooling in primary one. My mother is also sick now and I don't have hope in her. I have a sister (12) and a brother (8) - they stay with our mother. I have been working as a baby sitter (nanny), sometimes I go and wash maybe somebody's plates and clothes or digging in people's plantations. Then I give my mother some money from what I get by doing work for people" (p.6)

The above extract demonstrates how HIV/AIDS-related parental illness can result in increased involvement in activities geared at generating income. Apart from the responsible child having to work in an attempt to generate income and support the ailing parent/caregiver and younger siblings, the above quotation also highlights a number of other issues that children in this situation are faced with. Firstly, the death of a father may result in the loss of income and financial support as well as the degradation into poverty. Such circumstances may also result in the child no longer attending school and withdrawing from other developmentally appropriate activities. Secondly, more than one person in the household infected or living with HIV/AIDS leads to the protracted trauma resulting from multiple deaths. The responsible child may even be forced to bear the responsibility of caring for more than one sick person.

Due to what can be classified as cultural factors and socialisation, the burden of household responsibilities is unequivocally carried by female children (Foster & Williamson, 2000; Malinga, 2002; Marcus, 2002). Male children, on the other hand, will be expected to find work outside the home to generate income (Foster & Williamson, 2000). As illustrated by the above quotation, these gender role expectations are, however, not always fixed and immutable.

A number of studies point to various psychosocial effects resulting from this situation. A number of reasons may result in children becoming anxious and fearful during this period (Sengendo & Nambi, 1997; Malinga, 2002). This can be demonstrated by five orphaned youths participating in a focus group discussion in Uganda:

> "Interviewer: "What were your thoughts when he became very sick?
> Child one: Felt very badly, I feared.
> Child two: My thoughts were all disturbed.
> Child three: I got very frightened.

> Child four: I did not want people to come home.
> Child five: Did not know what to do. I knew he was going to die." (p.113)

Another extract taken from Malinga (2002) is used as illustration:

> "During the time of my father's sickness, I used to feel bad…I was sad during my father's sickness because sometimes when he became very ill my grandmother, uncle and aunty would begin to cry, so I cried too. Sometimes I would get a feeling of fear and even could not eat food as I saw my father get so sick. Sometimes I don't have peace of mind. I have not talked to anybody about how I feel" (p.8)

The above quotations illustrate a number of effects that children in this situation are faced with. The children demonstrate fears and anxieties as to what will happen to them and who will take care of them when the parent is no longer there, especially where there is no other surviving parent (Sengendo & Nambi, 1997; Malinga, 2002). A narrative study (Bawa Yamba, 2005), reviewed in more detail at a later stage, supports this assertion but also emphasises the finding that the older sibling, i.e. the potential child-head, is likely to be concerned with caring for and avoiding separation of siblings.

The children in the above extracts also feel helpless regarding their inability to either alleviate the suffering endured by their parent or even averting the possibility of death. These children reported crying incessantly as a result of seeing their parent suffer (Sengendo & Nambi, 1997; Malinga, 2002). The above quotations also illustrate the children's attempts to distance themselves from those around them, including friends and possibly even relatives. Although motivated by an attempt to avoid discrimination, ostracism and feelings of shame, such behaviour will only result in the children depriving themselves of much needed social support during such a difficult time.

Cree et al. (2006) found that children and young people reported feeling different from their peers that do not have a parent infected with HIV during periods of parental illness. Such feelings can be ascribed to increased responsibilities at home (e.g. increased housework, cooking, helping the parent bath, caring for younger sibling, and so on).

Studies conducted on the African continent have yielded similar results. Foster and Williamson (2000) and Malinga (2002) found that the older children, especially those that have assumed care-giving responsibility for the parent and the other children in the household, worry about surviving without an income when the parent falls ill and is bedridden. Siegel et al. (1992) found that where the parent is terminally ill, such fears and anxieties are exacerbated by experiences of loss resulting from increasing separation due to hospitalisations, physical and emotional unavailability as well as changes in family routines and emotional climate.

Comparable findings or patterns have been observed in other developed countries. Research conducted in the United States of America has shown that adolescents with HIV infected parents, particularly those with severe symptomatic illness, experience increased rates of emotional distress (Rotheram-Borus, Stein & Lin, 2001). However, most of the studies cited above are quantitative and do therefore not provide more elaboration on the findings. Notably, however, is the finding from Rotheram-Borus et al. (2001) that draws a correlation between increased levels of sorrow among parents with HIV-related illness and higher levels of distress among their adolescent children. It would thus appear that the way in which the parent responds to an HIV sero-positive status influences children’s response and coping styles. However, the pain experienced by the affected children fluctuates with time. Rotheram-Borus et al. (2005) hold that adolescent children with parents suffering from HIV experienced the highest levels of distress more than a year before the death of a parent. These levels appear to diminish in the year directly prior to the parent’s demise.

The studies thus far suggest that emotional pain among children affected by HIV/AIDS may be at its highest during periods of intense parental illness. At this stage, the household is still grappling with the meaning and consequences of a parent’s HIV sero-positive diagnosis. A parent’s HIV diagnosis requires significant adjustment both psychologically and physically, which is very stressful for the affected children. According to the Rotheram-Borus et al. (2005) study, the children may with time learn to adjust, depending on a number of factors, such as the availability of both physical and emotional support.

In a number of instances, the anxiety and distress surrounding the illness also affects the children, even though other adults in the household may help care for the terminally ill member (Marcus, 2002). The next two quotes taken from the Marcus (2002) study of ‘poor people's perceptions of death and dying' in the context of HIV/AIDS provide an illustration of the above:

> "It was also very painful for his children because they could see that their father was very ill. They did not want to be separated from him. They wanted to sleep in the same room as him. I could see that it was really hurting the children and they could not eat anymore because their father was not eating. They did not want anything and even when he told them to drink juice they would refuse" (p.26)

In the next extract, one of a few children interviewed in the Marcus (2002) study describes the extent of the anguish and anxiety that a child may suffer as result of parental illness:

> "I couldn't even concentrate at school, worrying about my father's condition back at home and wondering how he would be when I got back from school. It affected me so badly that I had to repeat Standard 9 that year" (p.26)

According to Marcus (2002), it is clear that "caring for the terminally ill is extremely exhausting physically, financially and socially" (p.26). It is also psychologically gruelling. The Marcus (2002) study was conducted in seven peri-urban and urban communities in Kwa Zulu Natal. It is an exploratory qualitative study that employed focus group discussions and in-depth interviews with a number of stakeholders. By employing extracts, the study findings demonstrate the effects of parental illness on children's mental wellbeing.

Poulter (1997) found that children from families living with HIV/AIDS felt worried or sad, became less playful and were generally more tearful. They also appeared more dejected and distressed. Furthermore, in scenarios where parents have discussed the illness with their children, the children were more likely to be distraught.

The Poulter findings are based on a study of a sample of households receiving home-based care in three urban areas of Zambia. These areas were visited for a nine-month period. Roughly 196 children were assessed using the Child Behaviour Checklist and compared against controls.

The prospect of death is complicated further when it is AIDS-related, as it is not notifiable. In many instances, people are unaware of the terminally ill person's health status until that individual is dying or close to death (Marcus, 2002).

In another extract taken from the Marcus (2002), this point is illustrated through the bitterness expressed by a daughter regarding her father's experience:

> "Just before he died it was suspected that he might have TB or something else and he was admitted at SANTA, near Eden dale. He was ill for two years. He used to be treated by private doctors and we also took him to Grey Hospital, where he was admitted for a week. There after he was told to go to SANTA because he was getting worse. We had to hire a car to take him to Grey Hospital. If the private doctors I had been taking him to could have detected the illness earlier, he wouldn't have died. All the time I had been taking him to these private doctors. None of them could tell what was wrong with him, but I could tell that he was dying…the doctors did not explain anything to us" (p.29)

Having explored the effects of HIV-related parental illness, the question remains: how does an AIDS-related parental death affect children? Which changes, if any, occur after the process that begins with parental HIV infection, followed by illness, and ultimately culminates in bereavement?

The next section attempts to respond to these questions through an exploration of the literature on children and young people orphaned and rendered vulnerable by HIV/AIDS.

2.3 From the anticipated to the actual: effects of HIV/AIDS-related parental death on children

Although the effect of parental death on children has been studied widely in developed countries, research on this subject in sub-Saharan Africa is minimal (Bawa Yamba, 2005).

Bawa Yamba (2005) holds that even though children maybe excluded from active participation in funerals and other processes related to the death of a parent, they are nonetheless affected and are very much a part of the process of dying and death.

Upon the death of a parent or parents from the complications of AIDS, the child or children concerned are confronted by a number of prospects. Parental death from AIDS, resulting in the children being orphaned, marks a major crisis in the already existing trauma of illness, emotional devastation, economic decline and often social ostracism (Foster & Germann, 2002). When the level of social support is adequate and pre-bereavement succession planning has been done, the chances of the children adjusting to the new situation successfully is increased. However, a great deal of anecdotal evidence from service providers and the media suggest that a number of children orphaned by HIV/AIDS lack social support and pre-bereavement succession planning. This situation is compounded further by the deafening silence and the stigma that often surrounds this epidemic. Marcus (2002) found that for several participants in focus group discussions in peri-urban and urban settings in Kwa Zulu Natal, the appropriateness of talking about death, especially an AIDS-related death, elicited mixed responses:

> "I would talk to the child I am living with…" (p.32)

For another participant, the issue of maturity was very important:

> "I would talk to a child who is 21 or over. I wouldn't talk to a younger child. They will just have to figure it out on their own when I don't wake up the next morning" (p.32)

Proper and adequate mourning is stifled or made worse in an environment that does not permit or encourage openness (Sherr, 2001).

Parental bereavement from HIV/AIDS has a number of socio-economic and psychological consequences. A number of studies and reports have widely documented that one the main problems faced by children orphaned as a result of HIV/AIDS are reduced opportunities for schooling (Nyambedha, Wandibba, Aagaard-Hansen, 2003; UNICEF, 2004). Significantly, a lack of access to schooling has been shown to deprive orphans of the much needed life skills necessary to prevent HIV infection, other sexually transmitted infections and pregnancy (Pettifor et al., 2005). Schooling is also crucial for children's socialisation and self-efficacy. Participation in school improves children's chances of becoming productive members of society.

Further physical hardships that are experienced by children orphaned by HIV and AIDS include a lack of food and social security (Nyambedla et al., 2003; UNICEF, 2004). Reduced access to food manifests in various forms, such as lack of proper and nutritious diet and insufficient daily meals. An example cited from Naicker and Tshenase (2004) is that of a 15-year-old female head of a household who shares her daily struggles around obtaining food.

> “We do not have any food. Sometimes the social workers bring us some food. Our neighbours share their food with us. Many times they have none themselves so we go to bed hungry” (p.56)

Anecdotal South African media publications report that children orphaned and rendered vulnerable by HIV/AIDS also have poor access to social grants, due to a number of factors, such as lack of birth registration documentation, delays experienced in the processing of grants at the Department of Social Services, and so on.

Although often overlooked or overshadowed by the socio-economic consequences, children orphaned by the pandemic also suffer from a number of psychosocial consequences. According to Ebersohn and Eloff (2002), the psychosocial difficulties confronted by children orphaned as a result of HIV/AIDS include grief, loss of identity, such as the self, family and cultural identity, dealing with shame, stigmatisation and abandonment as well as rejection and death.

The death of a parent can lead to depression, behavioural problems as well as reduced self-esteem and self-confidence (Rotheram-Borus et al., 2001). Siegel and Gorey (1994) point out that typical grief reactions are intensified when the cause of death is AIDS-related. Diagnosis of HIV/AIDS elicits both shame and stigmatisation (Telingator, 2000). Furthermore, the effect on the emotional, social and behavioural development is profound. Rotheram-Borus et al. (2001) found that adolescents that have lost a parent to HIV/AIDS reported significantly higher levels of emotional distress and additional behavioural problems compared to non-bereaved youths with HIV positive parents. The bereaved adolescents reported more ‘acting out’ behaviours than their non-bereaved counterparts.

In another study, children orphaned by HIV/AIDS portrayed higher levels of psychological distress compared to non-orphans (Atwine, Cantor-Graae & Bajunirwe, 2005). The orphans were reportedly more anxious and experienced higher levels of sadness and depression. Furthermore, with HIV/AIDS, there are likely to be multiple deaths with some children having to face a protracted bereavement process (Atwine et al., 2005).

However, the Rotheram-Borus et al. (2001) and Atwine et al. (2005) studies were informed by a quantitative positivistic paradigm. Both these studies thus lack the depth and nuance offered by an interpretative qualitative paradigm.

In another quantitative study, Makame et al. (2002) found that, compared to non-orphans, children orphaned by AIDS manifested elevated levels of depression, anxiety, irritability, hyperactivity and antisocial behaviour. Some orphans confessed that they have thought about taking their own lives.

Makame et al. (2002) also found that the sex of the child, with female children scoring higher than male children, going to bed hungry, a lack of reward for good behaviour, not being in school as well as orphan status were strong influences on the above internalising problems. Orphans that lived alone, i.e. child-headed households, experienced significantly higher internalising problems, such as depression and anxiety.

Makame et al. (2002) reached a general conclusion that the long-term mental health of orphans was in jeopardy in the absence of mitigating interventions. It was also highlighted that orphans may not have had opportunities to mourn and grieve properly, as their social environment discouraged such behaviour.

As alluded to earlier, the studies cited above shed light on the psychological and material problems faced by children orphaned as a result of HIV/AIDS. As these studies employ quantitative techniques, they offer little insight on the perspectives or perceptions of these children regarding their situation. The studies also draw from a positivist paradigm.

The benefit associated with more qualitative-oriented approaches is that they would offer a more nuanced insight into the ‘lived experiences’. The fact that this literature review extrapolates largely from quantitative studies attests to the dearth or paucity of research studies on this specific subject employing qualitative approaches.

One of the few studies with a qualitative component is research undertaken by Pivnick and Villegas (2000) on depression and risk among children affected by HIV/AIDS enrolled in a therapeutic after-school and summer programme in the United States of America. Twenty-five children between the ages of 10 and 18 years whose parents were infected or had died from HIV/AIDS were interviewed. Forty-eight clinical assessments and ethnographic interviews were conducted. The method of analysis was unspecified.

The study found that a substantial number of children had histories of parental neglect, parental drug abuse as well as sexual and physical abuse. In particular, the study found that HIV/AIDS, coupled with histories of parental neglect and drug abuse, parental incarceration and frequent changes in residence, had heightened the children's sense of insecurity. It was also found that the children's social spaces are characterised by fragility and damaged attachments. This causes the children to be "cautious and distrustful that any engagement will have a positive outcome" (Pivnick & Villegas, 2000, p.110).

According Pivnick and Villegas (2000): "a prominent outcome of this shifting ground is the effort on the children's parts to parent their parent, to gain a degree of control in a circumstance in which the future is unknown and the past opaque and threatening" (p.110).

The orphaned children in the study described feeling different from their peers. The children were advised not to reveal the causes of their parents' death, thus creating a sense of confusion (Pivnick & Villegas, 2000).

Malinga (2002) provides a necessary gendered perspective on the implications of HIV/AIDS for orphaned children and adolescents in a study conducted in Uganda. The strength of the study is its use of a combination of research methods. Thirty orphans, both children and adolescents, were interviewed. Participants consisted of children from widow-headed households, child-headed households as well as children living with grandparents, relatives and non-relatives. Four parents, i.e. two widows and two widowers, were also interviewed. Qualitative interviews were conducted with open-ended interview guides and semi-structured questionnaires, covering gender, socio-economic and psychosocial issues. Psychological scales were also used to measure depression, anxiety, anger, suicide and loneliness.

Malinga (2002) found that the huge burden of caring for orphans and people living with HIV/AIDS tends to fall on women, resulting in psychological difficulties. The female children shoulder most of the care responsibilities for siblings and sick parents. They also take on household responsibilities and paid work. This results in higher school drop-out rates and depression among girls. The study found that the high levels of trauma worsen the situation even further. The children are first subjected to the fear and anxiety of witnessing a parent or parents suffer from a debilitating and fatal illness. This trauma is followed by the death itself, which leaves a painful wound.

According to Malinga (2002), the children reported feeling cheated and robbed from the care and love provided by a parent, especially a mother. The study also found that the lack of openness and the resulting silence surrounding sex and HIV status deprives the children of an opportunity to share and voice their fears and concerns while their parents are still alive. Psychosocial difficulties are compounded by the possibility of dissolution of families and separation of siblings. Some of the children in the study were withdrawn and resigned, as they had not addressed some of their fears and concerns.

In another study conducted in Uganda, children from child-headed households reported during focus group discussions that they felt both bad and angry for periods ranging from one to three months when a parent/s died (Sengendo & Nambi, 1997). This finding is based on a study aimed at investigating the psychological effect being orphaned. The study assessed how orphans felt while parents were alive, became sick and finally when they died. A purposive sampling technique was employed to recruit 193 children ranging between six and 20 year old under the sponsorship of World Vision in Uganda's Rakai district.

The sample for the above Ugandan study consisted of orphans and children from intact families. The children along with their teachers and, where possible, guardians were interviewed. Focus group discussions were held with teachers, some orphans and community workers. Depression scales were administered. Locus of control was also assessed and correlated with depression scores. One of the weaknesses of the study is that only children under the sponsorship of World Vision were included. The donor's core objectives and goals thus informed the study.

Children in the above study reported poor eating habits in addition to feeling angry at the death of a parent/s. The presence of relatives during funerals appeared to improve matters, although these feelings and behavioural patterns returned once relatives left after the funeral. In focus group discussions, the children narrated how they sometimes thought or dreamt about the parent. The children talked about the things that the parent used to do and how they behaved. During the focus groups, the children also reported how the death of their parents from AIDS had disrupted their schooling.

It is, however, unclear from the study whether this was one of the rare occasions on which the children had the opportunity to talk about their parents. It is also unclear what qualitative methodological approach was used to inform the qualitative component of the study.

One of the difficulties in translating results from the two above studies is that the social and economic circumstances from one country to another may differ.

One of a few studies with a clearly articulated theoretical perspective is a fairly recent psychoanalytic South African study. The study employed the Sceno test, a play assessment technique, to explore the intrapsychic themes in a play featuring children affected by HIV/AIDS (Hough, 2001). A hermeneutic phenomenological methodology within a narrative framework was employed to interpret the text of the children’s play. Four children between the ages of seven and 11 affected by HIV/AIDS and living in a children’s home were assessed. Children not affected by HIV/AIDS but who had lost parents were also included. The assessment sessions were videotaped, after which the actions and dialogue were transcribed.

Hough (2001) found that the children were concerned with structure and routine as well as demonstrated a need for security. The role of a mother as caring and nurturing was another important theme that emerged, which could demonstrate the children’s wish for attachment with such a figure. The children were also concerned about organising the environment and having control over the context of the play, which gave them a sense of mastery. It is interesting that out of all the literature reviewed thus far, this is the only study that portrayed a theme on spirituality (Hough, 2001).

Each child used either the heart or some aspect of spirituality, for instance prayer or the presence of an angel. The author postulates that the heart appears “to serve the dual role of showing love and signifying a special space, as well as showing the presence of a transcendent being” (p.19). The following quote illustrates the aforesaid:

> “Angela (Interviewer or facilitator): Who is the heart for?
>
> Smangele (Participant): Jesus. The heart is for protection in the night.
>
> Jabu (Participant): “These people have God; they are having God in the house.” (p.19)

The merit of the above study is its use of videotaping. This enabled both the verbal and non-verbal communication patterns to be captured. The play assessment technique is a useful method of gathering data with young children, as children sometimes lack adequate verbal skills to articulate their inner most feelings. However, the children were of a younger age group. In general, experiences, outlook and understanding vary as a function of increasing age. It should also be noted that the children who participated in the study were recruited from a children’s home. There might be differences in the experiences of children residing in such a home and those in a ‘normal’ community.

Movement from one household or community to another is also challenge that children orphaned by HIV/AIDS sometimes have to confront, particularly in the absence of another capable adult in the household or due to financial constraints. The grieving process is further complicated by the migration, especially when the new environment is unsupportive and uncomfortable for the child or children concerned. Attempts to avoid migration and facing the complications of relocation may possibly explain why children find themselves in child-headed households.

Depending on a number of supportive and aggravating factors, moving children orphaned by AIDS to other households and communities may constitute either a source of distress or adjustment. According to Forehand et al. (1999) a singular transition in residence, as well as moving into a stable family environment, improves adjustment post-parental bereavement. The death of a parent/s presents significant challenges for the children left behind. Apart from the issues of grief and mourning, the children face the very real prospect of migrating to new home environments.

A number of studies have found that moving AIDS-affected children to new homes is a complex and strenuous process for the children involved (Foster, Makufa, Drew, Mashuma & Kambeu, 1997b; Sengendo & Nambi, 1997; Forehand et al., 1999; Pivnick & Villegas, 2000; Malinga, 2002; Ansell & Young, 2004; Safman, 2004). Rotheram-Borus et al. (2001) argue that the quality and stability of the living situation after the death of a parent/s plays a crucial role in the adjustment of children orphaned by HIV/AIDS. Pivnick and Villegas (2000) found that orphaned children not only dealt with grief but also reported high levels of anxiety and depression during their adjustments to living with new families.

In a study conducted in urban and rural areas in Lesotho and Malawi, Ansell and Young (2004) found that migration of AIDS-affected children to 'new' families and communities appears to be very difficult in the short term due to the challenges of assimilation into the 'new' families and communities. In the long term, some of these challenges appeared to dissipate.

The study employed qualitative methods. A total of 822 children between the ages of ten and 17 from randomly selected classes at local schools completed questionnaires to identify both the children that had migrated and experienced parental death/sickness as well as those from households that have taken in children in a similar position.

The Ansell and Young (2004) study sample consisted of 226 children within the schools as well as 70 children not within the participating schools, i.e. children living on the streets or in institutions, who participated in focus group discussions (Ansell & Young, 2004). Out of this group, 65 children were selected to draw storyboards depicting personal migration experiences. These were used to obtain detailed narratives. Interviews were also conducted with 40 guardians who had taken in children from other areas to determine the children's migration experiences.

Ansell and Young (2004) holds that the children felt that they were treated differently by their 'new' families, i.e. being fed different food, not being clothed adequately as well as being chastised unnecessarily or simply overworked. Other reported difficulties include:

- experiencing jealousy and rivalry from the natural or biological children in the 'new' household;
- experiencing difficulties with making new friends; and
- being required to work for their keep, which may disrupt schooling (Ansell & Young, 2004).

Moving to a 'new' community may also require learning a new language and adjusting to a new school curriculum. Moving from one community to another, such as from an urban to a rural area, is difficult. The tasks performed in rural communities are radically different and difficulties with performing them may not always elicit sympathy from the other children in the community.

Ansell and Young (2004) found that some of the children had migrated more than once. Reasons provided for repeated migrations include changed circumstances, such as the death of a guardian, i.e. multiple AIDS-related deaths and old age, abuse and discrimination, lack of care from guardians, ill treatment and being punished severely. Most of the above difficulties were found to complicate life psychologically for the children involved. Poverty and economic challenges, particularly in grandparent-headed households, exacerbate these difficulties

In a study conducted in Thailand, Safman (2004) found that children orphaned by AIDS that had moved in with grandparents were the most impoverished. The study aimed to assess the impact of being orphaned on Thai children affected by AIDS by using:

- semi-structured interviews with five key representatives from the public health system, three focus groups with 21 caregivers responsible for children that had lost a parent/s to AIDS; and
- three unstructured interviews with caregivers that were excluded from focus group discussions.

The semi-structured interviews assessed the scope of the local epidemic and community attitudes towards persons living with HIV/AIDS and their families. Focus group discussion topics assessed both the problems confronted by households caring for children affected by HIV/AIDS as well as their coping mechanisms. The three unstructured interviews with caregivers covered the topics discussed in the focus group discussions.

Most respondents in the Safman (2004) study felt that grandparents were the most appropriate family members to take in orphans due to their experience, availability and interest. The study did, however, cite a number of difficulties inherent to this option. These difficulties include the age, health, as well as the economic status of grandparents. Several grandparents in the study reported having gone back to work as a result of taking in orphans.

The strengths of the Ansell and Young (2004) as well as Safman (2004) studies are their use of a combination of research methods. In both studies, the qualitative methods employed were appropriate for addressing the questions that they sought to answer. Although the Ansell and Young (2004) study elicited both the views of guardians and the children regarding their experiences, the Safman (2004) study lacked this feature.

A narrative study exploring the experiences of a household with children affected by HIV/AIDS found that upon the death of their mother, the children relocated a number of times before resettling into their native home as a child-headed household (Bawa Yamba, 2005). Upon the death of their mother, the children moved in with their ailing grandparents, who themselves died shortly thereafter. The children then moved in with their aunt and uncle, who both died of what appeared to be signs of HIV/AIDS-related illnesses. During this period, the children underwent three phases of bereavement, characterised by the loss of caregivers, physical homes and environments that had offered love and security.

Questions may arise as to the reliability of translating results from these studies conducted in Asia and sub-Saharan Africa to a country like South Africa. Furthermore, the psychosocial adjustment of the children involved in these studies was either not assessed adequately or simply not investigated. Bawa Yamba (2005) did, however, acknowledge the difficulty in conducting interviews and exploring the feelings of children who were forced to relocate a number of times. There is also the challenge of staying detached as a researcher when dealing with vulnerable groups: “when one is torn between the demands of academic disinterest and a moral involvement to prevent those one is studying from harm and exploitation” (p.205).

Having discussed the experiences of children orphaned by HIV/AIDS in general, the next section turns to a sub-group within this population. The next section also explores supportive and aggravating factors for both children in child-headed households as well as other children living in difficult circumstances.

2.4 The life after: post parental death adjustment

Post-bereavement, many children orphaned by AIDS end up in what is commonly called child-headed households. Despite a growing body of work and recognition of children affected by HIV/AIDS at community level in countries like Zambia and Zimbabwe, the very existence of such households are often denied (Bawa Yamba, 2005; Roalkvam, 2005). These households are often seen as isolated and almost ‘invisible’ to their communities and extended families.

An ethnographic study conducted in a semi-rural area in Zimbabwe found that extended family and community support for many of these households has vanished altogether. These children thus lack relationships, social networks or groups that they can go to for support, comfort and relief (Roalkvam, 2005). Through a detailed case study, this study sought to explore the factors leading to the isolation of one child-headed household.

Typically, relevant literature as well as Non-Governmental Organisations (NGOs) working with these families use factors, such as HIV/AIDS-related stigma as well as poverty, to explain why child-headed households becomes secluded. Roalkvam (2005) has shown that these explanations are not always adequate by employing the above case study to demonstrate that some child-headed households become isolated because “they are left in a specific time, in a specific situation, when the relationships that should surround them still have to be made, recognised and named” (p.211). In particular, Roalkvam (2005) points out that “the *lobola* tradition creates a protective space, when successful, secures not only identity, belonging and care for children, but in fact organises relations between families, lineages and communities” (p.218)

Roalkvam (2005) goes on to say that “in poverty-stricken communities *lobola* remains an unfinished and vulnerable business throughout the span of a marriage. In this context, deaths due to AIDS are premature. Relations are yet to be established…” (p.218)

In the end, the result is that children do not receive the support and care that all children deserve.

Another illustrative study was conducted in Rwanda among what the authors termed youth-headed households (Thurman et al., 2006). By employing quantitative-based measuring scales, the study aimed to assess psychosocial support and marginalisation of these households. A total of 16% out of 692 children between the ages of 13 to 24 interviewed reported that they had nobody to go to when presented with a problem. Significantly, 86% of participants reported feelings of rejection emanating from the community. Another 57% indicated that the community was more antagonistic than helpful. In general, these results seem to indicate that youth-headed households experience a high degree of marginalisation. However, the study lacks a sufficient exploration as to the factors creating the marginalisation as well as how the children make sense of the support or lack thereof.

As noted earlier, the responsibility of caring for siblings may for some children begin when AIDS incapacitates a parent and may continue even after bereavement. The media has written a fair amount on child-headed households, especially on special occasions, such as World AIDS Day. Relatively few empirical studies, particularly those published in peer-reviewed journals, have been conducted on the experiences of children in child-headed families. The majority of literature reviewed in this section comprises reports intended to support particular client’s programmes. Despite their limitations, these reports offer some useful insights into the lives of children in child-headed households.

Children from child-headed households face a number of challenges and difficulties, such as a lack of access to food and shelter, lack of access and continued participation in education due to poverty, risk of sexual abuse, exploitation and child prostitution as well as destitution (Ayieko, 1997; Sengendo & Nambi, 1997; Nelson Mandela Children’s Fund, 2001; Naicker & Tshenase, 2004).

Foster et al. (1997b) found that sibling-headed households in a peri-urban area in Zimbabwe constitute some of the poorest orphan households. Based on factors such as these households’ living conditions as well as the unavailability of adult support, love and care, Foster et al.

(1997b) concluded that these children are also at the greatest risk of poor long-term mental health.

As far as sexual exploitation is concerned, Bawa Yamba's (2005) study based on a narrative account of a child-headed household concluded that the absence of commitment of relatives in preventing such exploitation only serves to fuel this problem. Reasons for the absence of commitment may include the potential for monetary rewards in the form of *lobola* or bride-price, as well as other rewards such as food.

Before exploring some of the factors that are constitutive of resilience for these and other children living in adverse circumstances, the review explores a few recent studies on child-headed households in some detail.

A study commissioned by the Nelson Mandela Children's Fund in South Africa in 2001 'sought to evaluate the problems, priority needs and the special challenges facing child-headed households', in particular, those households headed by children as a result of parental death due to HIV/AIDS. The study was conducted to obtain information to support the Nelson Mandela Children's Fund programme, targeting households headed by children (Nelson Mandela Children's Fund, 2001).

One of the merits of the study is its use of a combination of research methods to gather data. These included a desk literature review, administration of a structured questionnaire to 47 individuals involved in the provision of healthcare, social welfare, education and care of the terminally ill, interviews with 34 representatives from NGOs, community leaders, government officials as well as health and social workers. The children were given the opportunity to speak for themselves when 117 children from child-headed families were interviewed.

However, in the above study, the children were interviewed in the presence of locals who regularly visit them to provide home-care services. Eleven focus group discussions were conducted with social and health workers, educators and caregivers. Site visits were also conducted to assess the children's living conditions. The research was carried out in Gauteng, the Northern Province, Mpumalanga and Kwa Zulu Natal (Nelson Mandela Children's Fund, 2001).

Apart from the problems relating to food, security and school participation, the children are vulnerable to both sexual and physical abuse. The children also reported being stigmatised as well as rejected by friends, relatives and communities. This resulted in child-headed households becoming isolated from their communities. Such isolation made it difficult for the households concerned to look to those around them for help and assistance. Growing up without parental support, love, care and guidance leads to an interrupted childhood and increases susceptibility to diseases, reduced health status, substance abuse and teenage pregnancy. It also reduces opportunities for education. Interestingly, focus group participants emphasised the children's need for emotional support and adult guidance (Nelson Mandela Children's Fund, 2001).

In a study focussing on the needs of child-headed households, Naicker and Tshenase (2004) gathered data through interviews with service providers and 126 children from child-headed families in the nine South African provinces. One special focus group discussion was conducted with Child Welfare Societies working in the Durban Metropolitan area in South Africa. The study found that children do not have access to trauma counselling. In most instances, the children had very little time to reflect on their loss, pain and grief before they were thrust into survival mode.

According to Naicker and Tshenase (2004), these children also face the threat of dispossession of belongings, which heightens their fears and insecurities. Interestingly, the study reported that the children did not express any psychological, spiritual or recreational needs.

In the two studies (Nelson Mandela Children's Fund, 2001; Naicker & Tshenase, 2004), community support was seen as mixed. On the one hand, participants reported examples of people within the community reaching out to help, while on the other, participants also experienced ostracism and exclusion associated with HIV/AIDS. "The stigma carried by these children is a big problem – the community isolates them and they respond by isolating themselves from the community; parents discourage their children from playing with kids from child-headed families because they are believed to also have AIDS; the children who go to school tell us that their friends don't want to play with them as they might infect" (Focus group participant in Nelson Mandela Children's Fund, 2001, p.22).

A number of stresses confront those children carrying the responsibility for child-headed families, which distinguishes their experiences from the other children in similar households. To date, very few studies have focussed on children heading households. Studies investigating the psychosocial effects are particularly scarce.

Sengendo and Nambi (1997) have found that children that head families are more externally oriented than other groups of orphans. The study also reports a positive correlation between external locus of control and high depression scores. Locus of control consists of two dimensions: internal and external locus of control. Individuals with an internal locus of control view outcomes as dependent on expended energy and effort. On the other hand, people with an external locus of control perceive outcomes as externally generated (Lefcourt, 1980).

The Nelson Mandela Children's Fund study on the situation of children in child-headed households revealed that the younger siblings in the households seemed helpless and relied heavily on the child-heads, which in turn places undue stress on the child-heads. Older siblings responsible for child-headed households carry the burden of providing both physical and emotional support to younger siblings. This puts them at risk of psychological distress "The children lack guidance, they have no one to give a sense of direction, they don't have a role model in the home so they adopt less desirable values" (Focus group participant in Nelson Mandela Children's Fund, 2001, p.22).

The child-heads also lack the skills and knowledge to both provide protection against abuse and exploitation as well as ensuring healthy living (Nelson Mandela Children's Fund, 2001; Nyambedla et al., 2003).

In the Naicker and Tshenase (2004) study, some child-heads point to difficulties experienced with controlling and managing siblings as well as lack of respect among siblings. "My brother brings home his girlfriend and makes our younger brother sleep on the floor. He misused the donation (R500) given to us by the church. He bought alcohol and cigarettes with that money. All these things depress me. I was on my way to lay charges against him, but my grandmother who lives in the next town promised to talk to him. He still continues with his unruly behaviour despite my grandmother talking to him" (pp.59-60)

Another child alludes to the problem of being taken seriously by other siblings. “It is just difficult to exercise any discipline on my younger brother and sister” (p.61)

Strode (2003) examined the nature and extent of problems facing child-headed households in Kwa Zulu Natal, South Africa. The study set out to examine the problems faced by children carrying responsibility for households by providing them the opportunity to describe the problems they face daily. The study employed a combination of qualitative and quantitative methods. The qualitative research component examined the specific and general problems faced by child-headed households.

The children cited a number of challenges. These include physical, emotional and developmental vulnerabilities. Emotional difficulties were not recognised as often. The children did, however, emphasise that due to their responsibilities at home they hardly had enough leisure time. Some members of the households interviewed had problems with the law. One household head was facing a criminal charge. Some children reported that they felt discriminated against in the community (Strode, 2003). One significant methodological weakness in this study is that all the interviews were conducted in the presence of both the researchers and the community workers assisting these households. The presence of others may have affected the way the children responded to questions.

The following section reviews the critical survival strategies employed by children in this situation as expounded in the relevant literature. Some studies have indicated that a segment of young people growing up in difficult circumstances do not develop emotional and psychological problems (Compas, 1987). These studies point to both intrinsic and extrinsic protective factors.

Dispositional factors include personal characteristics that shape responses to challenges. The following three factors have been identified to characterise invulnerability in children and adolescents across a number of studies

- personal dispositional characteristics, e.g. temperament, high self-esteem, internal locus of control and autonomy;

- family support, e.g. parental warmth, cohesiveness, closeness as well as order and organisation; and
- extra or outside support from other individuals (Rutter, 1981).

Social support can act as buffer against the development of psychiatric disorders in later adulthood for children and young people that are exposed to adverse experiences (Rutter, 1984). A number of studies (Compas, 1987) found an association between social support and levels of psychological or physical symptomatology. This association is, however, tempered by factors such as subject characteristics, e.g. gender, age and socio-economic status, as well as the dimension of social support under examination, e.g. number or size of supportive associations, appraisal of social support and socially supportive behaviours from other people (Compas, 1987).

Cree et al. (2006) found that both children and young people in Scotland living with an HIV positive parent or having lost a parent to HIV/AIDS drew on different individuals and agencies for support. These may include local youth and sports clubs. The other significant source reported in the Cree et al. (2006) study is support from voluntary HIV support agencies, which was mainly described as more emotional and family oriented in style and nature. These voluntary agencies provided weekly youth clubs, recreation, relaxation as well as safe space for children with an HIV infected parent to talk about their experiences with other children in a similar position (Cree et al., 2006).

Perhaps the least investigated area is the role of support groups in helping orphans adjust psychologically. Atwine et al. (2005) found that from their sample of children orphaned by HIV/AIDS, those that were part of a support group involving other orphans in a similar position had healthier self-concepts. However, being part of a support group was not predictive of decreased levels of anxiety and depression.

The role of family and society as a moderator valuable to children's adjustment challenges after parental death is important (Wild, 2001). Some evidence suggests that children affected by AIDS cope better in a stable family environment (Collins-Jones, 1997) if they are not separated from siblings (Nampanya-Serpell, 1999) and provided that they are receiving care and love from relatives (Pivnick & Villegas, 2000). Support from peers, neighbours, teachers and church leaders as well as members of the community also facilitate psychosocial adjustment (Wild, 2001).

Gray (1989) found that bereaved adolescents described their peers as the most helpful, compared to surviving parents, other family members, teachers, school counsellors and nurses as well as others community members, e.g. adult friends of their parents. Peers were found helpful for a number of reasons, including emotionally sustaining behaviours, e.g. talking and listening as well as feeling understood. Peers also assisted by distracting children from their pain.

The above coping mechanisms hold implications for the experiences of children affected by HIV/AIDS. The next section discusses coping mechanisms used by children in child-headed families.

The coping strategies employed in child-headed families are varied. The Nelson Mandela Children's Fund found that these include child-heads having part-time work, the children running errands for neighbours in return for payment by cash or in kind, turning to relatives and churches for help. Others reported begging for food. Strode (2003) also found that heads of such households use a number of survival strategies, such as working, getting support from relatives and even non-relatives as well as providing favours in exchange for support. Consistent with Naicker and Tshenase (2004), the Nelson Mandela Children's Fund study also found that some young girls were married off early as a survival tool. The developmental implications of this tool was, however, were not explored in the studies.

Malinga (2002) points out that orphaned girls are more inclined to marry young as a coping strategy. There is also the 'sugar daddy' phenomenon where teenage girls have relationships with older men as a means for survival and other material benefits. Psychological coping mechanisms were, however, not investigated in either of the studies. This is due in part to the nature of the studies. The studies were commissioned and carried out to answer questions that address the commissioning bodies' areas of function.

The next section explores the effects of either parental illness or death from HIV/AIDS from a developmental perspective. In particular, the focus is largely on adolescence, as anecdotal evidence suggests that most child-heads are adolescents.

2.5 The adolescent as the head of the household

A fairly recent study (UNAIDS, UNICEF & USAID, 2004) revealed that approximately 55% of all orphans are between the ages of 12 and 17. Typically, most studies on the effects of orphan hood on children affected by HIV/AIDS, such as those reviewed in this chapter, include adolescents in their samples. Although most children heading households are adolescents, very little attention is given to the specific effects for adolescents.

Orphan hood presents specific consequences for adolescents. The next case study extracted from Zayas and Romano (1994) pp.68-70 incorporates some of the developmental, emotional, and behavioural problems. The case study is based on a 14-year-old boy named ‘Buddy’, whose mother and uncle are both HIV positive. He has two younger siblings. The case highlights many of the issues confronted by children living with an HIV positive parent.

“Buddy’s mother’s HIV diagnosis worsened a pre-existing depression that she had apparently medicated with alcohol she took a passive stance towards the illness and planning for her family”. This resulted in Buddy and his younger sibling having to assume more household responsibilities. His mother also became increasingly unavailable emotionally and physically, even for family therapy. What was even more exasperating for Buddy was that his mother appeared “not interested in helping herself”. Typical for adolescents his age, “Buddy tended to displace” his anger, especially over his mother’s illness and “the sense that she did not take care of herself enough to prevent the illness…onto his younger brother”. Furthermore, what made matters even more difficult for ‘Buddy’ was his preoccupation with the stigma associated with HIV/AIDS.

Adolescence is characterised by a need to establish extra familial relations, especially with peers. Although relations with peers can prove destructive and negative in the case of young people who, through negative peer influence, participate in activities such as crime and other risky behaviours. This is, however, not always the consequence. Some young people do through friends find other positive ways of dealing with their problems. “Buddy was engaged with some friends with whom he discussed God’s existence and goodness, and the existence of the devil. Buddy’s intimacy with these boys helped him deal, though indirectly, with his fear of his mother’s death, his sense of impending loss, and his loneliness”. Distancing himself from his family is characteristic of this life stage. Yet, in his case, “the friends validated” his “self-worth in ways his family could not”.

Ruland et al. (2005) demonstrated that adolescent orphans share the need for housing, food, social supports and education with younger orphans. However, due to the physical, sexual and psychosocial changes that occur during adolescence, the effects are exacerbated even further.

Cognitive development also takes place during adolescence. For Inhelder and Piaget (1958), adolescence is characterised by the development of formal operational thinking. Development in cognitive abilities permits adolescents to employ advanced levels of thought and reasoning (Zayas & Romano, 1994).

Significantly, this stage of development is characterised by the movement towards identity formation, autonomy and intimacy (Erikson, 1968). The movement towards autonomy in adolescence is characterised by the development of independent thought and formulation of own moral code and judgment. This movement does, however, not result in a complete detachment from family and parents. Such a movement is rather something that normally takes place within the family context. The feelings most closely associated with this movement are sadness and loss since, in effect, the ‘omnipotent’ and ‘omniscient’ parent is expropriated or killed. Parental roles also become internalised (Viorst, 1986). The adolescent becomes less dependent on the parents as these adolescents begin to exercise their own judgments and decision (Zayas & Romano, 1994). Furthermore, these adolescents begin to look to the outside for emotional attachments. Crucial to this movement is the style of parenting that the adolescent is subjected to. The majority of literature on adolescent development presupposes the presence of a parent/s (Zayas & Romano, 1994).

Research suggests that adolescent development in AIDS affected households takes a different form, which may be characterised by the adolescent assuming developmentally inappropriate adult responsibilities (Zayas & Romano, 1994). Zayas and Romano (1994) have identified five possible reactions to parental death, namely bereavement, depression, acting out, overcompensation or the ‘super child’ manifestation as well as withdrawal.

Depression is manifested through varying features, e.g. withdrawal, sadness, isolation, moodiness, below or above average appetite, sleep disturbances, risk taking behaviour, etc. (Zayas & Romano, 1994). Acting out may include disciplinary problems in the school environment. Zayas and Romano (1994) define overcompensation or the ‘super child’ as the adolescent taking on the role of a parent and caring for younger siblings. The adolescent child also becomes involved in the decision-making process as well as the household chores, which are similar responsibilities as those undertaken by a child in a child-headed household.

However, in the case of child-headed households, the idea of the ‘super child’ as expounded by Zayas and Romano (1994) may not adequately explain the situation of children heading these households, since many of them have simply been thrust into such positions. It can be argued that a child that is carrying responsibility for a household is simply fulfilling a role that no one in the immediate or extended family is willing or able to fulfil. There are three possible reasons why an adolescent may become a “super child”:

- keeping busy to avoid painful feelings associated with parental illness and anticipated death;
- seeking attention and the approval of a parent; and
- indicating his/her readiness to assume the responsibilities of a parent/s in their absence.

Lastly, some adolescents respond by withdrawing. Withdrawal is characterised by running away or staying away from home for long periods. According to Zayas and Romano (1994), this represents one of a number of developmentally appropriate reactions, as distance not only offers time and space away from the household but also provides an opportunity to develop outside relationships. The above reactions as identified by Zayas and Romano (1994) may apply to children bereaved by causes other than HIV/AIDS. Nevertheless, the specific features of HIV/AIDS, such as the stigma and the secrecy that often surrounds an AIDS-related death, serves to complicate the situation.

2.6 Conclusion

Pre- and post-bereavement phases are characterised by increasing poverty in households affected by HIV/AIDS, particularly in sub-Saharan Africa. Studies on children affected by HIV/AIDS indicate that children living with a terminally ill parent experience an inordinate amount of stress. Adverse and stressful life events during childhood and adolescence may be associated with adult depression later on (Rutter, 1984). Whilst the foregoing review failed to explore the impact of stressful life events during childhood for later adult mental health, evidence does suggest that victimisation, for example, sexual assault, maltreatment, etc. in childhood and adolescence lead to poor mental health even during these life stages (Turner, Finkelhor & Ormrod, 2006).

It has also been found that caring for and witnessing a parent suffer from a debilitating illness such as HIV/AIDS might lead to the affected children becoming worried, sad and helpless. Children orphaned by HIV/AIDS appear to be more depressed and anxious. The affected children also describe feeling different from their peers. After the parent/s' death, some children migrate to new families and communities, which may be a traumatic experience, depending on the availability of support and care in the new environments.

However, some children become part of child-headed families. These households face a number of challenges and needs. The children responsible for the households are burdened with caring for siblings. Literature on protective and coping mechanisms for children living in adverse circumstances show that a set of individual personal characteristics and environmental factors may enhance as well as hamper psychosocial adjustment. Child-headed households in particular employ a number of socio-economic coping strategies. Most studies on these households have, however, paid little attention to psychological coping mechanisms.

Chapter 3: Methodology

3.1 Introduction

This chapter provides a description of the research approach used in this study. The research design, the data collection process, ethical issues, study context as well as the data collection process are described.

3.2 Interpretative research

This study employed an interpretative approach. This approach comprises a set of assumptions about the nature of lived experience. The approach is mostly concerned with interpreting meaningful human and social action, while emphasising that all manner of explication or theorising in the social sciences should be understandable to the human actors themselves (Babbie & Mouton, 2001). The ontological focus of interpretative research is the internal world of subjective experience (TerreBlanche & Kelly, 1999). For interpretative theorists, elucidation and investigation of this internal world of subjective experience is best conducted using interactional, qualitative methods.

Although interpretative research approaches may differ in terms of the manner in which they view the purpose and aim of human inquiry as well as in the manner in which these phenomena are investigated, these approaches nonetheless share a general conceptual framework (Shwandt, 1994). According to TerreBlanche & Kelly, this framework assumes that "… people's subjective experiences are real and should be taken seriously, that we can understand other people's experiences by interacting with them and by listening to what they tell us, and that qualitative research techniques are best suited to this task" (p.123).

Interpretative research approaches such as phenomenology and interpretative anthropology emerged as a reaction to the 'natural attitude' inherent to positivism and its language of variables and quantification (Holstein & Gubrium, 1994). Interpretative approaches attempt to use ordinary language and expression to expound 'the social world' or social phenomena, thus relying on 'first hand accounts'. As TerreBlanche and Kelly have pointed out: "The interpretative approach tries to harness and extend the power of ordinary language and expression, developed over thousands of years, to help us better understand the social world we live in" (p.123).

Interpretative research aims to learn and understand what is meaningful to research participants through their eyes or perspectives (Neuman, 2000). This process requires understanding the meaning behind particular behaviours, in a specific context. To understand subjective experiences, one needs to gain access to people's 'point of view' (TerreBlanche & Kelly, 1999).

There are certain limitations as to how much access a researcher can gain into the subjective world of a research participant. Two possible barriers are:

- the researcher's own pre-conceptions or expectations, modes of understanding reality and interpretation; and
- the research participant's willingness to open up or share his/her world.

The approach does, however, represent an attempt to give the research participants a voice.

A number of persuasions within the social sciences can be classified as interpretative (e.g. grounded theory, symbolic interactionism, etc). The specific interpretative approach adopted for the present study is phenomenology. For this reason and for the purpose of the present chapter, the author will present the historical and philosophical roots of phenomenology, followed by a description of the IPA as a research method.

3.3 Phenomenology: the history, philosophical underpinnings and the approach

The term phenomenology stems from the Greek word *phainemenon*, which means appearance (Spinelli, 1989). The term is used to define and distinguish the appearance of things from things as they really are. Edmund Husserl, the person responsible for the development and initiation of phenomenology into a school of thought, used phenomenological reduction to introduce the notion of objects or states given in consciousness as opposed to reality (Giorgi & Giorgi, 2003). Before the introduction of phenomenological reduction, Immanuel Kant distinguished between the ‘noumenon’, i.e., the thing itself, and the phenomenon, which is what appears in the mind (Spinelli, 1989).

Closely related to the idea of phenomenological reduction is the concept of bracketing, which is sometimes assumed to be part of reduction (Giorgi & Giorgi, 2003). Bracketing involves setting aside knowledge about the phenomenon under study that emanates from other sources or instances.

Husserl adopted the term phenomenology and used it to develop a rigorous science of phenomena free from presuppositions and biases (Brennan, 1998). His phenomenology rejected reductionism as espoused in the empirical sciences and sought to “…ground radically the foundations of knowledge so that sceptical attacks on rationality and its procedures could be overcome” (Giorgi & Giorgi, 2003, p.25).

Husserlian phenomenology represents one of two interconnected philosophical branches of phenomenology: transcendental and existential phenomenology. Transcendental phenomenology is characterised by an exploration of the subjective experience in an aim to illustrate how our consciousness imposes itself on our experiences, i.e. the notion of intentionality, thus consciousness directed at an object or experience (Spinelli, 1989; Giorgi & Giorgi, 2003). Husserl argued that the contents of the mind are characterised by acts such as remembering, desiring and perceiving. He labelled these acts’ abstract contents meanings. In turn, these meanings enabled the acts to be directed at an object. Husserl thus viewed consciousness as intentional or as directed at something else (Luijpen & Koren, 1969).

The second branch of phenomenology is existential phenomenology. One of its most famous representatives was Husserl’s university assistant, Martin Heidegger. Other existential phenomenologists include Jean Paul Satre and Paul Ricouer. Martin Heidegger, in particular, emphasised that phenomenology should illuminate the hidden or that which is taken for granted in ordinary, daily experience (Luijpen & Koren, 1969). In his most famous work *Being and Time* (1927), he attempted to articulate what he termed the structure of everydayness or ‘being-in-the world’, which he considered to be an interconnected system of equipment, social roles and purposes.

According to Ashworth (2003), "It was partly the divergence between Husserl and Heidegger, on the question of whether phenomenology is truly a disciplined description of experience or whether interpretation is inevitable, which led to the rift in phenomenology…" (p.20).

Heidegger sought to move beyond the description of phenomena to interpretation. Beyond or in conjunction with perceiving an object or experience, construction or interpretation takes place (Smith & Osborn, 2003). However, phenomenological psychological research generally seeks to explore situations experienced in everyday life (Giorgi & Giorgi, 2003).

In what Ricouer (1970) called the 'hermeneutics of meaning-recollection', phenomenology strives for a faithful revelation or exploration of the life worlds of people under study. The idea is to capture as closely as possible the way in which the phenomenon in question, for example, children carrying the responsibility for households as a result of parental death due HIV/AIDS, is perceived or experienced by the person actually experiencing the phenomenon (Giorgi & Giorgi, 2003). This exercise discerns the psychological essence of the phenomenon in question. According to Giorgi and Giorgi (2003) "phenomenology seeks the psychological meanings that constitute the phenomenon through investigating and analysing lived examples of the phenomenon within the context of the participants' lives" (p.27).

Kvale (1996) describes phenomenology as follows: "Phenomenology is interested in elucidating both that which appears and the manner in which it appears. It studies the subjects' perspectives on their world; attempts to describe in detail the content and structure of the subjects' consciousness, to grasp the qualitative diversity of their experiences and to explicate their essential meanings. Phenomenology attempts to get beyond immediately experienced meanings in order to articulate the prereflective level of lived meanings, to make the invisible visible." (p.53)

In the implementation of the present study, especially during data collection and analysis, an attempt was made to remain 'faithful' to the way in which the interviewees experienced their worlds, while at the same time interpreting the meaning of those experiences.

Generally, the phenomenological paradigm as postulated by Husserl and later expanded by Heidegger and other existential phenomenological theorists tends to focus more on the 'experiencing' individual. Recognition of the socio-cultural influences that have an effect on the experiencing has to date received little attention. The notion of lived experience encompasses and includes a person's social and cultural location (Hook, 2003). Any reasonable interpretation of a person's account of the world has to recognise the role and importance of the socio-cultural contexts or location.

The next section describes the specific phenomenological approach employed in the present study, namely the Interpretative Phenomenological Analysis (IPA).

3.4 Interpretative phenomenological analysis

The particular phenomenological research method used in this study is called Interpretative Phenomenological Analysis (IPA). IPA is a recent qualitative approach to research that is concerned mainly with exploring in detail how research participants make sense of their personal and social world. This approach emphasises the meanings that specific experiences, events and states have for the participants (Smith & Osborn, 2003). The method attempts to go beyond what people are saying. By taking that which research participants say, the method aims to uncover what participants think and feel. Even though IPA is similar to discourse analysis in terms of its dedication to language and qualitative exploration, IPA places more emphasis on cognitions (Smith & Osborn, 2003).

The IPA is an idiographic or case-by-case approach. The process starts with a detailed analysis of case studies before cautiously moving to more general statements about groups of individuals. The method is normally used with small numbers of participants, i.e. between six and 15, as the method intends to illuminate and depict an intimate interpretation of an individual's experience (Smith & Osborn, 2003).

The author chose this specific method as it allows exploration of the way in which different participants think about their experience of carrying the responsibility for a household as children.

The IPA derives from three theoretical approaches: phenomenology, hermeneutics and symbolic interactionism (Smith, 1996). The approach contains phenomenology's concern with an individual's personal perception of an experience and symbolic interactionism's emphasis on meanings given to those experiences, which are obtainable through interpretation. For symbolic interactionism, these meanings transpire and are comprehensible through social interactions (Smith, 1996). Thus, as important as it is to understand a respondent's world and perspective regarding the topic under exploration, IPA recognises that research is a dynamic process.

IPA also recognises that exploration of the participants is complicated by the "researcher's own conceptions which are required in order to make sense of that other personal world through a process of interpretative activity" (Smith, 1996 p. 264). The method holds that while the researcher attempts to understand the world of a research participant, this can, however, not be achieved without interpretation by the researcher (Smith & Osborn, 2003).

According to Smith and Osborn (2003), IPA employs two interpretative stances: empathic hermeneutics and questioning hermeneutics. Empathic hermeneutics is concerned with elucidating what life is like from the participant's view. Questioning hermeneutics involves the researcher asking critical questions of what is being said by the participants.

A number of qualitative research methods, such as diaries, semi-structured interviews and personal accounts, can be used to gather data within an IPA method. The present study used the semi-structured interview method.

Semi-structured interviews are less formal (TerreBlanche & Kelly, 1999). This interview method is flexible and useful for gaining insight into people's personal beliefs and perceptions (Smith, 1996). Using semi-structured interviews provides an opportunity to get to know people closely and gain insight into how they feel and think (TerreBlanche & Kelly, 1999).

Although semi-structured interviews are implemented with the assistance of a guiding set of questions, the questions do not need to dictate or control the flow of the interview (Smith, 1996). The interviewer's role in semi-structured interviews is paramount. An interviewer or researcher is responsible for the collection and analysis of data, which compels the interviewer/researcher to develop skills such as empathy and listening (TerreBlanche & Kelly, 1999). This type of interview method is valuable when dealing with complex emotional processes and personal issues (Smith, 1996).

As demonstrated in the previous two chapters, limited research using qualitative methods has sought to explore the subject of orphaned and vulnerable children, including children carrying responsibility for households. Research conducted thus far has focussed largely on quantifying the issues involved. The semi-structured interview method offers a number of advantages. The method provides an opportunity for developing rapport with participants (TerreBlanche & Kelly, 1999). The interviewer is also able to follow the interests and concerns of the interviewee (Smith & Osborn, 2003). Another advantage is that the questioning tends to be more open-ended.

3.5 Research contexts and environment

Research interviewees were recruited from three areas: Soweto; Atteridgeville and Gingindlovu. Soweto and Atteridgeville are located in South Africa's densely populated Gauteng province while Gingindlovu is located in Kwa Zulu Natal. In 2005, HIV prevalence among respondents aged two years and older in Gauteng and Kwa Zulu Natal is estimated at 10.8% and 16.5% respectively (Shisana et al., 2005). At present, Kwa Zulu Natal has the highest HIV prevalence rate in South Africa. By proxy, these statistics indicate the level of households headed by children in these provinces, since the increase in HIV prevalence and AIDS mortality results in a consequent rise in the number of such households.

The following information about Soweto was extracted largely from Bonner and Segal (1998) and the Municipal Demarcation Board (2006). However, some of it encapsulates the researcher's own observations. Soweto, an acronym for South-Western Townships adopted in 1963, is the largest black township in the country and comprises 26 cluster townships. As the name suggests, it is located south-west of the City of Johannesburg Municipality. Klipspruit, the oldest of the cluster townships, was established in 1904. This cluster was created to accommodate black mining and industrial workers. Perennial problems that have been a permanent feature of Soweto since its establishment include poor housing, overcrowding, high unemployment and poor infrastructure. These problems have resulted in the proliferation of shacks made from corrugated iron sheets. Furthermore, high unemployment has spawned a number of social ills, such crime, prostitution, substance abuse, and so on.

Other housing types include four-roomed houses and housing extensions built in various areas throughout the township intended to accommodate the middle class. Some of the research participants from Soweto reside in informal settlements. Soweto has been at the centre of a number of politically charged campaigns, the most notable being the 1976 student uprising. The township has produced many notable political, sporting and social figures (e.g. Nelson Mandela and Desmond Tutu). Soweto is undoubtedly at the forefront of trends in politics, fashion, music and dance.

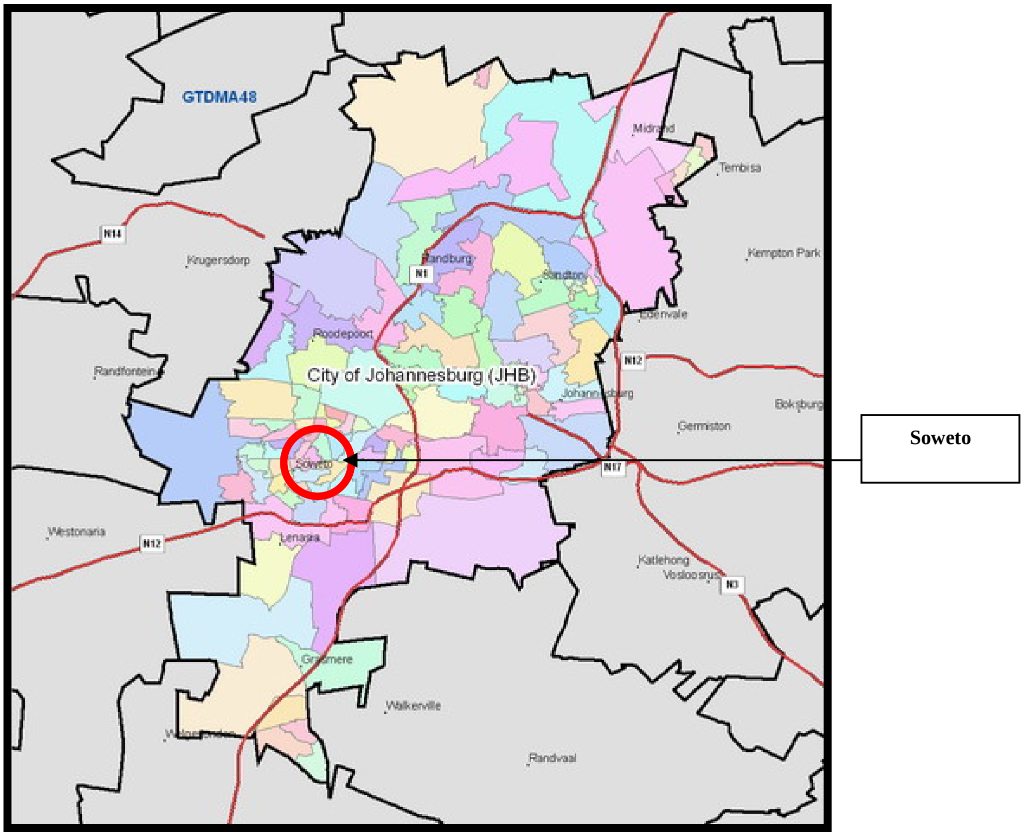

Figure 1: City of Johannesburg
Source: Municipal Demarcation Board (2006) *http://www.demarcation.org.za*

The City of Tshwane township tourism book (2005, pp. 6-9) was utilised to formulate the following description of Atteridgeville township**.** Atteridgeville, one of Tshwane's (Pretoria) townships, was established in 1939. It is situated south-west of Pretoria, bordered by Saulsville to the west, Proclamation Hill to the east, and Laudium to the north. Originally, the proposed name for the area was *Motsemogolo*, which is SeTswana for large town. The township, was, however, named after a former council member, Ms M.P. Atteridgeville.

The township was developed for a number of reasons. Firstly, when ISCOR began production, a need for labourers and nearby housing emerged. Secondly, houses were built in the area to accommodate Africans who had been removed forcibly from surrounding Marabastad, Newclare, Bantule, Lady Selbourne and Hove's Ground under the Slums Act of 1934. Lastly, the township was built to accommodate rural Africans displaced by the Native Trust and Land Act of 1936. Like most other townships at the time, it was viewed as a temporary facility for labour.

Atteridgeville is divided into three sections: Phomolong, Concerned and Jeffville. The population of the area is estimated at approximately 200 000. Housing structures range from modest four-roomed fixtures to shacks. Most of the interviewees resided in informal settlements, areas characterised by high levels of poverty, unemployment, substance abuse and crime.

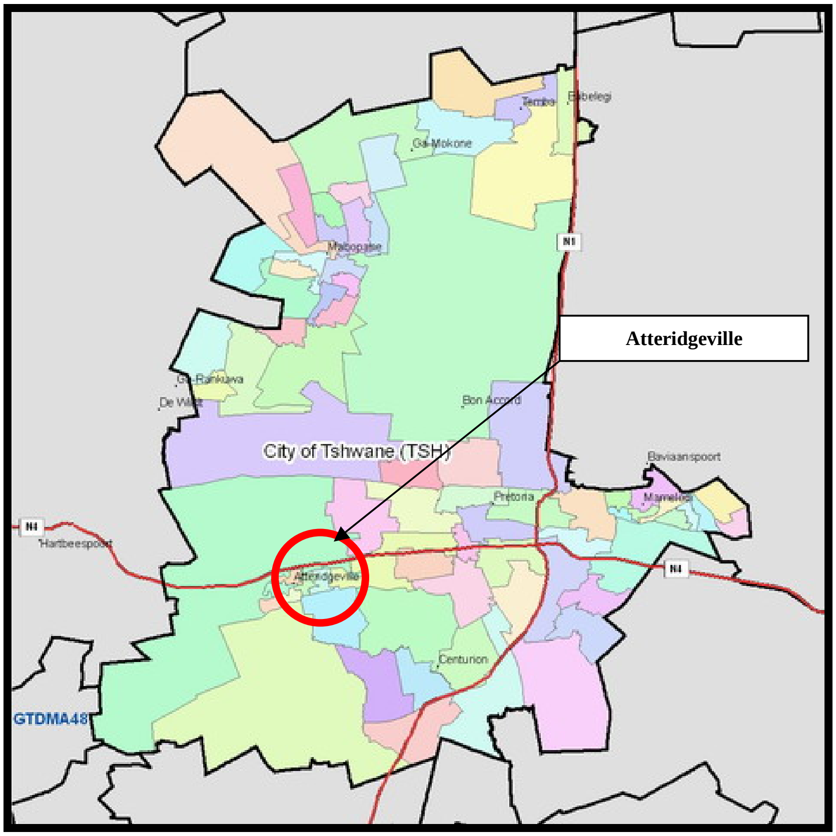

Figure 2: City of Tshwane
Source: Municipal Demarcation Board (2006) *http://www.demarcation.org.za*

The information about Gingindlovu was extracted from the Standard Encyclopaedia of Southern Africa (1972, p. 199) and the Municipal Demarcation Board (2006)**.** Gingindlovu was one of King Cetshwayo’s kraals in the uMlalazi Local Municipality of Kwa Zulu Natal. The name in IsiZulu means ‘the swallower of the elephant’, a term coined to commemorate Zulu King Cetshwayo’s victory against his brother Mbulazi in 1856. Although the kraal itself was destroyed when Cetshwayo was defeated in 1879, the name is still used.

Gingindlovu is a rural area. Housing structures consist mainly of traditional huts called *rondawels*. The interviews were conducted at Emoyeni Holy Cross, a Catholic Mission house dating back to 1895. The interviewees reside in surrounding homesteads.

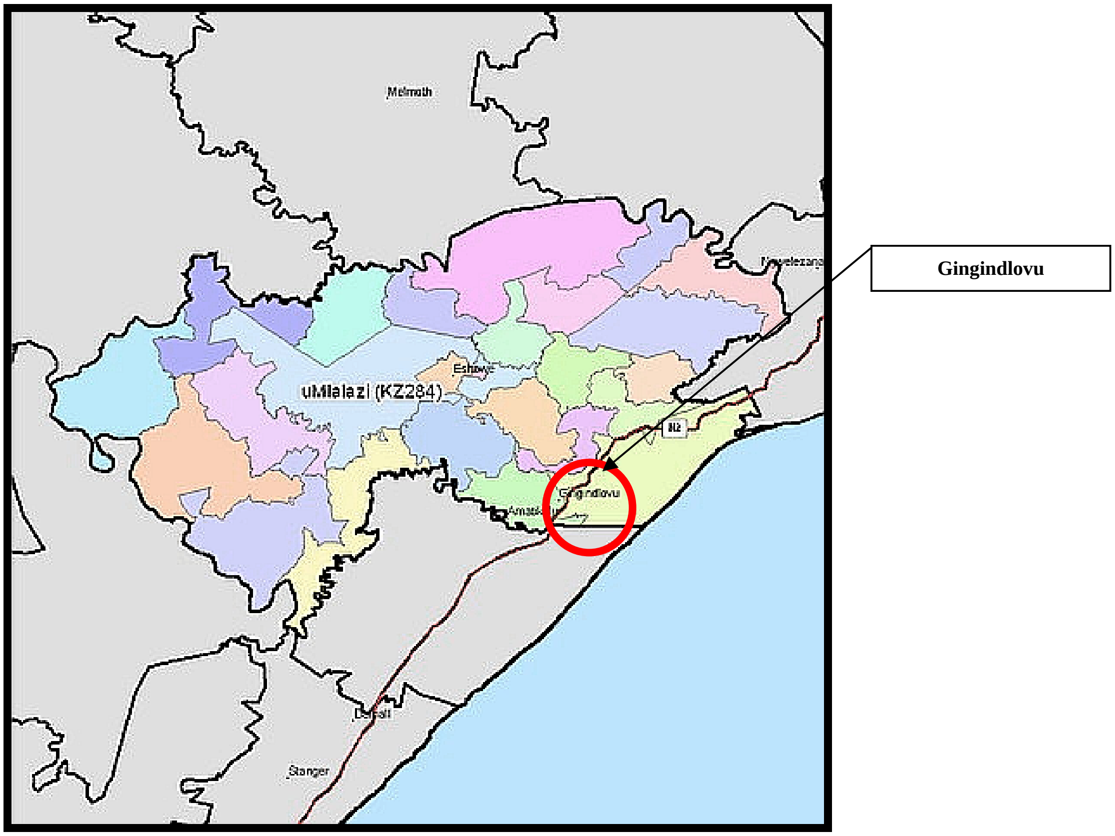

Figure 3: uMlalazi Local Municipality
Source: Municipal Demarcation Board (2006) http://www.demarcation.org.za

3.6 Recruitment process and preparation

Ethical approval for the study was obtained from the University of Pretoria’s Ethics Committee. Permission to conduct the interviews was obtained from the three organisations that assisted the researcher with recruiting interviewees. The first communication between the researcher and the organisations approached to assist with the recruitment was telephonic. Representatives from the organisation requested a letter of introduction, which was either faxed or emailed.

The letter of introduction provided information on the study, the research participants as well as how the organisation could assist with recruiting participants (see Appendix A). The letter also provided both the researcher and the academic supervisor's contact details. The letter thus served to facilitate communication between the researcher and the organisation concerned as well as provide a means by which any queries could be addressed before, during and after the research with either the researcher or the academic supervisor.

One of the organisations approached requested a face-to-face meeting with the researcher before allowing the researcher to interview children under its care. During the initial meeting, the positions of both the researcher as well as the respective organisation were clarified. The organisation also requested the researcher to read and sign their childcare policy, which protects respondents' confidentiality and guards against malfeasance on the part of the researcher.

Once the Non-Profit Organisation (NPO) granted overall consent to interview the children, the researcher and the organisation agreed telephonically on the dates and times of the interviews.

3. 7 Setting the scene: who are the respondents?

A total of 14 children carrying the responsibility for households as a result of parental death due to HIV/AIDS were interviewed. Except for one, all interviewees had younger siblings under their care. While the majority of participants indicated that they cared for at least one younger sibling, five interviewees were responsible for three or more younger siblings. The participants were recruited through NPOs rendering assistance to orphaned and vulnerable children.

Out of the 14 children, only three participants were males. Ages ranged from 15 to 20 years. Eight of the participants were from Soweto, while four were from Atteridgeville. The other two participants were from Gingindlovu.

3.7.1 Interviewee # 1

The first interviewee was a 19-year-old male living with his younger sister and older brother in Soweto. He matriculated in 2004 and intended doing a computer-programming course when funds become available. The interviewee was very forthcoming. On one occasion, the interviewee cried as he related the difficulty of being responsible for his younger sister. Only when the interviewee felt ready to go on did the interview proceed. Despite having lost both his parents at the age of 16, he displayed a positive outlook on life.

3.7.2 Interviewee # 2

The second interviewee was a 15-year-old female in grade 10. She was looking after six younger siblings at the time of the interview. The interviewee also cried during the interview. It appears as if the scars of her mother and little brother's demise were still fresh. She was also grappling with her older sister's frequent disappearances. This interviewee was also very forthcoming.

3.7.3 Interviewee # 3

The third interviewee was an 18-year-old female. She was doing a post-matric draughting course at the time of the interview. The interviewee was relaxed throughout the interview. At the end of the interview, she even voluntarily recited her own poem to the interviewer. Unlike the previous two interviewees, she rarely displayed visible emotional distress, which can be attributed to her self-declared introvert nature. She was looking after her three younger siblings at the time of the interview.

3.7.4 Interviewee # 4

The fourth interviewee was an 18-year-old female who was busy with her matric studies. Her story centred mainly on her experience with her mother's illness and death. Her relation of the facts was, however, very calm. It seemed as if there are a lot of emotions bottled up inside her. Her father also died recently. Unlike her mother, her father had, however, never been a part of her life. At the time of the interview, she was still very angry with her father. She has seven siblings. This includes two older siblings, both of whom currently reside elsewhere.

The interviewee was very upfront about most issues, including the cause of her mother's death, which she voluntarily shared with the interviewer without being prompted.

3.7.5 Interviewee # 5

The fifth interviewee was an 18-year-old female looking after two siblings. She was talkative and frank.

3.7.6 Interviewee # 6

The sixth interviewee was an 18-year-old female matric student looking after one younger sibling. She also has three older siblings, none of whom at the time of the interview lived with her.

3.7.7 Interviewee # 7

This interviewee was a 16-year-old grade 10 female. She lived with her younger brother at the time of the interview. The interviewee appeared to be relaxed and comfortable. She was very open and forthcoming about her thoughts and feelings.

3.7.8 Interviewee # 8

The eighth interviewee was conducted with a 16-year-old grade 10 female. She took care of two younger siblings at the time of the interview. Her father died approximately three or four years ago. Although her mother was still alive, she did not live with them. It seems as if the mother abandoned them while the interviewee's father was still alive. The respondent indicated during the interview that her mother's absence was the source of her anguish and pain, as she felt that a mother should be concerned about her children's wellbeing.

3.7.9 Interviewee # 9

This interviewee was a 20-year-old male who lived on his own. He was in Grade 11. The interview in general went very well. The interviewee was very relaxed and spoke freely. During the interview, he cited difficulties with his school performance. His twin sister was married to an older man at the time of the interview.

3.7.10 Interviewee # 10

The tenth interview was carried out with an 18-year-old female. She appeared very shy and her responses were consequently brief and curt. Long periods of silence occurred throughout the interview. Overall, it was not an easy interview. Perhaps the interviewer needed to have spent more time with the respondent to build rapport. Ironically, she voluntarily disclosed the cause of her mother’s death. She lived with her younger sister.

3.7.11 Interviewee # 11

The eleventh interviewee was an 18-year-old female. The interview on the whole went well and the respondent was honest and direct. The interviewee appeared relaxed throughout the interview. The respondent lived with her four younger siblings. She has an older brother and a sister. Both lived elsewhere.

3.7.12 Interviewee # 12

This interviewee was a 19-year-old female with two siblings. The atmosphere of the interview was very relaxed and at no point during the interview did the interviewer sense or pick up on any distress from the interviewee.

3.7.13 Interviewee # 13

The thirteenth interviewee was a 17-year-old male living with an older sister and her young child. As the older sibling was away most of the time, the burden of looking after the household fell directly on him. He was very soft spoken.

3.7.14 Interviewee # 14

This interviewee was a 15 to 16-year-old female. The interviewee was very shy and spoke very little. Her responses were very short. During the interview, she looked away from the researcher and used her hand to shield and cover her face, almost as if she did not want the interviewer to see her while speaking. Despite repeated requests to face the direction of the interviewer for the sake of the audio recorder, she maintained this position throughout the interview. The interviewee also cried at some point during the interview.

3.8 Data collection process

One researcher conducted all the interviews. Data collection took place over a period of two days in the second week of January in Kwa Zulu Natal and from the first to the third week of March 2004 in Gauteng. The number of interviews conducted on each day varied. On some days, two or three interviews were conducted. Interviews were conducted after school hours or on Saturdays since most of the participants still attended high school. Only two interviewees had finished high school. These two interviewees were, however, also interviewed on a Saturday. An interval of 10 to 20 minutes was allowed between interviews.

Interview sessions were all conducted on the premises of the NPO that assisted with the recruitment. The NPOs all had an office where the interviews could be conducted. Each office had a table and chairs for the interviewer and the interviewee. The interviewer offered snacks at each interview session to create a relaxed atmosphere. Although mentioning the snacks might seem trivial, this added to the methods employed to build rapport with interviewees.

Upon arrival at the venue, both the researcher and the representative from the NPO co-ordinating the recruitment received and welcomed the interviewees. Representatives from the three NPOs that assisted with recruitment extended the invitations to the interviewees and arranged transport to ensure that they arrived for the interviews. The representatives also introduced the interviewees to the researcher.

Before starting the interview, its purpose was explained to each participant. At this stage, it was also explained that everything discussed during the interview would remain confidential. The researcher also discussed the contents of the consent form (see Appendix B) with the interviewees. Although the consent form was in English, it was, however, necessary to translate the contents into the interviewee’s home language (i.e. SeSotho, IsiZulu or SeTswana). The interviewer also asked the interviewees to express themselves in any language that they felt comfortable with. At this stage, the interviewer also requested the participants’ permission to record the interviews.

The interviews were recorded using a SANYO TRC – 580M audio cassette recorder. The audio recorder was placed on the tabletop between the researcher and interviewee, to maximise the quality of the recording. The interviewer and the interviewee sat at a 90-degree angle adjacent to each other. The tape recorder was switched on once the first question was asked and switched off at the end of the interview. The interview schedule (see Appendix C) was also placed on the tabletop to guide the direction of the interview. The tape recorder was switched off in instances where interviewees became emotional to allow them to regain their composure.

The researcher transcribed the interviews. One advantage of this approach is that it allows the researcher to become familiar with the material at a much quicker rate. Crucial information, such as the meaning and significance of a long pause, laughter and other non-verbal cues, may be lost where an independent person is recruited to transcribe the tapes.

The duration of each interview was approximately 45 minutes to an hour. Upon completion of the interview, each tape was labelled appropriately. The labels contained the name, age, sex, venue, date and time of interview.

Although minimal, field notes were made during the interview on issues such as non-verbal cues and the interviewer's general impressions regarding a particular interview. These notes were also incorporated into the analysis. At the end of each individual interview, the participants in Gauteng were given a list of free mental health services in their area (see Appendix D). The South African Department of Health provided this list. The same type list for Kwa Zulu Natal was, however, not available.

Interviewing children on their experiences of carrying the responsibility for households, particularly as a result of HIV/AIDS, is a very sensitive area. There is stigma associated with an HIV positive status, for both AIDS victims and their families. Many children are not informed about the cause of their parents' deaths. As the author is aware of these issues, the interviewer refrained from mentioning HIV or AIDS at any point. The subject was also not mentioned in the consent forms or the interview schedule.

Each child was given R20 at the end of each interview to cover transport costs and also as a token of appreciation for their time and participation in the study. The interviewer also met with the relevant NPO representatives at the end of all the interview sessions to share experiences and preliminary observations. This proved quite helpful as it gave the interviewer an opportunity to better understand behaviours or issues that emerged during the interviews. For instance, one interviewee attributed witchcraft as the cause of her mother's death. Upon discussing this issue with the NPO representative, it became clear that such a belief is quite common in the rural setting where the interview was conducted. The brief feedback session with the NPO representatives also provided an opportunity to arrange for further interview sessions.

Chapter 4: Data Analysis, Interpretation and Findings

4.1 Introduction

This chapter presents the data analysis, interpretation and the findings of the study. The findings emanate from both an analysis of the transcripts as well as from field notes made during the interviews. These findings have been grouped into super ordinate and sub-themes, which are supported by material from the text and the interpretative write up. Before providing the findings of the study, a description of the data analysis will be discussed.

4.2 Data analysis

In qualitative research, data analysis is an ongoing process that often begins when the relevant literature is read during the data collection phase and/or while the interviews are being transcribed (Kvale, 1996).

The IPA approach is employed in the present study. This approach is concerned with a respondent’s psychological world (Smith & Osborn, 2003). When dealing with a respondent’s psychological world, meaning becomes important. According to Smith and Osborn (2003), the aim of interpretative phenomenological analysis is to understand and explore the richness of those meanings. This is achieved through an interpretative engagement with the transcripts by the researcher. The steps that were followed when analysing the current study’s interview transcripts followed the steps described by Smith and Osborn (2003) very closely. A number of additional sources (e.g. Smith, 1996; Kvale, 1996; TerreBlanche & Kelly, 1999) were also consulted.

First, each transcript was read a number of times. The left margin was used to make notes on anything significant that the interviewee was saying. Rereading each transcript several times proved useful in assisting the researcher to become familiar with the interviewee’s accounts. The extensive reading of each transcript also helped shed insights on what each interviewee was saying (Smith & Osborn, 2003). Some of the notes made in the margin attempted to summarise, paraphrase and pick up on contradictions, similarities and differences as well as do a basic interpretation of the responses. Comments were made on each interviewee's use of language or idiosyncrasies. The field notes made during the interviews on the respondent's non-verbal cues supplemented these comments.

The next step involved using the notes and comments in the left margin to develop psychologically meaningful constructs or themes of what was said in the responses. It was important that the link between the text, the commentary in the left margin and the themes in the right margin should be evident. When generating the themes, the author aimed to use expressions that allowed theoretical connections within and across cases yet was still based on the interviewees' specific responses (Smith & Osborn, 2003).

This study made no attempt to connect or cluster the themes generated from the first transcript. This was done only after each transcript had been analysed using the method described above. This approach diverges slightly from the description provided by Smith and Osborn (2003). Contrary to the example in Smith and Osborn (2003) where themes from the first interviewee were employed to orient further analysis, this study analysed each interview transcript separately. It was deemed imperative that recurring patterns and the new issues in the transcripts were recognised.

Once the researcher had worked through the fourteen transcripts, a list of themes was compiled in table format for each transcript (see Appendix E). At this stage, the themes had not yet been connected theoretically or analytically.

The transcript analysed first was used to generate super ordinate themes. These super ordinate themes from the first transcript were in turn used to group or cluster the themes generated in the other thirteen interviews. As recommended by Smith and Osborn (2003), the clustering was validated from the interviewees' responses. The text was engaged with, as the themes for each transcript were clustered. Where unique and additional themes were identified, other super ordinate themes were generated in the subsequent transcripts. At this stage, some themes from each transcript were either merged with other themes or were not used further.

This process generated its own lists, which were subsequently tabulated (see Appendix E). In these lists, identifiers, for example, page and line number as well as opening sentences from good and representative extracts, were added to organise the analysis and to assist with finding the material when documenting the findings. The merging of some sub-themes and formulation of the appropriate main themes continued until the final list was generated (see Appendix E).

4.3 Findings

Four super ordinate themes emerged from the analysis. These are:

- **living with the effects of illness and coping with bereavement in the household;**
- **post-bereavement adjustment and psychosocial consequences;**
- **the mediating and aggravating role of the community/society; and**
- **coping and resilience in the midst of adversity.**

Within each of these super ordinate themes, a number of sub-themes emerged.

4.3.1 Living with the effects of illness and coping with bereavement in the household

A host of issues that could be grouped within this super ordinate theme emerged from the transcripts. These issues reflect experiences with illness and death in the family in general. The following sub-themes will be presented:

- reversal of roles;
- living with illness;
- denial and fear of impending reality;
- grief and a sense of loss; and
- apportioning of blame.

Some of these sub-themes specifically highlight the significance of the period before bereavement. The first part under this section will thus present all the sub-themes that deal with experiences regarding illness. The second part will address sub-themes related to coping with bereavement.

4.3.1.1 Reversal of roles

One of the experiences reported is having to adjust to the reversal of parental and child roles when a parent becomes ill. This experience presents vexing challenges. Under this sub-theme, the accounts provided reveal a range of emotions, including pain and hurt as well as loneliness and depression. These emotions are illustrated in the following extracts. Interviewee # 2 gave the following answer to the question of what life was like during the time that her mother was sick:

> "It was hard! We were used to (pause)…my mother was the sort of person that used to do everything herself…so when she became sick all this changed. We now had to do things for her. We had to wash her – we just had to do everything for her. That was very hard! (The interviewee had tears in her eyes)."

For this interviewee, memories of this time in her life were still filled with pain and hurt, as evidenced by the tears in her eyes as she described what life was like. The next extract poignantly captures the shift in her understanding of what her mother's illness meant. This particular extract is taken from a description that the respondent provided regarding a time when she had to take her mother to a clinic after her mother fell ill. The events of the day intensified her realisation of the seriousness of her mother's illness:

> "At the time, my sister was writing her exams…I took her to the clinic…she could not even walk…I had to organise transport but in the end we sat at the clinic until 8 o'clock in the evening waiting for the ambulance to give us a lift back home. That was probably the very first time I realised that my mother was very ill. She was the sort of person that did things for herself. So this was unlike her. But then I realised that we now had to do things for her."

The change of roles represents a shift in dependence between parent and child. Interviewee # 10 not only realised this fact but also found it very hard to accept. The experience induced feelings of intense loneliness and depression as well as suicidal tendencies:

> "It was difficult because she was ill and I was all alone…I also had to be with her all the time because she always wanted me next to her all the time. At the time my younger sibling was about one year old. I had to look after everyone. I really felt so small at the time. I felt like I could just kill myself… (The interviewee took a long pause)."

The despair and panic is apparent from the above extract. The suicidal ideation points to feelings of exasperation and complete helplessness to avert what was happening. Her life and world, as she knew it, must have appeared to be crumbling and falling apart right in front of her eyes.

4.3.1.2 Living with parental illness

Apart from and in conjunction with the reversal of roles described above are the effects that living with parental illness held for some respondents. As illustrated in the extract below, the adverse effects related to school performance or attendance. Interviewee # 4 describes the events around the time of her mother’s illness. In the extract, she provides a very clear account of how her mother’s illness impacted on her ability to attend school as well as pay attention in the classroom:

> “At the time my mother was ill I could not attend school…I had to dodge school on a daily basis just to look after her. She was HIV positive and she had or there is a small child at home…all this made it hard for me to concentrate at school…I just could not concentrate at school. I just could not concentrate at all. When I was at school I would worry about her. I was just not coping at all. I even failed my standard seven.”

What is most apparent from the above response is the anxiety that the respondent experienced during this period. The fact that she struggled to concentrate reveals how worried she was about her mother’s condition. This interviewee also lived with her mother’s illness in secrecy. It appears as if she felt a sense of shame regarding her mother’s illness. She did not want her teachers to know the real reason behind her inability to attend school regularly or worsening academic performance. The respondent mentioned later during the interview that she failed Standard seven during this time:

> “I had to dodge school very often and whenever my teachers would ask to see my parents I would always make up excuses. I would tell them things like that my parents stay far away or they are not around - just anything to prevent them from coming over. Whenever they asked where I stayed I would give wrong and different addresses each time just to stop them from coming over.”

The sense of shame and the need to keep her mother's illness a secret may have been related to her mother's HIV positive status. In fact, she mentioned later in the interview that she was the only one that knew her mother's status. This issue is discussed in the next sub-theme. Even her older siblings, who were not staying with them during the time of her mother's illness, was unaware of their mother's illness. The interviewer was unable to establish whether the secrecy was something that her mother wanted and encouraged.

For interviewee # 9, the thought of his mother's illness was persistent and obsessive at some point after his mother's death:

> "I remember that, you know, many times before I went to sleep I would always think about my mother. I just could not stop thinking about her. I just could not stop thinking about how sick she was. Eish!" (The respondent looked very sad at this point).

The above extracts illustrate the debilitating effects of parental illness, especially HIV/AIDS-related illness, on the daily functioning of these interviewees. The constant worrying had very negative consequences for the fourth interviewee's school performance. The interviewee struggled to maintain regular attendance at school. Yet, even when she managed to attend, she had difficulties concentrating in the classroom. In the end, she failed Standard seven. Exacerbating her problem was the sense of shame and the fact that she wanted to avoid her teachers finding out about her situation at home.

With interviewee # 9, the thought of his mother's illness became obsessive. He mentioned that he would always think about how sick his mother was every time before he went to bed. Although this is not indicated in his description, these thoughts could possibly have affected his sleeping patterns.

4.3.1.3 Denial and fear of impending reality

With the increasing illness and incapacitation of the parent comes a fear of the impending reality. As illustrated in the next extracts, this point to the fear of the meaning of the loss itself as well as the implications of the loss, i.e. uncertainties around future prospects:

> "I was very scared because I could see that she was going to die. I was scared of what was going to happen to us after her death (There was a long pause at this stage. The interviewee also cried)." (Interviewee # 2).

> "The question then was: What are we going to do because it looks like our relatives are not going to take care of us. I was just confused and didn't know what I was going to do." (Interviewee # 7)

In seventh interviewee's case, the absence of support from the people whom she thought would provide it, i.e. her relatives, made matters even more difficult during this period. However, the difference between the above responses and the following extract from interviewee # 4 is what appeared to be fear coupled with denial of the reality of impending death:

> "She (the respondent's mother) liked to joke a lot. She would even ask what I would do if she was not around. In response, I would tell her that she was still young and she still has lot of years ahead of her…my grandmother was ninety six years when she died. So why would this be any different in her case even though I was the only one at home that knew that she was HIV positive."

In spite of the interviewee's better judgment, i.e. the fact that she knew about her mother's HIV positive status, the interviewee had a hard time accepting the reality of her mother's illness and its implications. The difference between this interviewee and the previous two is what appeared to be differences in the way in which the three accepted the reality of the illness. Even though fearful and apprehensive, the two interviewees discussed first appeared to be willing to accept or acknowledge the inevitable. Both interviewees # 2 and # 7 showed more concern about future prospects post-parental bereavement.

4.3.1.4 Grief and sense of loss

One of the emotions felt acutely was grief and a sense of loss. Although not always articulated explicitly, it was nonetheless evident in various interviews. On a number of occasions during the interview, interviewee # 2 cried when she spoke about her loss. Mostly, this was in relation to losing her younger brother six months before the interview:

> “There are seven of us. Actually, there were eight of us, but the other child passed away (At this point the interviewee cried)”.

Without being prompted, she later described the events on the day her brother died. She started crying, after which the interview was paused:

> “He (the interviewee’s younger brother) was taken to B hospital where they tried to revive him. He was alive for only just five minutes and he then died… (Long pause. At this stage the interviewee cried again).”

The next two extracts capture the varying ways in which participants responded to their loss. In the first extract, interviewee # 3 articulates very clearly the sense of loss and the pain she felt when her mother died. The second extract reveals interviewee four’s initial attempt at repressing her emotions and later how she cried as she told a neighbour about what had happened to her mother:

> “Actually, as I have already told you earlier that I consider myself an introvert, my mother was really the only person I was close to. It really hurt. It really did hurt because I lost the one person I felt comfortable opening up to. For me she was the only person that knew right from wrong. Loosing her really did tear me apart.”

> “I did not cry because I had seen that she had not been well. If I had cried that would have been silly because I was next to her when she became ill…a certain lady from the same street where I stay came over to visit. Initially, I just told her that my mother is not well – she should come back on another day. In the end, I just had to tell her the truth. As I told her everything that happened tears just came rolling down my eyes.”

The loss was devastating for both interviewees. Interviewee # 3 in particular felt that she had lost a best friend and maybe even a part of herself. However, the way she felt about loosing her mother was the opposite of what she reported to have felt when she lost her younger brother:

> “I would say that I was okay because I could see that he was sick and all that. In a way it was easier than my mom because I was not very close to him. I was okay. It did hurt me a bit but then I was okay because I could see that he was sick.”

As opposed to the way in which she responded to the death of her mother, she was more despondent or apathetic and understanding in the case of her brother. Interestingly, there also appears to be differences between the way in which interviewee # 3 responded to the death of her younger brother compared to the way in which interviewee # 2 responded to the loss of her younger sibling. Unlike interviewee # 3, interviewee # 2 took it very hard to the point of blaming herself for the sibling's death. She felt as if she could have done something to avert it. After she had described the circumstances surrounding her brother's passing, the interviewer asked her whether she had gone for counseling and whether counseling was something she felt she needed. This is how she responded:

> "I think so. Sometimes I ask myself questions. For instance, had I not left the room or had I phoned someone immediately or something maybe it would not have happened (At this point the interviewee cried)."

The way in which participants respond to loss differed from respondent to respondent. The interviews also revealed that while some respondents had to deal with their own grief and sense of loss, they also had to cater for what their siblings were going through emotionally with very little outside support:

> "Back then it was very difficult for my sister because she would cry every night…she would complain about missing our mother and stuff…this I would say was very tough for me (Interviewee cried at this point)" (Interviewee # 1).

The following extract also paints a vivid picture of this dire situation.   The extract depicts interviewee seven's response to the question as to how she thought her brother was coping with the fact that it was just the two of them at home. In her response, the respondent focuses on the impact that losing their mother had on her younger brother:

> "My brother would isolate himself quite a lot. He did not want to go out or do anything for that matter. He just did not want to believe. It was almost as if the whole thing was not real for him"

Later on, she describes how this affected her:

> "It was very painful. I think he made things very painful for me because whenever I looked at him…I mean he was not like that. He wasn't like that before. So, I had to think of him and what he was going through in addition to the concerns I had on what was going to happen to us. I was also badly affected because I could not stop thinking about my mother as well."

The fact that respondents had to deal with what their siblings were going through emotionally on top of their own grief and concerns about the future complicated matters only further.

4.3.1.5 Apportioning of blame

Another sub-theme that emerged from the transcripts relates to apportioning of blame for the death of a parent. Interviewees # 13 and # 14 viewed the deaths of their parents as caused by people that did not wish them well. These views illustrated their belief in witchcraft. Interviewee # 14 revealed that certain members of the community are calling her and her siblings names because of fear that the respondent and her siblings have intentions of avenging their mother's death. When asked by the interviewer exactly what she thought they did to her mother, this was her response:

> "A bird came in the middle of the night and killed her. At other times they would send (Inaudible), and it would defecate outside our home."

For interviewee # 13, there was both a sense of confusion and uncertainty around what caused his parents' death. A belief that people were behind the death may be impeding closure and the resolution of his pain. He reported to have felt dissatisfied with explanations provided about the cause of his parents' death. This is what he initially had to say on this issue:

> "I do get angry because I do not even know what the cause of my parents' death was. I wish to know. When I ask about their deaths, I do not get a satisfactory explanation. My mother just became ill and died. At the hospital they just said that she died of a 'natural disease', but I do not know what this 'natural disease' is. That really does get to me."

Later in the interview, he revealed the following:

> "Sometimes I think that somebody caused it but I am not very sure that somebody could have killed them. But there was a disagreement between my family and some neighbours…"

Although the interviewee did not clarify exactly what he meant by the last statement, it would seem to imply that he believes the disagreement might have been behind what happened to his parents.

As a final note on this sub-theme, it is worth mentioning that interviewees # 13 and # 14 reside in a rural area of Kwa Zulu Natal where beliefs in witchcraft still hold sway and are likely to be believed as opposed to a more medical diagnosis, such as HIV/AIDS. This can, however, not be generalised to similar respondents in the same context. It may simply reflect the accounts and understanding of these two interviewees.

4.3.2 Post-bereavement adjustment challenges and psychosocial consequences

This section focuses on the respondents' post-bereavement experiences. The section will present findings on how the interviewees make sense and derive meaning from being child-heads. The following sub-themes will be presented:

- lost childhood and self;
- sense of obligation to family;
- sense of abandonment and neglect;
- concern over survival;
- grappling with conflicting demands;
- helplessness and uncertainty.

4.3.2.1 Lost childhood and self

One of the significant issues that emerged from the texts relates to lost childhood and self. For some of the respondents, this issue captures feelings around having to assume responsibilities of an adult when they still consider themselves children. It also includes a sense of deprivation and exclusion from developmentally appropriate activities, i.e.

participation in activities that other children of their age are involved in. This issue describes feelings of losing a distinct and separated identity.

The following extract depicts third interviewee’s response when asked to describe what it meant for her to carry responsibilities at home:

> “I feel that my childhood has been taken away from me. I am now not only a child but I have to be both a child and a mentor at the same time. I now have to adjust from the things that I used to do before like going out to have fun. If I go out, who will look after my siblings? I have to look after them. I have to ensure that they are well and that when they come back from school they do their home work. I mean, who does that at my age? People at my age want to do their own stuff. The last thing on their mind is being a mother and a father at home. It really is difficult getting used to.”

Interviewee # 4 had something similar to say when the same question was posed to her:

> “Being responsible at home is tough you know. Seriously it is tough. You know there are things that you think you can do…I am only human. I’m still a child after all. I still want to be like other teenagers. Before I found myself performing this role I was not thinking about getting food, doing washing or things like that. When you have money you do not enjoy it like other children your age because you constantly have to think about the situation at home. You know your parent’s house is now like your own…when people ask about the mother of the house they are actually referring to you.”

Both extracts express very strong views and feelings on the subject. The accounts present lucid snap shots of the suffering and the pain endured as a result of losing one’s childhood from having to assume adult responsibilities at an early age.

It is also apparent that adjusting to the role is an ongoing activity. For example, interviewee # 3 points out that she now has to be a mentor. This may also involve being a role model, a burdensome task that leaves a very small margin for mistakes. The last extract in particular points to the sacrifices that the respondent has to make. Unlike other children her age, she cannot afford to be self-centred. She is hinting at the fact that, perhaps unlike other children her age, the role that she performs at home requires that she think about herself last.

Interesting is the somewhat contradictory, although optimistic, view that interviewee # 3 later expressed regarding her situation:

> "In the beginning it was very difficult adjusting from a being a kid to looking after other kids. But after a while you get used to it because it is like 'okay so this is what I must do' and 'this what I must not do'. You just get used to it. It is difficult, though, because on the one hand you have to be a child and on the other hand you also have to be a mother and mentor to the other children. It is difficult but then you can deal with it."

The above extract suggests a certain degree of adjustment, especially from the practical point of view, i.e. the practical things that need to be done when running a household. It does, however, not imply acceptance of the role, particularly from an emotional point of view. Interviewee # 3 seems to recognise the conflicts inherent to the role. It appears as if the role for her entails or requires adjusting and living with two divergent identities, i.e. being both child and mother.

4.3.2.2 Sense of obligation to family

In combination with the loss of childhood and self, some of the respondents revealed a feeling of obligation to the family or siblings. What is interesting about this issue is that while there is a sense of feeling aggrieved by what life had thrown to them, there is also a strong feeling of responsibility and obligation to the younger siblings. The following three extracts serve as examples. The first extract was taken from interviewee # 1. Although short, it paints a very lucid picture of the seriousness with which he views his responsibility:

> "The first thing that is of concern for me is her happiness (the interviewee's younger sister) instead of mine. It is the most important thing at this point in my life."

This is what another interviewee had to say:

> "Just like I have already mentioned, there are six of us at home. There are four boys and two girls. I am the oldest girl. When it comes to the boys in the family…well boys will always be boys. They don't take things seriously. When one of them has money he won't bother with the rest of us. In my case, I have to think for the others. What they eat is a concern of mine." (Interviewee # 5).

The next extract is interviewee twelve's response to a question aimed at getting a sense of how she sees herself in comparison to other children that are not in her situation:

> "It is different for me because I have to think for my younger sibling all the time. Finishing school is important for me because at least with an education I will be able to continue looking after my sibling."

It is apparent from these three extracts that the respondents are driven by a sense of duty and the need to close the gap left behind by the death of their parents as best as they can. This is also complimented by a feeling of compassion for their siblings. The researcher did not establish whether these feelings stemmed from a promise they made to their parents. It appears from the next sub-theme that these feelings are fuelled to some degree by a sense of abandonment.

4.3.2.3 Sense of abandonment and neglect

This sub-theme focuses on experiences of abandonment. It transpired during the interviews that some interviewees felt a sense of abandonment, especially from people that they expected support from, such as relatives. Interviewee # 5 displayed visible signs of anger and disappointment when she spoke about the lack of support from relatives:

> "My aunts are only concerned about their own children. They don't bother to care if you are not their biological child. When they ask about my siblings whenever I see them I always tell them that they are all right. Even when they offer to buy bread for us I always refuse their help. I don't want their money because they don't care. They were only with us during the funeral and left soon after. When they left they did not bother leaving us some money for food or for my younger sibling's crèche tuition. We had to find means to raise the money. I don't put them anywhere."

Interviewee # 5 feels a great deal of disappointment. It appears as if she may have expected her aunts to play a significant role in their care in the event of her mother's death. This did, however, not transpire. In her case, the anger also emanates from a feeling that neither she nor her siblings are as important to her relatives as their own biological children. Furthermore, she is angered by what appears to be a family dispute that she and her siblings are caught in middle of:

> "There has always been this rumour that my step grandmother has a bad heart. You know things like that. My aunts don't like her. I used to stay with her and I am still very fond of her. I think my aunts are just being irresponsible. They have no interest in what we eat or how we sleep…"

The influence of unresolved family disputes on present circumstances was also an issue for interviewee # 6. In her case, the dispute was between her father, who was still alive at the time of the interview, and her mother's family. Although it could not be established clearly during the interview, the issue involved may originate from unsettled dowry or *lobola* negotiations:

> "My father's family does not get along with my mother's side of the family. They claim that my mother's family is uncaring and they say bad things about my mother. My mother and father were supposed to marry…those things have nothing to do with me. These things do affect me because these two people to me are one person."

What emerges from the two extracts is the role of complicated unresolved family disputes and histories in the interviewee's current predicaments. This, in turn, has resulted in the respondents feeling neglected and deserted.

For interviewee # 10, the feeling of abandonment is heightened not only by the lack of assistance and involvement by her relatives but also by the negative things that her relatives are saying about the way in which she cares for her siblings:

> "They (the respondent's relatives) are not helpful at all. They don't visit and they talk about me with other people. They say that I don't look after my siblings…it feels bad because the way I see it that they don't love me. At the moment, I really do need the love of an adult that I am related to."

This interviewee's last statement raises an interesting point: the need for her to feel loved and connected to her relatives. It may also be indicative of a need for continuity and connection to her past and family roots.

The issue of absent parents, especially fathers, also emerged during the interviews. This issue was, however, not explored in greater detail in the interviews. Only interviewees # 4 and 8 discussed the issue in detail. For interviewee # 4, the focus was on her father's absence in her life before his passing. For interviewee # 8, the issue is her mother's continuing absence, even though she is still alive. The similarities between the two respondents, as illustrated in the following extracts, are the feelings of anger and hurt that the two described regarding the two people concerned:

> "My father and I met only last year February. I was unwilling to forgive him. Even if he had been the richest man in the country or the president, I would not have forgiven him…when he passed on, I only attended the church service and I never went to the cemetery. After the funeral, his relatives came over to see me. They inquired about my behaviour. I responded by asking them where he had been all this time"

> "In my case it can be very difficult because I know that my mother is still alive, although I don't know where she is. Is she at all concerned about us? Does she even care whether her children eat before they go to bed or whether they have lunch money for school? Maybe she is okay wherever she is, but has no idea how her children are doing."

Even though the fourth interviewee's father has since passed on, it was apparent from the interview that she still carried a lot of anger inside. Both her past and present difficulties may be fuelling these feelings of anger. In the past, she carried the responsibility of looking after both her siblings and a mother who died from the complications of HIV/AIDS single handedly. As mentioned previously, interviewee # 4 was the only one in her immediate family that knew about her mother's HIV status. At present, she is still responsible for her siblings. Interviewee # 8, on the other hand, appeared to be struggling to make sense of her mother's absence in view of her present challenges.

4.3.2.4 Concern over survival

Probably the most commonly cited concern relates to survival. This manifested itself in statements with underlying messages illustrating concern or preoccupation with survival. The issue focuses specifically on how the respondents survive in the absence of parents or adults. This sub-theme focuses on the effect of economic disadvantage and financial hardship on the relevant respondents' experiences The various manifestations include anxiety over a number of issues, such as food, clothing, school fees as well as having electricity at home. The next extracts demonstrate these concerns:

> "Yes we do run out of food. Last weekend we did not have food and it looks like we won't have food this week either. We have not yet received food parcels for this month." (Interviewee # 4).

> "You know because I am the oldest at home at the moment, when we do not have bread and my younger sibling is hungry I have to think of something. You know if my mother were still alive I would not have to worry or be responsible for these things because I would be looking at her to provide for us." (Interviewee # 6).

> "Even when you have an opportunity to do something at school or even just enrolling, one needs money to do this. You don't know where you will find money to go to school. It is those kinds of things that make life very difficult." (Interviewee # 12).

The last extract captures the sense of desperation often experienced by the respondent when there is no money. In this respondents' case, what discourages her from acting on the desperation is the sense of obligation and responsibility towards her siblings. A further discouragement is that if she were to act on her impulse she might subject her siblings to more illness, suffering and hardship.

The following response follows from the question posed as to what carrying the responsibility for a household meant to her:

> "It is a very difficult thing because sometimes I don't have money and there is really no one that can help except HB…I feel like I could just sell my body and yet at the same time I feel like it would be wrong for me to do this because I will get sick and only make matters worse." (Interviewee # 10).

Despite all the respondents receiving some form of assistance from the organisations responsible for their recruitment, these concerns represent ongoing challenges. These challenges can only fuel the sense of vulnerability and instability experienced by the respondents, often to a point of desperation, as indicated by interviewee # 10.

4.3.2.5 Grappling with conflicting demands

This particular sub-theme deals with the challenges of running a household as a young person in the context of other competing demands on time, i.e. the pressures of juggling and managing multiple responsibilities. Having to deal with the social pressures confronted by siblings complicates matters even further. These challenges are exacerbated by the fact that the persons concerned are also young people themselves with their own individual concerns and difficulties.

The following extracts depict feelings of being overburdened. These extracts served as responses to the interviewees being asked to describe the challenges they are faced with:

> “The challenges that are there…I mean you can’t be a school child, a mother, a brother, and a sister all at the same time. At most times when you come back from school you have your own books and home work to look at. Yet, when your siblings need something, you have to attend to that as well. You can’t say ‘this or that person will handle this’. Everything falls on your shoulders. Those are the challenges I’m faced with.” (Interviewee # 6).

> “You know sometimes at my brother’s school there are parents meetings that I have to attend. These meetings clash with other activities, such as school. In the end, it becomes very difficult to do both. I can’t be at school and at he same time be expected to attend parents meetings at my brother’s school.” (Interviewee # 7).

> “Sometimes it is very difficult to balance taking care of them (the respondent’s siblings) and attending to my school work. There are a lot of responsibilities…between school and activities at home, there is just too much. One does not even find time to think because there are just too many responsibilities…in the end one feels pressured to do the right thing. There is pressure to get good marks at school on the one hand. On the other hand, one also needs to be someone that one’s siblings could be proud of. There is just too much pressure sometimes.” (Interviewee # 2).

For interviewee # 2, the feeling of being overburdened also betrays a fear of failure both at home as well as at school. This contention is supported by another statement by the respondent made later in the interview. The response was in reference to the interviewee being asked to describe some of her fears and concerns:

> “To fail would be my first fear. I have never failed any grade ever since I started school. This year things are very challenging. That is like big. On the family side, I would like to see us remain as we are.”

At home, in particular, the reported fear emanates from a feeling that her family is disintegrating, to be reported later under helplessness and uncertainty. It is also apparent from the two extracts as well as from other responses to be reported on later under helplessness, and uncertainty, that she saw it as her major responsibility to ensure that 'things', especially things at home, do not fall apart. The extracts give the impression that these young people take their roles very seriously. They show a great concern for getting things right. Yet, what is clearly evident is the stress and pressures involved in doing everything and also striving to get everything right.

One other difficult issue confronted by child-heads that became evident during the interviews relates to the need that siblings experience to conform or fit in with their peers. This often presented itself in the form of a desire to have the latest fashion outfit, cell phones, etc. What makes this particularly hard is that considering the difficulties at home, fulfilling these desires is almost impossible. In a sense, this issue leads to frustration and even despair, especially for the child-heads, as indicated by the following extracts:

> "I would say that some of the challenges, especially when it comes to looking after my sister is growing in this world where everybody is trying to keep with the world…it is very difficult to provide for certain things because nobody at home is employed. Whatever money that we have is there to cater for the basic needs…at the moment, my sister does not have a cell phone…she complains about this often…that is the one challenge I am confronted with where she is concerned…" (Interviewee # 1)

> "My situation becomes more difficult because my younger sibling is very fashion conscious…for her fitting in is very important. Her friends are also just as fashion conscious." (Interviewee # 5).

4.3.2.6 Helplessness and uncertainty

The issue of helplessness, vulnerability and uncertainty emerged from the discussions held. This manifested in various ways: preoccupation with personal safety; concerns over family disintegration; instilling discipline; preventing abandonment as well as uncertainties over the future.

Some of the female respondents expressed concerns and fears regarding personal safety. One of the interviewees pointed out during the interview that many young females in similar situations feel that they are vulnerable to sexual assault as they live alone. In this regard, she cited an example of someone that she knows who is also a child-head and has been sexually assaulted by a relative. Other interviewees mentioned living with the uncertainty or fear of being burgled because of the same reason provided above, i.e. living alone.

Although unique to interviewee # 2, another concern and source of helplessness to emerge is family disintegration. This fear is borne from the experience of having one of her siblings disappear constantly. As depicted in the following extract, she feels helpless and unable to do anything to prevent this from happening:

> "If only my sister could come back, sit with us and explain why she always wants to run away. What is it that she thinks is going wrong, and what she would suggest we do differently to correct…I feel like my family is falling apart. It is not the same family I knew before my mother died (long silence). Our home was very warm when my mother was still alive. You could feel the love and the warmth but now it just feels empty."

Various other manifestations of helplessness and vulnerabilities transpired from the interviews. The next extract, taken from interviewee # 3, focuses on her feelings of helplessness when it comes to instilling discipline in the household:

> "You cannot take sides because if you do the other child might get angry with you…at times you just have to speak to them, but then this does not always work. It has happened that when trying to discipline one of my younger siblings, the fight just got bigger to a point that everybody got involved…my younger sister is stronger than me when it comes to instilling discipline…when she talks everybody listens. But then when I talk nobody listens. I end up crying as a result."

The interviewee expressed her concern regarding how her siblings would turn out, considering that the sister she speaks of in the extract above is pregnant. She mentioned that she was most worried about her 13-year-old brother, whom she says she has difficulty controlling as he grows older. When asked what it is about him that she finds difficult, the only thing she could say was that she "cannot handle boys". This reveals that she is feeling somewhat out of control. There is also the concern or wish that her siblings would turn out well, that they would follow her example. This is a similar concern as the one expressed by interviewee # 6: “I so wish that my younger sibling could follow in my footsteps...I so wish that she could turn the way that I have”.

For both of these respondents, discipline and instilling obedience amongst their siblings are clearly issues of great concern.

The next extract centres on the eighth interviewee’s anxiety over losing her home. It is apparent from her response that she feels this way because there are only children at home and that they are thus helpless and vulnerable to property grabbing. When asked about her fears and concerns, she responded as follows:

> “My biggest fear is that somebody may decide to take our house, especially because there is no adult at home…what has brought this fear about is because there is no adult at home. Anybody could just come and lay claim over the house. Anybody could claim to be a relative and produce documents that prove that the house belongs to them, and we would not be able to do anything about it.”

The following extract revealed both a fear of abandonment and a sense of helplessness. The extract was taken from the first interviewee’s response to a similar question as the one posed to interviewee # 8:

> “The one fear that I have is that what will happen to us if the help that we receive from II were to cease. Before we got help from them there was another organisation that used to assist us. When it withdrew we were left stranded for two months without food… so the one thing that worries most of us is this” (Interviewee # 1)

It should be mentioned that the above fear and the feeling of helplessness inherent therein were very common among the respondents. This attests to the significant role that the organisations assisting the respondents are playing in their lives. However, in the case of interviewee # 1, the feeling stemmed from an actual experience with being abandoned by an organisation that used to provide assistance to his family. The role that these organisations are fulfilling in helping the interviewees cope will be addressed in greater detail in the last section in this chapter.

The next case reveals a different source of helplessness and uncertainty. Before this response, the interviewee mentioned that he tends to think a lot. The excessive thinking seems to indicate a great deal of anxiety over his future. When asked by the interviewer to describe what he thinks about, he responded as follows:

> "I am always thinking about my life and the future. I think a lot about my future. What is going to become of me when I finish school? What am I going to end up as in life? I have dreams of becoming a chartered accountant. Will I be to fulfill this dream considering that I have nothing at the moment? Those are the things I think about a lot." (Interviewee # 9).

The above extract also indicates a need by interviewee # 9 to make succeed in life, so much so that it is something that he is constantly preoccupied by. What came up earlier in the interview with interviewee # 9 is that at the time his mother illness, she asked him to persevere with schooling. It is probably against this background that the need to continue with education post-matric becomes very significant. Yet, the fact that he has no foreseeable promise of support with education presents a challenge and a source of helplessness and uncertainty regarding his future.

4.3.3 The mediating and aggravating role of the community/society

Some of the questions asked focused on the interviewees' experiences in the community/society and with social support. This section presents the findings on these issues. As was the case in the previous sections, these findings will be presented on the basis of sub-themes that emerged from the data. The following sub-themes are to be presented:

- social support;
- trepidation over community support;
- social criticism and judgement; and
- community intervention.

4.3.3.1 Social support

Experiences of social support cited can be classified under spiritual, instrumental and moral support. Spiritual support reflects experiences with support from church members. This was mainly expressed through church members praying for particular interviewees. What is also apparent from the responses is the significance and importance that this holds for the particular interviewees. When the interviewer asked interviewee # 11 where she gets her strength from, she responded as follows:

> “I go to church. I talk to people in church about how things are at home. They always make it a point that they come over to visit and pray for us. Everything after that always feels better...”

The next section explores the issue of religiosity and faith as a coping mechanism in greater detail.

Instrumental support included instances where some respondents reported having received tangible support from neighbours, relatives or even a school principal. After interviewee # 13 pointed out that the teachers at his school are aware of his situation at home, the interviewer asked whether he felt that the people at school were sympathetic. He responded thus:

> “I would say that they are sympathetic because the school principal has told me that I should not be paying school fees. This has certainly lessened my concerns.”

Another example of instrumental support comes from interviewee # 1. The interviewee’s response was in reference to the interviewer’s question on how he would describe his and his siblings’ relationship with their relatives:

> “When my parents passed away we became even closer...there is no one in the family that is well off. There is no one in the family that is wealthy or very successful financially. Yet, in spite of that our relatives always make it a point that they share whatever they have with us. Whatever they have they share with us.”

The above extract points to the poverty that not only affects the respondent and his siblings, but also extends to other family members. By drawing attention to this, the interviewee emphasises not only to the nature of the relationship. It would appear as if he is conveying a sense of gratitude.

In other examples, respondents reported instances where in the absence of tangible help, those around them have offered a word of advice, encouragement and motivation. These responses were classified under moral support. The next two extracts are illustrative:

> "Community members are very supportive you know. They always ask how I am or where I have been if they have not seen me for a while. Although I sometimes think that they are fussing over me but I have grown to understand that they are just concerned about us." (Interviewee # 5).

> "Certain community members know about our situation at home and they are very sympathetic. They always share a word of encouragement and sometimes help where they can." (Interviewee # 11).

Although a number of respondents could cite examples that could be classified under these three levels of support, some were quite sceptical regarding the interest and support shown. The next theme reports on this scepticism.

4.3.3.2 Trepidation over social interest and support

Interviewees # 1 and # 13 conveyed a sense of trepidation regarding the interest, and to a certain degree, the support received from some community members. There were, however, differences in how this issue was expressed. Interviewee # 1 was very interested in the interview's occupation at the beginning of the interview. In fact, he wanted to know whether the researcher is from the media. This comment made sense later on during the interview when the respondent made the following reference to heartless and insensitive people:

> "There are people in the past that have made promises. Certain people have made promises, empty promises, which at the end of the day add up to nothing....others, especially the media, when they want a headline story, they make certain promises. They promise to help you with this or that thing. These become just empty promises at the end of the day...it feels like we are a laughing stalk really..."

In a similar tone, the respondent also showed scepticism later during the interview over support shown by certain community members. He felt as though some community members were not genuine with their support and only provided help so that "the whole township knows about it":

> "Other community members let me say that you urgently need money...they always take time to help you...you have an urgent need for it and yet they always take their time. They do have the money. They just want to give you the run around. This feels like they are making fun of you and they just want to feel important at your expense...when they do something for you, the whole township has to know about it."

In both extracts, the interviewee shows a deep level of scepticism and cynicism. It appears as if he feels that those around him take his situation for granted. He seems to feel that other people are using his situation only for their own gain and glory without due regard for him or other young people in his situation. Whether justified or not, it is apparent from the extracts that interviewee # 1 felt very aggrieved when it comes to this issue. Another example pointed out during his interview related to do with instances at school where teachers use young people in his situation as examples during class discussions on poverty:

> "At school when there is a discussion about poverty and suffering – you provide the perfect example. Whatever you say will be considered as authoritative or wise because you have been or are going through that situation. When another person who is not in the same situation makes a contribution to the discussion it will not be considered...this is not nice because you are actually being judged at that point..."

Although the teachers may mean well in inviting his input in the discussion, such behaviour causes damage to interviewee # 1.

Interviewee # 13 felt that moral support alone was not sufficient. In his view, moral support would be more meaningful if backed up with actual tangible support:

> "Most people in the community just talk to us only – they do not give us anything. They just tell us to get educated. It's just that and it does not help us very much...it should not be words only and no action. People should back up their words with action."

Interviewee # 13 may perhaps be overlooking the possibility that other people in his community, which happens to be in a rural setting, are also caught up in their own poverty. Thus, although they may want to help, they may often be unable to. As a result, the only form of support that they could provide is moral support. However, this assertion was not validated or reflected back to the respondent during the interview.

4.3.3.3 Social criticism and judgment

This issue deals with experiences of criticism, stigmatisation and judgment from other community members. The section also considers the responses reflecting fear or avoidance of criticism and rejection. It should be mentioned from the onset that, while these experiences emerged during the discussions held, the interviewer was unable to establish whether these feelings were related to how the respondents' parents had died.

The most lucid responses on experiences of criticism and judgment probably stem from the next few extracts. The first quotation is taken from interviewee three's response as to how she would describe her relationship with her neighbours. She commented on how some people are quick to judge her without a sufficient understanding of what it means to be in her situation or which factors within her home leads to her behaviour outside the home. The behaviour in question is what, in her opinion, some community members view as her 'arrogant' attitude. Although she initially stated that her relationship with her community "is quite good", she revealed the following later on in the interview:

> "Actually people can like reject you and stuff. They think that, okay the mother is not there or whoever is not there (inaudible)...they tell you about the things that you do outside but then they have no clue what happens once you go in that door. They are like outside you do this or that without any understanding what happens in the house that leads to what you may be doing outside."

The following response reveals how intense interviewee six's feelings are on the subject of how she thinks child-headed households are perceived. She had tears in her eyes, as she responded to the question on how she thinks the community perceives them as a household:

> "I could say that where I stay there is a problem...they say funny things without thinking how this makes you feel. When a white person comes over to see us, they say things like: 'she thinks she is better than us because there are white people coming to see her'. I don't understand why people have to be like that...I just don't know (the respondent had tears in her eyes)."

Some community member's behaviour towards interviewee # 6 is a source of confusion; "I just don't know why people have to be like that". Her response revealed, however, that these feelings might stem from jealousy: "She thinks she is better than us because there are white people coming to see her".

Unlike interviewees # 3 and 6, interviewee # 14 feels that this criticism seems to originate from a history of dispute between families. The interview was, however, unable to establish whether there had been other forms of violence other than the respondent's accusation that these neighbours killed her mother. This is what she had to say:

> "They (respondents' neighbours) call us names. They call us orphans (*intandane*). They also think that we want to avenge for what they did to our mother through their children (the respondent mentioned later that they killed her)."

The following extract comes from interviewee # 2. Unlike the previous extracts, this one shows a fear of criticism and rejection. This extract also refers, although indirectly, to the cause of the parents' death as something that might be a possible reason for other people to discriminate against the respondent. This reference was not present in any of the other extracts. The response is based on the respondent's answer to the question on what she believes to be the fears and concerns of young people carrying the responsibility for households:

> "A lot of us fear how other people would treat us if they were ever to find out how our parents died..."

It was not established whether this fear is based on actual experiences with stigmatisation or whether it is imagined. The interviewer was unable to ascertain the extent on her personal experiences with stigma and discrimination or whether this was something that she feared for herself as well as her younger siblings.

4.3.3.4 Community intervention

One of the questions asked during the interviews, although not consistently, related to how the how the respondents could be assisted. The question focuses on the role of the community in assisting young people who find themselves in this situation or, as in the case of one respondent, how the government could be of assistance.

Before discussing the findings that emerged, it is important to note that a sense of responsibility towards the community transpired from the texts. Despite the concerns expressed regarding their own survival, it was also apparent that the respondents recognised, at least to a certain extent, the suffering around them. Interviewee # 1 mentioned that he would like to help out in the community. When asked exactly how he sees himself assisting the community, she responded as follows:

> “Just give back to the community what they gave to me. I just want to help out in the community because when you look around there is a lot of poverty and suffering in the township. There is a lot of suffering in the country. I just want to help out and make a difference some day”

Responses from other participants had a similar tone. Examples are apparent in instances where respondents were asked what they would like to do when they finished school. Some mentioned professions centred on helping others as possible future career options, with social work being the most popular idea. When asked to elaborate further, these respondents identified difficulties faced by other people around them that they would like to make a difference in. Perhaps out of their personal experiences with suffering and poverty, there is a growing sensitivity and empathy for the suffering of those around them.

Some interesting ideas emerged from the texts on how young people faced with adversities could be assisted. The following response focuses on action that will result in material improvement. Central to this proposal is the need for the community to become proactive and achieving community solidarity in the interest of vulnerable children in the communities:

> “What I would like to see, what I hope will be done in the future is for the community to actually join hands and just not sit back, but spring to action...I believe that there is a lot that can be done if the community sat down and planned or if the community would donate like R10 towards some fund geared for buying clothes for disadvantaged children. The same fund could also be utilised for groceries and other things, such as school fees.” (Interviewee # 1).

The next respondents focussed on more attention, interest and having people from the community that they can talk to. Interviewee # 2, in particular, points specifically to the need for a mentor as well counselling and guidance for children carrying the burden of responsibility for households. Also important, as implied from interviewee 2's response, is the idea that community members should be doing more by simply being there. The central ideas emerging from the following extracts are one of a need for community acceptance and belonging:

> "For me, I would say that they should give us positive feedback and stuff like that...they should also just talk to us. Talking does help..." (Interviewee # 3).

> "To have somebody that one talk to is very important. Sometimes a person can be given things, but a person also has to be listened to...I think that people should take it upon themselves, I am not saying that they should replace our parents, but they could be mentors. Sometimes it is not easy to talk to one's friends at school or anywhere else for that matter on personal issues. We need people that can play that role of a mother or father, although I don't mean that they should replace them...we also need counseling because sometimes someone may do something stupid because they assume that it will ease the pain...so without people do educate us nothing will ever be right." (Interviewee # 2).

The previous sections reported on the interviewee's experiences with illness and death, both parental or sibling, post-bereavement adjustment challenges and psychosocial effects. The section also discussed the interviewees' experiences in the community/society along with their views on how the community could be assistance to them. The last section will focus on how the interviewees deal with the situation that they find themselves in.

4.3.4 Coping and resilience in the midst of adversity

In this section, the focus is shifted to the way in which the interviewees cope in the face of the difficulties presented in the previous sections. The attention turns to the ways in which the respondents make sense and generate meanings from the situation that they find themselves in. In total, eight sub-themes will be presented, namely:

- fatalism;

- religiosity;
- positive outlook and attitude;
- deriving meaning out of hardship;
- restored sense of purpose and meaning in life; and
- sources of respite.

As in the previous sections, the presentation follows the order of the listing above.

4.3.4.1 Fatalism

This particular sub-theme examines the interesting way in which some of the respondents have assimilated the reality of carrying the burden of responsibility for a household. What transpired in these instances is how the particular respondents involved have resigned to the reality that they find themselves in. It is a view that believes the situation to be fated or predestined, as demonstrated in the next example:

> "I've accepted this as my fate. Maybe, I am the sort of person that must struggle through life in order to succeed...I think this is something that God has given me – the fact that I must struggle. I have come to accept it". (Interviewee # 9).

In another case, acceptance is facilitated by seeing the responsibility as something that one could not possibly escape, considering not only the fact that the children she cares for are her siblings, but also by the circumstances that have precipitated it. When asked to share her thoughts and feelings about carrying the responsibility of running the household and looking after her siblings, in the absence of her older brother who has his own home and a slightly older sister who has disappeared, she responded as follows:

> "Well I do not see anything wrong with it because I have become used to it now. In the beginning when my mother died...my mother had been sick for two and a half years before she died. So right from the beginning we had to look after her, my sister and I. After my mother died my sister ran away. So most of the load fell on me. So I do not know – I cannot say I see anything wrong with it. Well it is wrong that I have to look after children, but then they are my siblings and there is nothing I can do about it" (Interviewee # 2).

It is interesting that although she feels that as a 15-year-old, she should not have to look after children and be responsible for a household, the circumstances have given her no choice.

The next extract reveals the interviewee’s believes that his situation was not only fated but that he would overcome and rise above his present circumstances. This emerges from his belief that God will not give to one more than what can be handled. It also emanates from the belief that everything in life happens for a reason. This is what the respondent had to say in this regard:

> “I think everything happens for a reason you see. God knows what He is doing. God always has a plan, as well as a solution to every problem you see. There is nothing God gives that He knows you won’t handle. He gives to you what He knows you can handle.” (Interviewee # 1).

The sub-theme of fatalism has very strong religious connotations. The next sub-theme turns to specific examples of religiosity revealed by the texts.

4.3.4.2 Religiosity

The issue of religiosity reports on references to faith and religion as a coping strategy and as a point of reference for making sense of difficulties.

Interviewee # 9 stated that “whenever I start feeling bad about things that happen I kneel down and pray. Through God I managed to overcome many struggles in my life...despite the difficulties, life still goes on. I think God really does feel for me. I really do thank God my man.” In the preceding response the relationship with God also serves to inspire hope and belief in triumph in the face of ongoing adversities. When the interviewer remarked to interviewee # 11 that it appears as if the support that she receives from her fellow church members is very important to the respondent, she responded, emphatically:

> “Yes! When you don’t have this relationship or when you don’t read the bible things don’t always work out. It is very important.”

From the above extract, it would appear as if the respondents' ability to cope is seen as dependent on her reading the bible. She believes that by reading the Bible, matters have the potential to work out for the better.

The next sub-theme presents findings on positive outlook and attitude as expressed in the interviews.

4.3.4.3 Positive outlook and attitude

This issue focuses on particular instances where a positive outlook and attitude was apparent. However, this involves more than just an attitude. This section includes instances where these respondents displayed a positive view of themselves and a determination to survive against all odds. This is apparent from the sort of career options that respondents mentioned pursuing. Examples varied. Interviewee # 1, for example, sees himself becoming the next Bill Gates in the sense of developing his own computer software. Interviewee # 2 imagines obtaining a business qualification at Harvard University. Other such examples can be found in the texts. This attests to the positive role that the organisations assisting the respondents are playing in cultivating self-belief. All of this becomes even more important considering the circumstances that these respondents have to live with. Interviewee # 1 exhibits a very profound and mature view:

> "The one thing I know is that the moment you put a little bit of negativity, everything turns negative. You have to be positive every step of the way. You just have to be positive. When you have a positive attitude things begin to happen. If I was not positive, I would not have met people like J and C, from the organisation assisting us with school funds, groceries and whatever financial problems that we have you see."

In the above extract, interviewee # 1 recognises that having a positive attitude has helped bring in support for his family. Implied in his response is that a negative attitude might not have attracted support and compassion from other people. The spirit of determination from the same respondent was also apparent when he was asked what being a head at home means to him: "it is about waking up each day with an inner resolve to make something of the day". Later on, he described to the interviewer what he regularly to motivate himself by saying: "I am going to make something new. I will not fail".

The next example comes from twelve interviewee's response to a follow up question on how she feels about not being able to participate in activities that young people her age are involved in. Instead of viewing this negatively, she provides a very positive account of how she sees it:

> "I feel very proud of myself because other children my age lack self control even though they have parents to guide them. Some of them are involved in very destructive activities. I feel very proud myself because despite not having parents I have self control and I can look after myself."

Interviewee # 12 seems to have an intuitive realisation that her character or the sort of person that she is saves her from trouble. Her response also betrays self-appreciation and pride as well as a positive self-esteem. It also reveals a steadfast determination to remain her own person when some other young people conform and capitulate in the face of negative peer pressure.

4.3.4.4 Deriving meaning out of hardship

In this sub-theme responses reflecting how some respondents derive positive and constructive meaning from their present circumstances are considered. This sub-theme encapsulates interviewee one's view that*:* "I feel like, for me, it is like a learning curve. I am learning to be responsible at such a young age". He continues: "when I encounter difficulties when I am older I will have experience dealing with them".

The experience of heading a household holds a similar meaning for interviewee # 12: "I think it shows that when I am older I won't have difficulties running my own home. I won't have difficulties looking after my own children".

It is apparent from both respondents that they see a foundation for the future in the current situation.

The respondents view this groundwork as something that will make them stronger individuals who will have experience in handling responsibilities. Also implied is the feeling of mastery over what may be considered adult responsibilities, something that makes them unique and separates them from their peers who are not in the same situation. Contrary to the focus on the future as is the case with the previous respondents, the next respondent finds meaning in the present:

> "I find inspiration from our present circumstances...the life we live inspire and motivate me. It teaches me to do things properly...for instance I must avoid rushing things. I should not get pregnant because doing so now will only worsen the situation at home...it helps discipline me. Even when I think of skipping a class at school I should always remember what life is like at home." (Interviewee # 7).

For interviewee # 7, the experience of heading a household has currency in the present. In her case, it helps instil discipline and reduces the inclination to be impulsive. Constant recognition and consciousness of her situation also serves to protect her from making the sort of decisions that are likely to have negative consequences not only for her alone but for her siblings as well. It helps her avoid getting into situations that can only exacerbate the situation at home.

4.3.4.5 Restored sense of purpose and meaning in life

An overwhelming number of respondents described how, through the association that they have developed with the organisations assisting them with their basic needs and other organisations in civil society, they have had their purpose and confidence in life restored. This association also includes certain people in their communities. The feeling of confidence is borne from the fact these respondents have seen improvements ever since their relationship with these organisations started. Attesting to this are the following responses by interviewees # 1 and # 9. Interviewee # 1 was responding to the question on what he thinks has changed from the time immediately after his mother's death to the present.

> "When we started receiving help from II and other organisations...with the help we received I was able to go back to school. They even helped us with the funeral...I would say that they actually gave me back my life. I had given up on life..." (Interviewee # 1)

Interviewee # 9 responded as follows to question on what has changed from the time immediately after his parent's death:

> "Ever since HB came into the picture, they have provided useful guidance...presently, in my view, I think things have improved a lot because of HB. The organisation is like a mother or

> a father...if it were not for them I would have left school. The organisation has given me the courage and guidance I need to succeed." (Interviewee # 9).

A number of other similar descriptions from other interviewees alluded to the same point, especially regarding the difference that these organisations have made. Some respondents also felt that a number of individuals within the community had played similar supportive roles. In this particular case, the interviewee was describing what her friends mean to her:

> "They have stayed the same throughout. In fact, they have not changed at all. They are still the same friends and the best people one can have...in 2002 when my mother died I almost broke, but they were there for me. They actually said to me 'you can do this' and all that. My friends picked me up at a very difficult period in my life."

Three issues emerge from the above extract. The first is that the respondents' friends have remained the same throughout her tribulations. Secondly, her friends were there for her during a very difficult period in her life when she lost her mother. Lastly, her friends encouraged and motivated her when she was inclined to give up.

4.3.4.6 Sources of respite

Two important and unique sources of respite that emerged from the texts include school and having the property of residence being paid in full. When asked whether she has ever felt judged, interviewee # 11 indicated that she found school to be uncomfortable: "at school when you tell other people that your parents have passed away and that at home there are no adults...this happens especially when teachers ask about children that are orphans...when you raise your hand they look at you funny. You end up feeling bad." On the other hand, when the interviewer asked her how she felt in general about being in school, she responded as follows:

> "I like school quite a lot because in a way it allows you to escape some of your problems at home. When I'm at school I forget for a short while about my problems at home. I also have friends at school that I can talk to about my problems and other things. So school really means a lot to me."

For interviewee # 11, being at school offers an opportunity to "get away from it all" even if it is only for a short while. School provides an escape route. Furthermore, when she is at school, she has the opportunity to interact and socialise with her friends. She is also able to share and attain relief by discussing problems with her friends.

Having her house paid off was a source of immense relief for interviewee # 2: “you know fortunately our house is paid off.” She carries on describing what this means to her:

> “You know for me that is the biggest advantage out of all things – the fact that our house is paid off. It was registered in my mother’s name. So when she died fortunately it was paid off. That is the one thing that we know will always be there. Our house will always be there no matter what happens...”

What interviewee # 2 is also hinting at is the security and continuity that having the house paid off provides. Although it was not established during the interview, it is possible that she may be aware of other young people in her situation who have lost their homes. Having the house paid off provides the stability needed in the light of the difficulties that she has and continues to endure.

4.4 Conclusion

The findings presented in this chapter demonstrate the type of challenges and psychosocial needs that the children interviewed in this study confront. The findings also show the effect that these challenges and psychosocial needs have on their perceptions of the situation that they find themselves in. Clearly, having to carry the burden of responsibility for a household as a young person is difficult. These children face a number of challenges at a social, economic, and emotional level. The findings also indicate the difference that social and material assistance (e.g. the provision of food, assistance with school funding, etc) can make to psychosocial adjustment and adaptation. In particular, the findings reveal the inherent resilience of children in the face of seemingly insurmountable challenges.

Chapter 5: Discussion, Contributions and Limitations

> “Man’s search for meaning is the primary motivation in his life and not a secondary rationalisation of instinctual drives. This meaning is unique and specific in that it must and can be fulfilled by him alone; only then does it achieve a significance which will satisfy his own *will* to meaning.” (Frankl, 1984, p.121)

5.1 Introduction

Carrying the responsibility for a household as a young person, and especially if this responsibility stems from HIV/AIDS-related parental bereavement, is a life changing experience. It is an unprecedented phenomenon, the long-term psychological repercussions of which are at present not fully understood. The findings from this study clearly illustrated that the responsibilities involved are immensely challenging for the children concerned. However, their ability to cope and remain resilient, mediated by social and intrinsic factors, in the face of tremendous suffering cannot be underestimated.

This chapter presents a discussion of the findings. Consistent with the research approach informing this study, the aim was not to form generalisations from the findings. The study instead set out to explore and develop an understanding of the challenges, psychosocial needs and the perceptions of South African children carrying responsibility for households as a result of parental death due to HIV/AIDS.

5.2 Living with the effects of illness and coping with bereavement

Focusing on the personal experiences of children carrying the responsibility for a household due to HIV/AIDS-related parental death, the study explored the ways in which experiences with illness and bereavement affect adjustment and outcomes. It is apparent that experiences with illness and bereavement present a number of profound challenges and impacts. During the time of parental illness, changes occur. The study revealed that the most significant of these changes is the reversal of parental and child roles. Consistent with findings from other studies, this manifests through increased household responsibilities, the most difficult of which includes caring for an ailing parent and other, in most cases, younger, siblings (Stein et al., 1999; Foster & Williamson, 2000).

Specific experiences with the effects of parental illness that emerged from this study include feelings of loneliness, anxiety as well as negative ramifications for school performance and attendance. Foster and Williamson (2000) point out that the increasing demands made on the young person concerned is likely to affect school attendance and performance negatively.

One example in this study revealed that experiences of loneliness were exacerbated by feelings of shame and the need to keep the illness a secret. A similar finding emerged from a study conducted among a group of children in Scotland who looked after parents with HIV/AIDS. The study revealed that some of these children lacked support and felt isolated partly because they did not want their teachers to know about their parents HIV sero-positive status (Cree et al., 2006).

The public images and views of HIV/AIDS can give rise to hopelessness and despair as well as fears of being stigmatised, as illustrated in the case of one of the respondents. One of the interviewees in the study did not want her teachers and others around her finding out about her mother’s condition. This, in turn, resulted in her isolation and alienation.

This result reveals that reducing stigma and discrimination directed at people infected and affected by HIV/AIDS may go a long way in alleviating or improving the plight of those affected. By lessening the negative connotations with HIV/AIDS, people would be more inclined to open up to others and receive help.

Denial and fear of the impending reality emerged from the discussions. In particular, this was found to reflect anxieties around the meaning of the reality itself (i.e. fear and denial of imminent loss, as well as the implications of the loss). As demonstrated in other studies, the fears revolve around what will happen and the looming future reality post-bereavement (Sengendo & Nambi, 1997; and Malinga, 2002). According to Bawa-Yamba (2005) the concern over the future becomes more vexing for children that do not have a surviving parent or when it seems unlikely that someone else will take over the responsibilities. What confirmed the latter in the case of one example from the study was the absence of support, even during the respondent’s mother’s illness. It was on the basis of this observation that she felt uneasy about the future, especially at the time of her mother’s passing.

Various reactions characterised responses to actual bereavement in the study. These ranged from a deep sense of loss and devastation to emotional repression. Responses were largely based on respondents’ recollections of how they responded to loss. Signs of grief were, however, still apparent as illustrated by some respondent’s crying.

One of the difficulties experienced by children affected by HIV/AIDS is being subjected to further AIDS-related losses (Bawa-Yamba, 2005). This was the case with two respondents in this study, both of whom lost younger siblings. Interestingly, their reactions to these losses were markedly different. One respondent reported to have been more accepting, while the other experienced it as a devastating blow. The mediating influence of social support is what seems to account or the difference.

For some of the respondents, access to social support proved helpful during this period in their life. One example of a source of social support cited in the present study included friends. Gray (1989) found that for bereaved adolescents the support from peers was considered more helpful than assistance from teachers or even other family members. Considering that some respondents in this study experienced difficulties in coping with bereavement, it would be greatly beneficial to learn from the experiences of those who were able find some resolution to their grief. It is suggested that the specific things regarding the available support that assisted participants in coping be recognised in an attempt to create pathways to coping through interventions that develop those conditions conducive to coping.

A number of respondents also reported that they were responsible for providing motional support to their siblings while dealing with their own grief and sense of loss. Another study (see Naicker & Tshenase, 2004) confirmed that child-heads carry the burden of providing physical and emotional support to younger siblings.

The way in which some respondents in this study understood or made sense of how and what factors precipitated the deaths of their parents appeared to be dependent, in part, on where they were situated. Two respondents in this study, both situated in a rural part of Kwa Zulu Natal, apportioning of blame to nefarious and supernatural acts of others. Caution needs to be exercised in generalising this finding to other children in the same context in similar positions. Although significantly mediated by an environment where such beliefs are held, this may also be seen in part as a reflection of individual predispositions.

5.3 Post-bereavement adjustment challenges and psychosocial consequences

This study suggests that the period following parental death is characterised by a number of adjustment challenges. These reflect ongoing experiences of respondents with the burden of carrying responsibility for a household. The severity of the difficulties, as well as personal meanings attributed to these experiences, depend on various factors both internal and external to the person. Internal factors include individual coping styles and personal ways of attributing sense to these difficulties, while external factors include support available to the respondent.

One of the most formidable challenges to emerge from the text is experiences around the loss of childhood and self. Ebersohn and Eloff (2002) identify loss of identity, which includes, amongst others, the loss of self, as one of the psychosocial challenges faced by children affected by HIV/AIDS. In this study, this took the form of respondents viewing the experience as an acceleration of development. Considering that most respondents are adolescence, this process results in a feeling of being robbed from experiencing developmentally appropriate activities.

The responses were also characterised by a feeling that there is less focus and development of the self. According to Erikson (1968), adolescence is characterised by movement towards the formation of a separate identity and autonomy. To emerge from this would be the development of independent thought and an individual’s own moral code of judgement. However, one of the significant weaknesses of Erikson’s theory as identified by Stevens and Lockhart (2003), is its inapplicability to contexts beyond the one in which it was developed. Erikson’s postulation presupposes that the parents are present and that the adolescent learns to be self reliant by gradually becoming independent from the parents. Central to this process is the style of parenting and the formulation or establishment of extra familial relations and attachments. The theory also presupposes involvement in developmentally appropriate activities.

The central question thus remains: What happens in the case of young people such the ones in this study? Would an identity crisis result from a situation in which the respondents who experienced this loss of childhood felt that their own views of self had become subsumed into the roles they are now expected to play (i.e. mother, father and mentor to the other siblings)?

Because this phenomenon of child-heads can be seen as relatively new, it is very difficult to predict what the long term effects are likely to be. The study revealed, however, that some of the respondents have pieced together ways of engaging with the reality and thus prove to be very adaptive. The process of adaptation itself is a meaning forming process. Furthermore, it would seem that access or lack thereof to social support may prove decisive for long-term psychological health (Rutter, 1981).

Also apparent from the discussions is the sense of ‘obligation to family’ as a driving force. In this regard, the responses centred on the respondents feeling obligated to look after or assume the responsibility of caring for their siblings as well as running the household. The feeling was partly spurred by the absence of somebody else that could fulfil this role. According to Foster (2000), the presence and availability of older siblings who are willing to take care of younger siblings is one of many other reasons why child-headed households appear to be on the increase. This factor was apparent from the texts. It was, however, evident from some of the respondents in this study that this was more than just a question of willingness. The most significant factor was the reported sense of obligation and a feeling of being duty bound. Tied to the aforesaid was resignation or fatalism to the fact of the reality.

The interviews revealed that abandonment and desertion by relatives played a part in the current predicament. Two of the main reasons for the abandonment, as seen by some of the respondents, included old family disputes and absent parents, especially fathers.

One of the other factors identified by Foster (2000) as leading to the proliferation of child-headed households is poverty stricken relatives. Although none of the respondents identified this issue, it might still be a factor. Whatever the reasons behind relatives not being involved in some of the cases in this study, some respondents experienced this as a source of great distress and disappointment. Respondents experienced this uninvolvement as being failed by the adults in their lives when they should have been protecting and caring for them.

Another reason illustrated by the texts, although clearly not established, is unfinished dowry or *lobola* negotiations. Roalkvam (2005) holds that in resource poor settings, *lobola* negotiations may remain an unfinished business that in the event of parental bereavement may leave the children vulnerable and lacking the support of relatives.

Children orphaned by HIV/AIDS face a number of physical hardships, including lack of access to food, clothing and social security (Nyambedha et al., 2003; Naicker & Tshenase, 2004; UNICEF, 2004). In this study, this challenge was apparent in the expressions of concerns and anxieties over survival matters. Examples include citation of financial challenges, running out of food in the middle of the month and concerns about having money for school matters, for example, school uniform, lunch money and tuition. It was apparent from the findings that these concerns represent ongoing challenges despite the fact that almost all the respondents received some form of help from the organisations responsible for their recruitment. A cause of concern was the indication of desperation by the respondents, e.g. “I feel like I could just sell my body”. As found in other studies (see Ayieko, 1997; Sengendo & Nambi, 1997; Nelson Mandela Children’s Fund, 2001; Naicker & Tshenase, 2004) children in child-headed households are vulnerable to sexual abuse, exploitation and child prostitution.

Child-heads face tremendous stresses (Nelson Mandela Children’s Fund, 2001; Naicker & Tshenase, 2004). A lot of this stress emanates from the pressures of juggling multiple responsibilities. The study revealed that these responsibilities include the pressures of running the household and caring for siblings as well as school work and maintaining part time work. For some respondents, this resulted in feelings of being over-burdened and led to fears of failure both at home and at school as well as loosing control in areas such as discipline in the household.

The idea of the ‘super child’ may help to explain these sentiments. According to Zayas and Romano (1994), an adolescent becomes the ‘super child’ to keep busy in an attempt to:

- avoid painful feelings associated with parental illness and anticipated death;
- obtain attention and the approval of a parent; and
- to indicate readiness to assume the responsibilities of a parent/s in their absence.

As far as the respondents in the study is concerned, this phenomenon might be an attempt to avoid the painful feelings associated with parental death, an indication of readiness as well as a process of assimilating the role of parent into their identity and self definition. The findings also revealed the stresses of dealing with the social pressures confronted by siblings.

Naicker and Tshenase (2004) found that child-heads experience challenges in maintaining discipline and order. This study revealed that instilling discipline is one of the areas that lead to feelings of helplessness. According to Nagler, Adnopoz and Forsyth (1995), life for children in AIDS-affected families is characterised by a high degree of uncertainty, especially over future prospects following illness and bereavement. The study also revealed feelings of uncertainty over personal future prospects and vulnerability to property grabbing. One respondent expressed feelings of vulnerability and uncertainty over family disintegration. It would seem that these anxieties clearly emphasise the sense of despair and lack of control over the future. For the respondents concerned, these anxieties in addition to experiencing multiple losses may make life seem very unstable and unpredictable.

Another abiding concern and a significant factor in uncertainties over the future was the question of termination of assistance from the organisations that have come to represent an important role player in the lives of some of the respondents. The study reveals that these organisations have assumed a very important and meaningful role in the lives of some respondents. They represent a source of meaning and hope in the future, where prospects at an earlier stage seemed bleak. For some of the respondents, these organisations played a pivotal role when it comes to accepting and living with the reality of their situation.

5.4 The mediating and aggravating role of the community/society

The study explored the respondents' experiences in their community. Previous studies revealed that child-headed households are alienated from their communities and extended families, often surviving with very little access to social networks that could provide relief and social support (Bawa-Yawa, 2005; Roalkvam, 2005). It is evident from this study the above is not always the case. The picture that emerges is not one of isolation or lack of access to social support. Most of the respondents in this study had access to some form of social support, for instance the support received from the NPOs that recruited them.

Three forms of social support were identified from the texts: spiritual; instrumental; and moral. With reference to spiritual support, one respondent clearly illustrated that the support from her church played a significant role in her reorientation with regards to making sense and deriving meaning from her situation. It is also apparent that she was able to find some solace from the spiritual support.

The texts also revealed indications that some respondents had reservations about the interest and support shown by community members. In one case, the respondent concerned felt that the support being shown by some members of the community was very superficial. The same respondent pointed out that young people in his situation are often being used to further other people's agenda without due regard for their feelings and how they are left traumatised by these people's unfulfilled promises.

Consistent with the findings by Strode (2003) from the study on challenges faced by child-headed households, some respondents in this study reported on their experiences with stigmatisation and discrimination. A number of respondents reported that they felt judged by other community members without a proper understanding of what it was like to be in their situation. One of the interviewees felt that the source of the negative things that people say about her is jealousy over the attention that she was receiving from NPOs and individuals assisting orphans and vulnerable children.

One of the respondents indicated that many children in her situation experiences fear as to what would happen if others find out what the cause of their parents' death was. Lee et al. (2002) found that knowledge of a parent's HIV status can generate fear and uncertainty for the child involved. They also found that maternal disclosure is significantly correlated to a daughter's emotional distress. It may be possible that the same fear, distress and uncertainty continue even after the death of parent, especially since many communities in South Africa still view HIV/AIDS negatively. The concern reported by the respondent referred to above might be revealing the need for 'unconditional' acceptance from the community in light of the cause of her mother's death. Her fear is also reflective of her internalisation of the stigma and discrimination surrounding HIV/AIDS.

5.5 Coping and resilience in midst of adversity

A striking feature about the respondents in this study is that despite the challenges that they faced, the level of resilience and coping reported was higher than expected. This is due to both personal coping mechanisms and available social support structures and systems. Personal dispositional characteristics, e.g. temperament, high self-esteem, internal locus of control, etc., have been found to improve the prospects of adjustment for children and adolescents faced with adverse living conditions (Garmezy, 1991). Other studies also found that social support enhance coping for children affected by HIV/AIDS (Cree et al., 2006).

For some respondents in this study, personal ways of making sense of the reality that they are faced with was characterised by a sense of resignation. For these respondents, the situation that they find themselves in becomes the organising principle in their lives around which they formulate meaning. Closely tied to this is the belief in a predestined and fated existence. It is a way of engaging with what has happened to them in an accepting and non-accusatory way.

Religion is often but not always associated with the above. For one respondent in particular, adherence to religious practices represented a way in which she could improve the prospects of adjustment and adaptation. This was accompanied by spiritual support from fellow church members. Other studies found that support from church leaders and members improved the psychosocial prospects for children and young people made orphaned and vulnerable by HIV/AIDS (Wild, 2001).

A ‘never say die’ attitude emerged as another coping mechanism for some respondents in this study. Two of its features are self-belief as well as a positive outlook and attitude. As noted previously, a high self-esteem improves adjustment for children and adolescents confronted by difficult living conditions (Garmezy, 1991). Central to this is positive self talk.

Viewing their burden of responsibility in ways that could derive meaning from hardship also emerged as a way in which respondents make sense of their situation. Respondents have discovered ways of viewing their situation as preparation for adult responsibilities and roles in the future. They see themselves as developing skills that will help them develop an edge over their peers.

There are many perceptions and ways of understanding the predicament of being a child-head and individuals are attuned to specific perceptions more than others. As opposed to deriving meaning for the future in the present one respondent saw relevance in the present.

For some respondents, the role played by the NPO that recruited them is crucial to the restoration of a sense of purpose and meaning in life. . The impression created by these respondents was that the organisations provided redemption or a second chance in life.

5.6 Contributions and implications of the present study

5.6.1 Contributions

This study's findings highlight some of the psychosocial challenges that children heading households face as a result of parental death due to HIV/AIDS at different stages, starting from the period prior to bereavement through to post-bereavement adjustment. This information provides service providers, the government and professionals with the kind of information that could inform the assistance that they provide to these children. At the stage when prospective child-heads are faced either with the task of looking after a very sick parent/sibling or dealing with death, a number of issues arise that point to psychological difficulties.

The gradual assumption of adult responsibilities as the parent becomes increasingly incapacitated is very stressful for a child. It is also likely that witnessing a parent succumb to the devastating effects of an AIDS-related illness can be a very traumatic experience for the child affected. The stress of increased responsibilities and the trauma of witnessing a parent or parents endure the ravaging effects of an AIDS-related illness are coupled with anxieties and concerns over future prospects in the face of impending death. Significantly, this is often a time of intense loneliness and isolation for the children concerned. Once the parent dies, the chances of mourning and dealing with the loss are minimal for the child that ends up assuming the responsibilities of running a household.

For a child, the responsibility of running a household is very challenging. This is complicated by the fact that the child involved confronts the stresses and pressures of juggling and responding to conflicting demands. The child is no longer only a child but also has to fulfil the role of parent and sibling all at the same time. Instilling discipline at home is complicated and made more frustrating by the fact that the responsible child may not be that much older than his or her siblings. In addition, concerns over survival needs, such as access to food and education, are pivotal.

The present study allowed for the expression of the children’s ‘voices’. In all matters concerning children and young people, it is important that they should be consulted and permitted to express themselves. This was done through an interpretative approach seeking to privilege personal understanding and meaning for each individual respondent responsible for a household as result of parental death due to HIV/AIDS.

From a theoretical standpoint, the broader themes may offer a useful framework for future research on this subject. The findings appear to illustrate how experiences in the community and individual coping styles support or aggravate adjustment for children in this situation. Furthermore, the study’s findings demonstrate the necessity of considering how experiences with illness and bereavement ultimately influence adjustment after bereavement.

One possible framework for depicting the experiences of children carrying responsibility for child headed households as a result of parental death due to HIV/AIDS is through the diagram illustrated below.

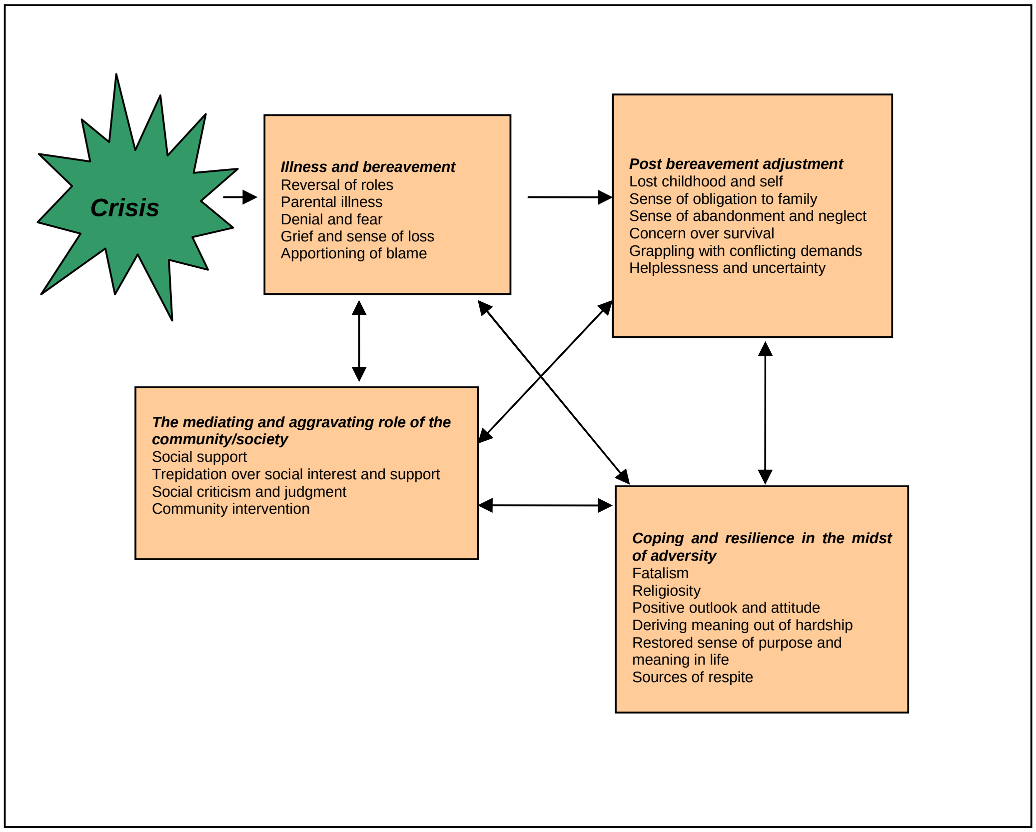

Figure 4: Framework for understanding the experiences of children responsible for child-headed households as a result of parental death due to HIV/AIDS.

5.6.2 Implications

The children's emotional needs before bereavement are often not sufficiently recognised. The reason for this is that external help only comes in after bereavement, as was the case with most of the respondents in this study. Apart from just provision of food and palliative care to the dying parent, provision also needs to be made for the social and emotional support for the children affected. Some of the emotional issues that deserve attention is the need to assist the children deal with their fears about the impending death and concerns over future prospects. Succession planning could also be addressed at this stage. Losing a loved one will always be a painful experience. As illustrated in most of the cases in this study, is the issue of guilt and self-blame for the loss of a family member.

In general, being responsible for and managing a household can be very stressful, even for an adult. This is more stressful for children, as they do not have the life experience that comes with adulthood. These children are thrust into roles and situations where they are required to make adult decisions. Coupled with juggling multiple responsibilities, there is often very little time for them to engage in activities appropriate for children their age.

There is clearly a need for programmes and skills that enhance these children's ability to manage households. Although not exclusively, these types of programmes could be integrated into the school curriculum. Some of the aspects to be addressed in these programmes could include areas such as conflict resolution, management and effective utilisation of limited household resources and so on.

There is a need for forums where children can express themselves more freely. In the case of a group such as children running households, this can include a support group. The purpose of such a support group would be to provide an opportunity for these children to express themselves more regularly and to share experiences with other children in a similar situation. Furthermore, such a support group, provided that a skilled professional acts as facilitator, could also provide therapy and the type of education needed to improve management of a household through the sharing of experiences.

Most respondents in this study had become heads of households when they well into their adolescent stage, and thus they would have had exposure to early parental instruction and guidance even though it has been interrupted. This early moral instruction may be proving useful for the child heads, who in the absence of parental guidance, have to instil discipline and provide moral guidance to their siblings. Of concern, is the need for continued moral education and socialisation, which the absence of parents compromises. Although it was not clearly established during the interviews, however, it is possible that for some of the children in this study their relationship with the 'church' fulfils the need for moral education and guidance. Thus, it is important that churches intensify their role as conveyors of morality to society. In particular, churches need to reach out to the increasing numbers of children who are left behind to fend for themselves as a result HIV/AIDS related parental death, some of whom may not attend church, to provide spiritual and moral guidance

5.7 Limitations

The present study has a number of limitations. These include the study's research design, lack of a comparison group and interpretative limitations.

5.7.1 Limitations of the research design

One of the glaring limitations of the present study is the way in which interviewees were recruited. Due to the manner of recruitment, i.e. via NPOs, the study's findings cannot be said to represent the experiences of other children in the same situation. Although the challenges confronted by the interviewees can never be taken lightly or underestimated, these children received some form of assistance through these organisations. As such, the interviewees may thus not be seen to represent the experiences of children in child-headed households that do not receive systematic and consistent help from the same or other similar organisations. The aforesaid alludes to the results' lack of generalisability.

It should, however, be kept in mind that the possibility of recruiting participants for a study of this kind without the help of organisations providing assistance to these households would have been very difficult, as these households are not always 'visible'. The other consideration is that recruiting participants through these organisations acts a protective mechanism against the violations of their ethical or human rights in any research process, especially where the research involves children faced with difficult living circumstances.

5.7.2 Lack of a comparison group

Research employing an investigation approach such as the one used in the present study makes it difficult to determine how comparable the experiences of children such as the ones interviewed for this study are to those of other vulnerable children from the same communities. The researcher thus believes that although in-depth qualitative studies are necessary for nuanced and in-depth understanding of a group such as the one considered in this study, further research incorporating comparison groups is also just as vital.

5.7.3 Interpretative limitations

The interpretative stance of the present study sought to allow for the respondents' interpretative accounts and personal understanding of what their situation means to each one them in line with an idiographic, case-by-case approach. This was facilitated by the researcher’s interpretative repertoire, which may have its own fallacies and weaknesses. A good example of this is the ability to follow up on significant areas mentioned during discussions. In this research, some areas of significance raised during discussions with interviewees were not explored sufficiently. Though subject to the researcher’s interpretative understanding, the picture that emerged from the results is a true as possible reflection of the participants’ experiences.

Chapter 6: Conclusion

> "Childhood provides the ingredients with which we make up our adult selves and explain the events that occur in our adult lives" (Orford, 2006, p.4).

The impact of HIV/AIDS on the family system and indeed the trail of destruction that it is leaving behind will be felt for many years to come. There is no doubt that the rising number of orphaned and vulnerable children resulting, predominantly, from the deaths of adults between the ages of 15 to 49 years is a serious matter requiring urgent, realistic and practical solutions. Due to the nature of the spread of HIV, if one parent is infected there is a very high probability that the other parent will also be infected. Thus, children risk losing both their parents within a fairly short period of time. UNICEF (2004) estimated that the number of 'double orphans' in sub-Saharan Africa would almost triple between 1990 and 2010.

Factors such as urbanization, migration and the rising orphan crisis due to HIV/AIDS are stretching the extended family system in Africa, resulting in children slipping through the extended family safety net (Foster, 2000). It is important to study the experiences of different types of orphans that find themselves living in different care settings after the death of a parent or parents. The present study adds to the body of knowledge on the experiences of orphans in child-headed households.

The experiences of children affected by HIV/AIDS are characterised by illness, death and survival challenges. The gradual assumption of adult responsibilities begins when a parent starts becoming sick (Foster, 2000). A number of studies (e.g. Poulter, 1997; Marcus, 2002) suggest that, during periods of intense parental illness, emotional difficulties among children affected by HIV/AIDS increase. Furthermore, the present study has revealed that increased household responsibilities deprive children dealing with HIV/AIDS-related parental illness of much needed participation in developmentally appropriate activities such as forming friendships and participation in other social and recreational activities.

Also, as was found in the present study, existing literature has shown that children orphaned and made vulnerable by HIV/AIDS show high levels of emotional distress (see, for example, Sengendo & Nambi, 1997; Malinga, 2002; Rotheram-Borus et al., 2005). In relation to child-headed households in particular, it has been found that psychological needs and challenges include the lack of emotional support and a sense of belonging, moral support and counselling, as well as parental guidance and family discipline (Nelson Mandela Children's Fund, 2001). However, most of the above studies sought to determine general patterns.

In the present study a number of challenges of living with the effects of illness and coping with bereavement emerged, *namely*: reversal of roles, living with parental illness, denial and fear of the impending reality, grief and sense of loss, and the apportioning of blame. Given that AIDS is a chronic and debilitating condition, interviewees in the present study experienced a disruption of normal routines characterised by a reversal of roles between a parent and a child. This manifested itself in increased dependence by the parent on the child.

The assumption of responsibilities of a parent by the child (e.g. taking care of other children in the household), places a heavy burden on the children concerned. As shown in this study, living with parental illness resulted in a number of effects. These included effects on school performance, attendance and concentration. It was found in this study that parental illness generated a sense of shame and secrecy, obsessive and compulsive concerns and anxiety over the deteriorating condition of the parent. For some respondents, the illness resulted in denial and fear of the impending reality. This fear revolved around the meaning of the loss and the likely implications of the loss for future long term survival without a parent or parents.

It is of grave concern that, for some respondents, dealing with the emotional aspects of their loss was a major challenge. Soon after bereavement, some of the children interviewed had to move on very quickly into the roles and responsibilities of being a child-head without having mourned sufficiently. One of the respondents reported on her attempts to avoid appearing weak by repressing or concealing her feelings when her mother died.

Also, some of the respondents reported that the death of their parent/s represented losing a friend and a part of their identity. Some respondents in this study also had to deal with the loss of a sibling due to AIDS. Thus, in addition to the trauma of losing a parent, these respondents went through the additional trauma and grief of yet another loss. With respect to the apportioning of blame for the death of parent, some respondents sought to attribute blame to the work of evil and wicked forces. Therefore, there is a need for social support and psychological assistance to children in this situation as they try to deal with pre-death difficulties and bereavement effects.

Representing ongoing challenges and difficulties in the absence of parents for the children in the study are the sub-themes grouped under post-bereavement adjustment and psychosocial consequences, and these include: sense of lost childhood and self, obligation to family and abandonment and neglect; concern over basic survival needs; grappling with conflicting demands; and feelings of helplessness and uncertainty.

Lost childhood and self, as it emerged in the present study, represents feelings of loss and confusion over identity and stolen childhood. It represents a feeling of accelerated development and maturation into adulthood while a deep yearning for developmentally appropriate experiences persists. However, despite a sense of lost childhood and self, for a number of respondents, carrying responsibility for a household was viewed with a sense of obligation. For a number of interviewees, the fact that the relatives known to them had not taken them in resulted in these respondents viewing the role that they play as their duty. Thus, it could be said that the feeling of obligation was fuelled by feelings of neglect and abandonment. Some respondents showed signs of disappointment over the fact that, in their time of need, close relatives had abandoned them.

An abiding concern for interviewees in the present study was survival. Although most respondents were receiving external assistance, many felt vulnerable to poverty and unsure of their livelihood. A considerable concern to the interviewees, however, had to do with juggling multiple responsibilities. Grappling with conflicting demands resulted in stress and a lot of pressure for respondents in this study. Many interviewees described feeling like they have to be many things to everyone, including themselves.

Another theme to emerge under post-bereavement adjustment and psychosocial consequences is helplessness and uncertainty. For some respondents, carrying responsibility for a household is characterised by feelings of helplessness over personal safety in the absence of adults at home, frustration and despair over instilling discipline and attaining obedience from siblings, as well as uncertainties over the future in the midst of family disintegration in some cases.

The challenges identified under post-bereavement adjustment and psychosocial highlight the respondents' need for sustainable material assistance, community support, and training in household management. While all the respondents in this study receive food parcels from Non-Governmental Organisations, this is not always sufficient. Extension of the school feeding scheme, currently offered to primary school children, to high schools could prevent some children starving during the day. Community involvement and interest could also help with reducing concerns over personal safety in the absence of adults. The responsibility of managing a household comes with huge pressures, more so when the person managing the household is a child. Churches could encourage congregants to become mentors for child-headed households in their communities. Training on crucial household responsibilities like the management of limited household resources, conflict resolution and so on could be incorporated into the school programme.

It also emerged from the study that personal coping style and negative or positive experiences in the community had the effect of either facilitating or impeding psychosocial adjustment. Sub-themes grouped under the mediating and aggravating role of the community/society include social support; trepidation over community support; social criticism and judgement; and community intervention.

Three forms of social support were described, namely: spiritual; moral and instrumental support. Some respondents reported feeling unsure and uncertain about social support. These respondents were sceptical of the support of some people in their communities. Of considerable concern, however, is that some respondents pointed out that they felt criticised and judged by community members over their conduct and running of the household. The interviewees in this study made a number of suggestions regarding how communities could intervene. These included emotional support and acceptance by the community. Significantly, the interviewees highlighted the need for communities to be the first line in the provision of services. Communities need to be mobilised and strengthened to assist children in child-headed households and other children affected by HIV/AIDS.

A major finding from the present study was the extraordinary coping and resilience that the children exhibited in the midst of adversity. The children used a number of coping mechanisms including: fatalism; religiosity; positive outlook and attitude; deriving meaning out of hardship; restored sense of purpose and meaning in life; and a number of sources of respite.

With respect to fatalism as a coping mechanism, some respondents mentioned that they saw their situation as predestined. These respondents felt that although their situation is difficult, they nevertheless believed that it happened for a reason. Also, references to faith and religion as a coping mechanism were quite apparent (for example, prayer and reading the bible as sources of relief).

It is quite important to acknowledge that overall, many of the children who were interviewed were highly resilient, psychologically, despite the extreme difficulties they were experiencing. Some of the respondents showed positive self-regard and attitude despite their negative life circumstances. Importantly, these respondents also seemed to have pieced together interesting and useful ways of deriving meaning out of their hardship. One example of this strategy is the view expressed by some respondents who viewed their situation as laying the foundation that will make them better and wiser adults unlike their peers who were not in the same situation.

All the interviewees in this study were receiving assistance from a Non-Governmental Organisation. A number of respondents pointed out that having an organisation assist them restored a life they felt they had lost when their parents died. To these children, these organisations, especially individuals within them, have come to represent mothers and fathers in the absence of their parents..

Child headed households appear to be a very unique and a relatively new phenomenon. At present, it is very difficult to predict what the long term mental health consequences are likely to be for children in this situation. It is evident from the findings from this study that the children who were interviewed face a number of very difficult challenges. Yet, what is also apparent is that these children appear to have found external and internal mechanisms of adjusting and coping with their situation. Thus, doomsday predictions are neither correct nor helpful. Instead, more research is needed to deepen our understanding of the psychological challenges faced by children in child-headed households. It also important that more research is conducted in order to understand how communities and resources can be mobilised and utilised to assist children living in child-headed households in such a manner as would optimise their quality of life and future prospects.

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Appendices

Appendix A: Letter of Introduction

Universiteit van Pretoria

DEPARTMENT OF PSYCHOLOGY

To Whom It May Concern:

My name is Nkululeko Nkomo, and I am a postgraduate student at the University of Pretoria. I am also a full-time employee at the Human Sciences Research Council, working in the Division of the Social Aspects of HIV. For my Masters dissertation, I have chosen to study the everyday life experiences of children carrying responsibility for child-headed households as a result of HIV/AIDS. I hope that the information that I will gather for this study will help policy-makers and other professional people to better understand the plight of these children as well as their needs. Hopefully, such information will assist in the planning and implementation of effective strategies for ameliorating their problems and challenges.

In particular, the study seeks to answer the following research questions:

- What are the major *challenges* confronted by South African children in this situation and *how do they deal with/find solutions* to the challenges?

- What is the nature of the children's *perceptions of their situation* and to what extent do these perceptions influence *the decisions they make* with regards to their fears and aspirations?
- What *psycho-social needs* do South African children carrying responsibility for child-headed households have and to what extent are these met within the context in which they live?

I would be very grateful if you could assist me to locate and access children carrying responsibility **(child-heads)** for child-headed households in your area that are between the ages of 14 and 18. I hope to interview both male and female children. The children will also take part in group discussions

I look forward to your indispensable assistance.

My contact details are as follows:

Cell/Mobile: 082 424-7037 Work: (012) 302-2611
e-mail: nnkomo@hsrc.ac.za Fax: (012) 302-2601

My dissertation promoter/supervisor is Professor P.M. Chiroro whose contact details are:

Cell/Mobile: 0761292727 Work: (012) 420 2653
e-mail: patrick.Chiroro@up.ac.za Fax: (012) 420 2404

Yours truly,
Nkululeko Nkomo

SUPERVISOR'S ENDORSEMENT: ___________________________________

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Appendix B: Consent Form

Universiteit van Pretoria

DEPARTMENT OF PSYCHOLOGY

Introduction/Consent Form (Interview)

Hello, I am Nkululeko Nkomo, a student at the University of Pretoria. I am asking children living in homes where there are no adults to answer a few questions on what life is like for children in this situation.

From my understanding, homes like yours exist throughout South Africa, as well as in other countries in Africa. These questions that I want to ask will hopefully help other people that are not in this situation to understand better what life is like for young people in your situation. Hopefully, the information you give to me will also help the government and non-government organisations to also understand your situation better and to plan effectively.

Please understand that you are not forced to participate in this research and the choice whether to take part or not is yours alone, but I would really appreciate it if you do share your experiences with me. If you choose not to take part, you will not be affected in any way whatsoever. If you agree to take part, you can stop at any time. If you stop at any time you will also not be affected in any way.

This interview will be confidential. What you share with me will stay between you and me.

I also ask for permission to tape record the interview. The choice whether to record or not, once again, is yours alone. Recording helps me to keep a record of everything you say. If you agree that I can record the interview, your name will not be mentioned on the tape recorder, and if you want the tape recorder switched off at any point during the interview, or you want something erased, I will do that.

The interview will last around 30 to 40 minutes. I request that you are as honest and open as possible in answering the questions.

Are you willing to take part in the interview?

Signature of interviewer: _____________________
Signature of witness: _________________________

Do you give me permission to record the interview?
Signature of interviewer: ______________________
Signature of witness: __________________________

Appendix C: Interview Schedule

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DEPARTMENT OF PSYCHOLOGY

The experiences of young people carrying responsibility for households

1. Can you tell me a little bit about yourself? Just give me a brief description of who you are and anything else that you think I might want to know about you.

- **Family background**
- **Hobbies, interests, likes and dislikes**
- **Future aspirations**

2. Could you describe some of your thoughts and feelings towards carrying responsibility for a household?

- Describe any negative/positive thoughts and feelings

- If negative how is it affecting your day to day living

- ‘Growing up fast or ahead of time’

- Doing/or not doing things that other people your age can do.

3. Could you describe how things are now compared to how things were when you first became responsible for your household?

- Support from people around you e.g. relatives, teachers etc.

4. What part of the experience of carrying responsibility for a household would you describe as challenging?

- Access to food, school, grants etc.
- Juggling responsibilities at home/school/part time work
- Looking after siblings
- Maintaining order and discipline at home
- Managing difficult siblings and sibling rivalry or conflict
- Describe some of fears and concerns or threats (physical, emotional)
- Can you describe what you perceive can be done to improve the challenges
- How do you feel about having a responsible adult that will help you from time to time and who do you think would be appropriate for such a role

5. Could you describe in as much detail as possible how you deal with the challenges that you just described?

- Describe sources of meaning and strength.

6. Can you describe how you think other people around you see/perceive you as a head or other young people that carry responsibility for households?

- Negative/positive attitudes.
- Sense of belonging/being part of the community or isolation/alienation and separation
- Describe how community can support child-headed households or young people that carry responsibility for households

7. Can you describe to me, in your words (language), what life is like for a young person that carries responsibility for a household?

- What it means to you

Appendix D: List of Community Mental Health Clinics in Gauteng

Region A: Johannesburg Metropolitan

Name	Address	Telephone	CMH Nurse in charge	Dr. Clinic day
Alexandra	8th Ave. East bank	443-7828	S. Sibisi (Mon to Fri)	Tuesday (3 Drs)
Brixton	77 Ingelby St. Crosby	837-7449	A. Patel (Mon to Thurs)	Tuesday (1 Dr.)
Chiawelo	Chiawelo CHC Rihlamfu St. Soweto	984-8336	F Makobonyane (Mon, Tues, Wed, Fri)	Monday (2 Drs (+ consultant with students)
Dobsonville	Roodepoort Rd Soweto	988-3101	M Mavundla (Mon, Tues, Wed – Snake Park)	Tuesday (1 Dr)

Child and adolescent mental health clinics

Name	Address	Telephone	CMH Nurse in charge	Dr. clinic day
Orange Farm	Bristlecone Nursery Golden Highway		S. Segonyane	Wednesday (1 Dr)
Mofolo	All Soweto clinics		S. Mashile, and other Soweto clinic nursing staff	Thursday (1Dr)

Region C: Pretoria Metro

Name	Address	Telephone	CMH Nurse in charge	Dr. clinic day
Atteridgeville	Ramohoebo Square Atteridgeville	373-5028	OB. Pelo	Mon to Fri
Saulsville	33 Sekhu Street Saulsville	308-5010	Mr. Makwetla	Mon to Wed
Skinner Street	Cnr. Prinsloo & Skinner Street	320-0346/7/8	FS. Vertue, J Olckers	Mon to Fri

Appendix E: Themes

Initial themes

Interviewee # 1 (IkIt)

Personal interests.

Future aspirations.

Sense of ambition.

Sense of gratitude and community responsibility.

Arrested childhood and accelerated development.

Fatalism.

Positive outlook and attitude.

Sense of obligation to family.

Determination to survive against the odds.

Coping with unfulfilled promises.

Feeling used, judged and ridiculed.

Avoidance of anger.

The role of family upbringing in coping with the current situation.

Instability and uncertainty following parental death.

Restored hope and purpose in life.

Compassion for siblings.

Feeling the gap left by parental death.

Self-drive.

Being the mentor.

Siblings and peer pressure.

Family support.

Trepidation over community support.

Supportive community members.

Fear of abandonment.

The need for the community to be proactive

The need for belonging.

Feeling different.

Supportive friends.

Interviewee # 2 (IkIt)

Personal Interests.
Future Aspirations.
Sense of ambition.
Positive sense of self.
Role models.
Determination to survive against the odds.
Positive outlook and attitude.
Grief and mourning.
Sense of resignation.
Adjusting to the reversal of parental and child roles.
Fear of impending reality.
Concern over survival.
Self imposed blame and guilt.
Lack of self assurance.
Feeling out of control.
Pressure of being the ‘super sibling’.
Family cohesion.
Dealing with uncooperative siblings.
The role of family upbringing in coping with the current situation.
Avoidance of conflict.
Fear of failure.
Dreading family disintegration.
Fear of abandonment.
Community support.
Shame and fear of stigmatisation.
Safety and security concerns.
Stability, continuity and predictability.
Suffering in silence.
Helplessness and instability.
The role of a mentor.

Interviewee # 3 (IkIt)

Personal interests.

Positive sense of self.

Self perception.

Means of self expression.

Positive view of family upbringing.

Adjustment to role redefinition.

Managing conflicting demands.

Inner resilience.

Maintaining a sense of stability.

Loss of childhood and self.

Restored purpose and meaning in life.

Community support and indifference.

Feeling judged and rejected.

Self assurance.

Helplessness and powerlessness.

Grief and sense of loss.

A solitary attitude.

Managing the private and public selves.

Loss and apathy.

Sense of resignation.

Lack of self-assurance.

The need for care and attention from the community.

Sense of stability and security.

Interviewee # 4 (IkIt)

Sense of accomplishment.

Dealing with conflicting demands.

Self perception.

Bereavement and loss.

Dealing with parental illness.

Secrecy and shame.

Restored sense of purpose and meaning in life.
Obsessive thoughts.
Denial of imminent reality.
Repression of feelings.
Suffering in silence.
Delayed reaction.
Helplessness.
Social comparisons and pressures.
Anger and pain.
Concern over survival.
Sense of obligation.
Deprivation and poverty.
Loss of childhood and self.
Hopefulness.
Learning responsibility.
Sense of estrangement to relatives.
Family cohesion.
Safety concerns.
Aversion of pity from other people.
Sense of isolation and separation.

Interviewee # 5 (IkIt)

Moralistic – grounded and focused.
Reserved – self isolation.
Future aspirations.
Family oriented – sense of obligation to family.
Lack of support from siblings.
Restored purpose and meaning in life.
Living in secrecy.
Pain of remembrance.
Difficulty accepting change of role.
Loss of childhood, loss of young self – accelerated development.
Preoccupation with survival.

Being the last priority.
Avoidance of judgment and embarrassment.
Social pressures, comparisons and siblings.
Social support – moral.
Sense of belonging.
Effects of family feuds.
Sense of neglect and abandonment.
Multiple roles and stress.
Helplessness.

Interviewee # 6 (IkIt)

Sense of focus.
Sense of altruism.
Lack of support from siblings.
Preoccupation with survival.
Loss of childhood, loss of young self – accelerated development.
Sense of estrangement to family members.
Sense of obligation to family.
Social comparisons, pressures and siblings.
Feeling judged and stigmatised.
Effects of family feuds.
Social support.
Sense of neglect and abandonment.
Helplessness and desperation.
Restored sense of purpose and meaning in life.
Multiple roles and stress.
Fear of failure.
Positive self talk.
Lingering pain.

Interviewee # 7 (IkIt)

Future aspirations.
Estranged father.

Lacking acceptance.
Learned self-reliance.
Sense of desertion, neglect and abandonment.
Traumatic effect of HIV/AIDS-related parental death.
Uncertainty over future prospects.
Catharsis and sense of relief from pain.
Wrestling with parental loss and intense feelings of loneliness.
The stress of juggling multiple roles.
Powerlessness and helplessness.
Determination to rise above current circumstances.
Deriving inspiration, purpose and direction from current circumstances.
Sense of continuity.
Enforcing cooperation.
Grappling with multiple roles and stresses.
Rationalisations.
Adjusting to insecurities.
Educational assistance.
Restored sense of purpose and meaning in life.

Interviewee # 8 (IkIt)

Family cohesion.
Lack of acceptance.
Dependence on external assistance.
Sense of abandonment and neglect.
Fear of destitution.
Sense of vulnerability.
Social support and acceptance.
Self-reliance and empowerment.
Restored purpose and meaning in life.
Sense of difference and alienation.
Avoidance of negative feelings.
Encouraging mentorship in the community.
Future aspirations.

Interviewee # 9 (HB)

Conflicting private and public selves.
Positive sense of self.
Sense of difference and alienation.
Concern with survival.
Negative effects on attitude toward school.
Estrangement.
Social/moral support.
Loneliness.
Sense of loss and grief.
Experience of parental illness.
Fatalism.
Religiosity.
Helplessness (experience of property grabbing).
Restored sense of purpose and meaning in life.
Poverty as a hindrance to tangible support.
Avoidance of negative criticism.
Self isolation.
Distress, anxiety and sadness.
Supernatural rationalisations.
Uncertainty about the future and life.
Determination to survive.

Interviewee # 10 (HB)

Sense of loss and grief.
Estrangement.
Sense of community responsibility.
Gratitude.
Concern with survival.
Desperation.
Sense of obligation to family.
Meaning making.

Resilience.
The stress of managing conflicting demands.
Suicidal.
Social/moral support.
Sense of abandonment and neglect.
Social criticism and rejection.
Need for acceptance.
Helplessness.

Interviewee # 11 (HB)

Conflicting perceptions.
Helplessness and not being in control.
External mediation.
Loss of sense of self.
Avoidance of criticism.
Feeling judged and different.
Sources of tension.
Mentorship.
Lack of understanding from the older siblings.
Denialism.
The pain of loss.
Social/moral support.
Perceptions on separation and cohesion.
Self knowledge and coping.
Sense of responsibility and obligation to family.
Spiritual and moral support.
Religiosity.
Future aspirations.
Source of respite.
Restored sense of purpose and meaning in life.

Interviewee # 12 (HB)

Sense of self.

Bereavement and loss.
Undervaluing one's role.
Self-isolation.
Future Aspirations.
Sense of loss and emptiness.
Concern over survival.
Sense of obligation and responsibility.
Preoccupation with school performance.
Deriving meaning out of hardship.
Positive sense of self.
Gender role identification.
Denial of closure and resolution.
Accelerated adjustment.
Avoidance of criticism and rejection.
Restored sense of security and meaning.

Interviewee # 13 (Hospice)

Bereavement and loss.
Feeling aggrieved.
Cognitive dissonance.
Confusion and uncertainty.
Apportioning blame.
Sense of neglect and abandonment.
Trepidation over social support.
Source of respite.
Instrumental support.
Moral support.
Self-restraint and perseverance.
Pressures of juggling multiple responsibilities.

Interviewee # 14 (Hospice)

Bereavement and loss.
Abandonment.

A life of uncertainty, unpredictability and desperation.

Concern over survival.

Stigma and discrimination.

Apportioning of blame.

Moral support.

Living in fear.

Moral/instrumental.

Difficulties with adjustment.

Sense of deprivation.

Sources of fear and uncertainty.

Emotional self-preservation.

Lack of resolution and closure.

Loss of sense of self.

Clustered themes

Interviewee # 1 (IkIt)

The community/society and social support

Community oriented: 9:1 “Just give back to the community what they gave to me”

Living with unfulfilled promises: 33:3; 5:9 “The problem is that people do things for selfish reasons”

Instrumental and moral support: 18:7 “They try by all means that they should share…” 16:11 “I have friends that have accepted my situation at home…” 31:7 “However, some people are okay”

Proactive community: 27:9 “What I hope will be done in the future is for the community to actually join hands…but spring to action”

Trepidation over community support: 28:7; 1:8 “Actually whatever they do has to get some attention, everyone has to know about it”

Need to belong: 6:10 “Most of them actually want to belong”

Post bereavement adjustment and psychosocial effects

Fatalism: 5:2 “That is why I think everything happens for a reason”

Sense of obligation to family: 1:3; 4:3; 22:8; 31:2 & 20:8 “So I feel that whatever I do I do it to help him and to help out at home”

Living with judgment and ridicule: 5:4; 30:5; 22:7; 1:8 “At school when there is a discussion about suffering and poverty – you provide the perfect example”

The effects of parental loss: 3:5; 38:5 “When my father passed away it left…in quite a lot of trouble”

Dealing with the effects on siblings: 9:8; 29:6 “And when it comes to my brother, I would say that he went through a lot of stress you see”

Fear of abandonment: 26:8 “the one fear that I have is what will happen were the help that we receive from IkIt were to stop”

Feeling of difference: 16:10 “Yes, we do feel different…”

Coping and resilience

Sense of ambition: 5:1 & 7:1 “I will create and invest in my own software”

Positive outlook and attitude: 14:2; 15:3; 26:4 & 17:4 “It is being positive that makes a difference”

Determination to survive: 24:3 “It is an inner resolve to make something new of each day”

The role of family upbringing in coping with the current situation: 29:4 “I would say that the family I grew in has instilled this in me”

Restored purpose in life: 11:5; 10:11; 29:10 “I would say that they actually gave me back my life”

Deriving meaning out of hardship: 3:2 & 15:3 “I am learning to responsible at such a young age”

Interviewee # 2 (IkIt)

The community/society and social support

Community support: 38:14 “They are all right”

Shame and fear of stigmatisation: 13:17 “A lot of young people fear how other people would treat them if they were to find out how their parents died”

Post bereavement adjustment and psychosocial effects

Sense of resignation: 17:6 “Well it is wrong that I have to look after children, but then they are my siblings and there is nothing I can do about it”

Concern over survival: 28:10 “Sometimes it does happen that we run out of electricity at the middle of the month and you cannot always call usisi c”

Fear of failure: 1:14 “To fail would be my first fear”; 20:10 “Sometimes you think of doing something but then you wonder whether tomorrow when you wake up it will still be the right choice"; 20:11 "Pressured…to always be someone that one's siblings could be proud off one day"

The challenges of managing the home: 38:11 "They are naughty; they do not listen" 1:13 "The tendency is that when there is a disagreement, in the end somebody always gives in"; 3:18 "When there is a problem at home I hesitate to inform him"

Helplessness: 6:11 "And sometimes it becomes difficult to balancing taking care of them and schoolwork"; 22:19 "I feel like my family is falling apart"; 12:17 "I know that many young people in my situation fear being broken into".

Dreading family disintegration: 6:14 "I would not like to wake up one day with one of us missing"

Fear of abandonment: 15:14 "usisi c should not abandon or cease to help us"

Living with illness and coping with bereavement

Adjusting to the reversal of parental and child roles: 25:6 "It was hard! We were used to…my mother was the sort of person that used to do everything herself"

Fear of impending reality: 13:7 "I was very scared because I could see that she was going to die"

Grief and mourning: 23:5 20:7 "Interview interrupted. Interviewee cried"

Self imposed blame and guilt: 4:10 "Sometimes I ask myself questions. For instance had I not left the room or if I had phoned someone…"

Coping and resilience

Sense of ambition: 4:2; 18:2; 35:2 "Because I would like to open my own businesses"; 2:2; 18:2; 35:2 "I want to do business management"

Positive sense of self: 35:2 "Well I like it because it is one of the best universities in the world and I want to be the best in the world"

Determination to survive against the odds: 15:4& 24:4 "He made something good out of a bad experience"

Positive outlook and attitude: 13:5 "There is a lot of it but it is good because we need the practice now".

The role of family upbringing in coping with the current situation: 7:13 "My mother always told us…"

Sources of stability and security: 37: 17 "fortunately our house is paid off…for me that is the biggest advantage".

Interviewee # 3 (IkIt)

The community/society and social support

Trepidation over community support: 32:12 "you get fifty-fifty"

Feeling judged and rejected: 30:4 "Actually people can be very rejecting and stuff"

The need for care and attention from the community: 5:13 "The community should make sure that we are okay"

Post bereavement adjustment and psychosocial effects

Loss of childhood and self: 13:3 "Actually I feel like my childhood has been taken away"; 12:3 "You have to adjust from being a kid"

Helplessness: 2:6 "I actually cry"

The pressures and stresses of managing conflicting demands: 15:3 "It is difficult'; 26:3 "everything has to be okay"

Living with illness and coping with bereavement

Dealing with loss: 4:12 "It happened and I just had to deal with it"

Apathy: 25:11 "I could see that he was sick"

Grief and sense of loss: 32:11 "It really did hurt, it really did..."

Coping and resilience

Deriving meaning and purpose out of hardship: 38:4 "From the negative I make up positive things"

Restored purpose and meaning in life: 19:4 "Now I get time"; 12:13 "Ikageng provides for us every month"

The role of family upbringing in coping with the current situation: 17:1 "I think I'm a well raised child"

Positive sense of self: 9:1 "Actually I'm the best writer you will ever find"

Interviewee # 4 (IkIt)

Post bereavement adjustment and psychosocial effects

Loss of childhood and self: 23:6 "Yes it has affected me because for instance my friends can go to movies..."

Concern over survival: 12:8 "I mean just like last weekend we did not have food and it looks like we won't have food this week either"; 10:6 "I sometimes go to school without money for food"

The pressures and stresses of managing conflicting demands: 7:1 "That is about the only things that I have time for"

Helplessness: 22:7 "Maybe they will brake in and rape the small child and myself"

Sense of abandonment: 7:4 "My father and I met only last year...I wanted to know where he had been all this time"; 5:8 "There are even times when he (uncle) is around and I would not even talk to him"

Aversion of pity and shame: 18:8 "My mother taught us to not go around asking people for things. Personally, I do not like doing that"

Living with illness and coping with bereavement

Living with shame and secrecy: 25:1 "Whenever my teachers would ask to see my parents I would always make excuses"

Living with parental illness: 17:1 'At the time my mother was ill I could not attend school'; 24:5 "When I was with my mother I would just tell myself that whatever she asks of me I would do it"

Grief and loss: 10:2 "She died in my hands"

Denial of imminent reality: 19:2 "So she would ask me what I would do if she was not around and I would simply respond that it is not time yet..."

Repression of emotions: 16:3 "If I had cried that would have been silly"; 19:3 "I then phoned my sister but I did not tell her anything"

Delayed emotional reaction: 28:3 "And as I told her tears just came down my eyes"

Internalised social pressures: 3:4 "About the funeral...nobody had anything to eat. This makes me feel bad sometimes"

Coping and resilience

Restored sense of purpose and meaning in life: 34:1 "If it were not for usisi c"

Deriving meaning out of hardship: 34:6 "Just looking after them has taught me to be a responsible person"

Sense of hope: 27:6 "Obviously, when I'm employed and that I'll be able to..."

Family cohesion: 9:7 "Fortunately, we do listen and respect each other"

Interviewee # 5 (IkIt)

The community/society and social support

Sense of belonging: 34:7 "I don't feel out"

Moral support: 26:9 "but then the community sympathises"

Post bereavement adjustment and psychosocial effects

Sense of obligation to family: 17:3 “I have got to think for the other two”

The stresses of managing siblings: 15:3 “He does not mind getting himself a bunny chow”; 26:6 “It is very important that she must fit in with her friends”

Living in secrecy: 12:4 “I have to tell them the truth”

Pain of remembrance: 29:4 “It is very painful”

Loss of childhood and self: 38:4 “I’m just a child”; 43:4 “You are now like the mother of the house”; 5:5 “My own things end up coming last”

Concern over survival: 42:4 “After all you may not have the salt at home”

Avoidance of criticism and judgment: 17:5 “People talk out there”

Sense of abandonment and neglect: 38:6 “They don’t care what I eat”; 27:8 “My aunts don’t like her”

The pressures and stresses of managing conflicting demands: 16:10 “I was all alone doing everything”

Helplessness: 18:12 “She does not see that I’m older than her”

Coping and resilience

Restored purpose and meaning in life: 6:4 “She closes somewhat that gap”

Self-restraint and sense of focus: 35:13 “Just do what you came here to do”

Interviewee # 6 (IkIt)

The community/society and social support

Feeling judged and stigmatised: 7:7 “I could say that...in fact the way that I see those children that have parents is that they look down on those children that don’t have parents”

Moral support: 18:9 “I prefer my mother’s family because they were there for me”

Community oriented: 8:3 “I would love to help another person”

Post bereavement adjustment and psychosocial effects

The stresses of managing siblings: 22:3 “He hardly ever thinks of his sisters”; 32:6 “It may well be the case that the person that you are comparing yourself to has parents”

Concern over survival: 31:3 “When we don’t have bread and my younger sibling is hungry I have to think of something”

Loss of childhood and self: 32:3 “You know if my mother were still alive I would not have to worry”

Sense of abandonment and neglect: 19:9 “They were there for me when my father and his family were not”; 38:3 “We don’t know our father”; 12:9 “My mother and father were supposed to marry...those things have nothing to do with me”

Sense of obligation to family: 42:5 “Yet with me every little amount that I have has to be used at home”

Helplessness: 19:10 “There was nowhere I can get help”

The pressures and stresses of managing conflicting demands: 13:11 “I mean you can’t be a school child, a mother, a brother, and a sister all at the same time”

Fear of failure: 27:11 “I so wish that my younger sibling could follow my footsteps and not go astray”

Coping and resilience

Self-restraint and sense of focus: 13:2 “I love my books and I’m not into street things”

Restored sense of purpose and meaning in life: 23:10 “But I think that now things are slightly better”

Positive self talk: 25:13 “I tell myself that I have to be strong”

Perpetual pain: 26:13 “Truthfully, though, in the heart it does not go away. In the heart it does not go away”

Interviewee # 7 (IkIt)

The community/society and social support

Educational assistance: 29:7 “I think that we can be assisted with our education”

Living with illness and coping with bereavement

Dealing with loss: 30:3 “the person then told me that when the memories of how my mother died keeping flooding back...”; 10:4 “The fact that my mother...I was very close to my mother”; 2:4 “The more I talked about it the more I felt better”

Uncertainty over future prospects: 23:3 “The question then was what are we going to do”

Post bereavement adjustment and psychosocial effects

Sense of abandonment and neglect: 3:3 “Because they now should be playing that motherly role”; 29:2 “So we have learned to handle things ourselves without them”; 23:1 “and then I don’t know my father”

The stresses and pressures of managing conflicting demands: 21:4 “There would be a parent’s meeting and I have to attend it”; 1:7 “On the other side, I also had to think about how we are going to live”’

The stresses of managing siblings: 8:5 “I think he sees in me someone his age, which is not the case”; 10:6 “You know sometimes when I ask him to do things he tells me that I like acting like a mother”

Lack of role acceptance: 5:2 “I like being responsible but not in this way...”

Coping and resilience

Determination to survive against the odds: 11:5 “but I always tell myself that I must get educated”

Deriving meaning and purpose from hardship: 17:5 “I find inspiration from the way we live now”

Restored purpose and meaning: 8:8 “Without them I don’t think that we would have survived”

Interviewee # 8 (IkIt)

The community/society and social support

Encouraging mentorship in the community: 4:6 “I think such a person could be a woman or man that could not have children”

Sense of belonging: 30:2 “Yes. We do feel lie part of the community”

Post bereavement adjustment and psychosocial effects

Lack of role acceptance: 26:1 “Actually I would describe it as not being nice”

Sense of abandonment and neglect: 11:2 “My father died and then my mother left us”; 2:2 “Because there is no one at home that we can depend on”; 2:4 “We have managed to stay on our own for all these years”

Helplessness: 30:2 “The other thing is that maybe somebody may decide to take something at home”; 29:2 “My biggest fear is that somebody may decide to take our house

Coping and resilience

Restored purpose and meaning: 11:4 “It was very tough because this was before we met II”

Feeling of difference: 35:4 “I don’t fit in such a conversation”; 9:5 “When it happens I usually exclude myself from such a group”

Family cohesion: 20:1 “We manage to work together”

Interviewee # 9 (HB)

The community/society and social support

Moral support: p.2; p.3; p.4 “They promised to assist me”

Poverty as a hindrance to support: p.4 “She’s also struggling herself”

Living with parental illness and coping with bereavement

Grief and sense of loss: p.2 “I would even wonder why God took her away from me”

Living with parental illness: p.2; p.4 “I would start thinking about how sick she was”

Post bereavement adjustment and psychosocial effects

Feeling of difference: p.1; p.3 “You know maybe behave like other students”

Concern over survival: p.1; p.2; p.3 “When I leave home there is never anything to eat”

Sense of abandonment: p.2 “My father left a long time ago”

Fatalism: p.2; p.6 “That is the way it was supposed to be”

Avoidance of negative criticism: p.4 “The other thing is that people like to criticize”; p.5 “I prefer to keep to myself”

Preoccupation and rationalisations over school performance: p.1 “This affects my attitude towards school”; p.5 & p.6 “Why? Why is this happening to me”; p.5 “Maybe somebody is bewitching me”

Uncertainty about the future and life: p.5 & p.7 “I think that I’m thinking about the future and my life”

Coping and resilience

Religiosity: p.2; p.7 “I ask God to help me achieve this or that thing”

Restored sense of purpose and meaning: p.3; p.6 “The thing is HB has brought some change in my life”

Determination to survive against odds: p.7 “I won’t give up”

Interviewee # 10 (HB)

The community/society and social support

Community oriented: 6:3 “I want to help orphans”; 8:3 “They make a lot of difference in people’s lives”

Moral support: 23:4 “I told them how I was feeling”

Living with illness and coping with bereavement

Grief and sense of loss: 10:2 “My mother died last year on mother’s day”

Living with parental illness: 16:4 "So it was difficult because she was sick and I was all alone"

Post bereavement adjustment and psychosocial effects1.

Sense of abandonment and neglect: 10:2 "I've never met my father"; 26:4 "It felt as though nobody loved me"; 4:5 "And at the moment I really do need the love of an adult that is related to me"; 28:4 "They talk about me to other people"

Concern over survival: 15:3 "Sometimes I don't have money"

Helplessness: 11:5 "I don't think that it will make a difference if I would speak to them"; 18:3 "I feel like I could just sell my body"

Sense of obligation to family: 19:3 "I will only get sick and make things worse for my family"

Suicidality: 21:4 "It felt like I could kill myself"

Coping and resilience

Deriving meaning out of hardship: 24:3 "The responsibility sometimes motivates me"

Interviewee # 11 (HB)

The community/society and social support

Mentorship: 30:4 "It has to be somebody who will understand and who won't loose patience with us"

Moral support: 30:5 "others even sympathise with our plight"

Spiritual support: 4:7 "They always make it a point that they do come and pray for us"

Living with illness and coping with bereavement

Grief and sense of loss: 18:5 "It is very tough for them"

Post bereavement adjustment and psychosocial effects

Cognitive dissonance: 12:1 "At home things are fine although there are times when things are not fine"; 14:5 "Yes... (then long silence) but I'm coping"

Helplessness: 20:1 "As the oldest child at home they have to listen to me but this is sometimes not the case"

Loss of childhood and self: 21:2 "I do worry that I might age quickly"

Avoidance of criticism: 27:2 "I prefer to be on my own"

Feeling judged: 7:3 "When you raise your hand they look at you funny"

Lack of understanding from the older siblings: 3:5 "The problem with them is that they don't listen or understand"; 25:3 "However, she also became quite judgmental"

Dreading family disintegration: 9:6 “I think it would be very sad to see one of us move”

Sense of obligation to family: 30:6 “I have to love them whether or not they love me”

Coping and resilience

Self-restraint and sense of focus: 27:6 “Though in my view there is some coping as long as know who you are”

Religiosity: 9:7 “Yes because when you don’t have this relationship, or when you don’t read the bible things don’t always work out”

Sources of respite: 25:7 “I like school quite a lot because in a way it allows you to escape some of your problems at home”

Restored purpose and meaning: 2:8 “They are very helpful to us”

Interviewee # 12 (HB)

Living with illness and coping with bereavement

Denial of closure and resolution: 12:4 “I never saw her before she passed away”

Grief and sense of loss: 6:2 “It is very hard to stay without parents because there are certain things that one goes through, which one would like to share with his/her parents”

Post bereavement adjustment and psychosocial effects

Gender identification and undervaluing of one’s role in the household: 15:1 “I spend most of my time at school, so I can’t say that I help out much”; 7:4 “In any household where there is a woman and a man, you will always find that the man spends more time at work and the mother will spend more time with the children”

Avoidance of criticism and rejection: 18:5 “They will always want to know why you are not dressed like them”; 21:1 “I enjoy reading and I enjoy being alone”

Accelerated adjustment: 2:5 “So we started living on our own even when my father was still alive”

Concern over survival: 14:2 “You don’t know where you will find money to go to school”

Sense of obligation to family: 1:3 “It is different because I have to think about what my younger sibling has to eat”

Preoccupation and rationalisations over school performance: 11:3 “I also have to wake up very early daily, and this affects my concentration in class”

Coping and resilience

Deriving meaning out of hardship: 18:3 “I think it shows that when I’m slightly older I won’t have difficulties running my own home”

Positive sense of self: 29:3 “It makes me feel very proud because other children my age that still have parents do wrong”

Restored purpose and meaning: 19:6 “For me having HB has really made a lot of difference”

Interviewee # 13 (Hospice)

The community/society and social support

Moral support: 28:5 “They also try to show me a different way of looking at my problems and they advice on what I should do”

Instrumental support: 23:5 “Yes because the principal at school has told me that I’m not supposed to pay school fees”

Trepidation over social support: 28:4 “That would be better because then at least we would see that people do want to help and they don’t just talk”

Living with parental illness and coping with bereavement

Confusion and uncertainty: 29:2 “I do get angry sometimes because I’m not exactly sure what caused my mother’s deaths

Apportioning of blame: 13:3 “Yes I do. Sometimes I think that somebody caused it”

Sense of grief and loss: 16:2 “I do not feel well about the situation because if we had parents we would not be like this”

Post bereavement adjustment and psychosocial effects

Cognitive dissonance: 19:2 “I don’t like it at all. I realise that, though, that it has to be done even though I don’t like it”

Sense of abandonment and neglect: 12:4 “Our relatives are still alive but they have neglected us”

The pressures and stresses of managing conflicting demands: 7:7 “Yes I do, but there is very little time for this and even soccer. There is just very little time”

Coping and resilience

Sources of respite: 15:5 “I find hope by being at school”

Self-restraint and sense of focus: 7:6 “They should look after themselves and those that are at school should persevere with schooling”

Interviewee # 14 (Hospice)

The community/society and social support

Stigma and discrimination: 6:3 "They call us orphans ('intandane')"

Moral support: 20:3 "They say that we should not do anything"

Living with illness and coping with bereavement

Apportioning of blame: 11:3 "A bird came in the middle of the night and killed her"; 21:5 "Just doing hurtful and bad things"

Post bereavement adjustment and psychosocial effects

Sense of abandonment: 7:1 "We do not know where he is"

Concern over survival: 22:2 "I always think that I must go out to ask for food from the neighbours"; 21:4 "In the evening we do not eat"; 9:2 "It is painful to stay on your own as children because a lot of the times we run out of food and we end not knowing what we will eat next"

Sources of fear and uncertainty: 27:4 "When our school fees have not been paid it does make things difficult"

Loss of childhood and self: 9:6 "It makes me feel bad, because sometimes I will just be busy looking for food to eat. So I have no time for a social life"

Sense of resignation: 4:5 "You just have to accept it, because thinking about it too much does not do one any good"

Final super ordinate and sub-themes

Living with the effects of illness and coping with bereavement in the household

Reversal of roles

Living with parental illness

Denial and fear of impending reality

Grief and sense of loss

Apportioning of blame

Post bereavement adjustment challenges and psychosocial consequences

Lost childhood and self

Sense of obligation to family

Sense of abandonment and neglect

Concern over survival

Grappling with conflicting demands

Helplessness and uncertainty

The mediating and aggravating role of the community/society

Social support

Trepidation over social interest and support

Social criticism and judgment

Community intervention

Coping and resilience in the midst of adversity

Fatalism

Religiosity

Positive outlook and attitude

Deriving meaning out of hardship

Restored sense of purpose and meaning in life

Sources of respite